**DURBAN UNIVERSITY OF TECHNOLOGY**

# An Interpretative Phenomenological Analysis of Family Involvement in the Hospital Nursing Care of Children with Autism Spectrum Disorder within eThekwini District

**by**

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# DECLARATION

This is to certify that the work is entirely my own and not of any other person, unless explicitly acknowledged (including citation of published and unpublished sources). The work has not previously been submitted in any form to the Durban University of Technology or to any other institution for assessment or any other purpose.

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Signature of student Date

Approved for final submission

_____ Date

_____ Date

# DEDICATION

This thesis is dedicated to my son John N. Williams and all children with autism and their loving and supportive parents.

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First and foremost, I would like to thank God almighty for granting me unmerited, undeserved favour in everything I do, thank you Jesus.

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# ABSTRACT


## Background

Autism spectrum disorder (ASD) is characterised by dramatic impairments in communication, social interaction and repetitive patterns of behaviour, resulting from a neuro-developmental disorder of the brain. Hospitalisation for children with autism spectrum disorder (ASD) can be very stressful because of sensory overload, their impaired ability to communicate, disruption of routine, a new unfamiliar environment and the illness for which the child was admitted. These factors can provoke difficult behaviour in these children such as uncontrolled crying, screaming, biting, scratching and other self-injurious behaviour. For these reasons, a nurse who is not knowledgeable about ASD often finds it very difficult to nurse a child with ASD in hospital. Nurses' lack of knowledge about ASD results in poor nursing care of children with ASD. Literature has shown that this poor nursing care can be resolved by effectively involving parents in the care of their children. In South Africa and especially in KwaZulu-Natal there have been no studies conducted to corroborate these findings and therefore a gap exists in the literature.

**Aim of the study:** The study aimed to develop in-depth insights into family involvement in the provision of in-hospital nursing care for children with ASD in the South African context, in order to develop a framework for the improvement of family involvement in the hospital nursing care of a child with ASD

**Objectives of the study:** The study's objectives were to critically assess the perceptions of professional nurses and families regarding the involvement of families in the hospital nursing care of a child with ASD; identify and describe the challenges perceived by professional nurses and families, in the involvement of families in the hospital nursing care of a child with ASD, explore participant perceptions on the range of corrective interventions and actions to overcome challenges and promote effective family involvement in the hospital nursing care of a child with ASD then develop a framework for the improvement of family involvement in the hospital nursing care of a child with ASD.

**Method:** The study design was interpretative phenomenological analysis (IPA), which is a qualitative approach. Sampling was achieved utilising the maximum variation

purposive sampling method and data were collected from ten nurses and ten families of children with ASD, using semi-structured interviews. The “Neil Williams framework for the improvement of family involvement in the hospital nursing care of a child with ASD”, was developed, utilising the Gray and Grove framework development process.

**Findings:** The data collected were categorised into four themes, seventeen subthemes and 6 codes. The findings highlighted the nurse’s perceived lacked knowledge and time, and they were not listening to parents. Nurses had an uncaring attitude toward children with ASD. However, both nurse and family participants acknowledged the importance of family involvement in the care of a child with ASD in hospital. Family participants made several suggestions to improve family involvement in the hospital nursing care of the child with ASD. In order to overcome the identified challenges and incorporate the participants suggestions, the “Neil Williams framework for the improvement of family involvement in the hospital nursing care of a child with ASD”, was developed, utilising the empiric data from this study and the theoretical frameworks of the Neuman’s systems model, Bowen’s family systems theory and the theory of family care during critical illness. This framework was validated using the Delphi method of validation.

**Conclusion:** The study findings confirm that nurses lack knowledge on hospital nursing care of a child with ASD, and it is important to involve family who know better about the child. This involvement can be strengthened by the empowerment of nurses and family members. This empowerment can be achieved by implementing the four components of empowerment, namely: information sharing, proximity, attitude and garnering resources. The framework developed in this study can contribute to improving nursing practice for paediatric ward nurses in the eThekwini region of KZN and may improve the in- patient experience of children with ASD and their families. It can ensure that families are meaningfully involved in the treatment of their children which may lead to improved health outcomes for children with ASD and increased positive work experience for nurses in this region, if implemented correctly.

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# DEFINITION OF KEY CONCEPTS

**Autism Spectrum Disorder**: Autism spectrum disorder (ASD) was defined as a pervasive developmental disorder with persistent deficits in (1) social communication and social interaction and (2) restricted, repetitive patterns of behaviour, interests or characteristics which occur across multiple contexts. Symptoms must be present in the early developmental period and should cause clinically significant impairments in social, occupational or other important areas of current functioning (American Psychiatric Association 2013: 119).

**Child**: Lansdown and Vaghri (2022: 407) defines the child as a human being who is below the age of 18 years.

**Family:** A group of persons united by ties of marriage, blood or adoption, constituting a single household and interacting with each other in their respective social; positions, usually those of spouses, parents , children and siblings, (Barnard 2021).

**Family Involvement**: (FI) can be defined as a method which involves the family as a component of the health care team by actively allowing them to assist with the planning and implementation of health care decisions and thus empowering the patient and family to take accountability for the patient's health, (Mol, Argent and Morrow 2018: 50).

**Paediatric Ward**: A Paediatric ward was defined as: "a ward or part thereof in which the beds are used exclusively for the care of children," (Segens Medical Dictionary 2011).

In South Africa, a **paediatric ward** is a specialized section within a hospital that focuses on the care and treatment of **children, usually younger than 14 years old** (South African Department of Health 2012: 1)

**Professional nurse**: A nurse that has undergone at least four years of training and is registered as such in terms of section 31 of Nursing Act 33 of 2005 (South African Nursing Council 2005).

# OPERATIONAL DEFINITIONS

**Autism Spectrum Disorder**: Autism spectrum disorder (ASD) was defined as a pervasive developmental disorder with persistent deficits in (1) social communication and social interaction and (2) restricted, repetitive patterns of behaviour, interests or characteristics which occur across multiple contexts. Symptoms must be present in the early developmental period and should cause clinically significant impairments in social, occupational or other important areas of current functioning (American Psychiatric Association 2013: 119). The definition of ASD for this study will be the same as above.

**Child with ASD:** Is a human being who is below the age of 18 years and has been diagnosed with having Autism Spectrum Disorder.

**Paediatric Ward**: In this study the Paediatric Ward is part of the hospital that is exclusively for the treatment of children and where children with ASD would be admitted to and cared for in the hospital.

**Professional nurse**

In this research Professional Nurse and Registered Nurse was used interchangeably and means a nurse that has undergone at least four years of training and is registered as such in terms of section 31 of Nursing Act 33 of 2005 (South African Nursing Council 2005), who is working in a paediatric ward caring for a child with ASD.

**Family**

In this research, family is defined as any person related to and caring for a child with ASD while admitted to hospital. This includes but not limited to mother (biological or adopted), father (biological or adopted), Legal Guardian, grandmother (biological or adopted), grandfather (biological or adopted), brother and sister.

**Family Involvement**

In this research, family involvement referred to, family members of a child with ASD, being included in the care of that child, whilst admitted to hospital. This includes activities of daily living, nursing care and medical treatment.

# ORGANISATION AND STRUCTURE OF THE STUDY

| | |
|---|---|
| **Chapter 1:** | **Overview of the study**<br>Chapter one provides a brief overview of the study that includes all aspects of the research. |
| **Chapter 2:** | **Literature review**<br>Chapter describes the literature review method used in this study and also presents the synthesis and analysis of literature related to this study. |
| **Chapter 3:** | **Theoretical and Conceptual Framework**<br>This chapter identifies and describes the three theoretical frameworks utilised to formulate a conceptual framework which guided this study. |
| **Chapter 4** | **Research methodology**<br>This chapter contains a detailed description of the research methodology used in this study. |
| **Chapter 5** | **Findings of the data analysis and Interpretation**<br>The presentation, analysis and the interpretation of the study results were covered in this chapter. |
| **Chapter 6** | **The Neil Williams framework for the improvement of family involvement in the hospital nursing care of a child with ASD.**<br>In this chapter the newly developed framework is described in detail to the reader **and the process of developing a framework** |
| **Chapter 7** | **Summary, conclusion and recommendations**<br>The chapter concludes the study with a summation of the thesis. The final chapter provides an overview of each of the chapters, limitations of the study, findings, and recommendations for further studies**.** |

# CHAPTER 1: OVERVIEW OF THE STUDY

## 1.1 Introduction

Autism spectrum disorder (ASD) is characterised by dramatic impairments in communication, social interaction and repetitive patterns of behaviour, resulting from a neuro-developmental disorder of the brain (Pillai, Makhetha and Aldous 2021: 125). Globally the childhood prevalence of ASD has shown an alarming year-on-year increase (Chiarotti and Venerosi 2020: 274). The Centres for Disease Control (CDC) in the United States of America (USA) has estimated that in the one child, out of every 68 children is diagnosed with ASD (Centre for disease control 2014: 4; Chiarotti and Venerosi 2020: 274). This makes ASD the number one neurodevelopmental disorder of children in the USA and worldwide. However, authors such as (Ndubaku 2018: 1) have reported that there is a deficit of knowledge about ASD amongst professional nurses and health care workers in the USA. These findings are also true for South Africa, as confirmed in a study conducted in KwaZulu-Natal (KZN) recently, where it was revealed that there has been rapid growth in children diagnosed with ASD and that parents of these children expressed that nurses displayed little ASD related knowledge (Pillai, Makhetha and Aldous 2021: 126). The deficit in knowledge of ASD by professional nurses has led to poor nursing care of children with ASD. This poor nursing care and lack of knowledge can be overcome by closely involving the parents in their child's nursing care.

This chapter provides an overview of the entire study, by introducing the topic and its context, as well as presenting the research problem, aim, objectives, significance, research methodology, sampling, theoretical frameworks used, and ethical considerations.

## 1.2 Background

Pillai, Makhetha and Aldous (2021: 125) describe ASD as a complex neurodevelopment disorder which is characterised by difficulties with social interaction, communication and repetitive patterns of behaviour. ASD is referred to as a spectrum disorder, because children with ASD may present with a wide range of symptoms and levels of impairment (New York State department of Health 2017: 2). While Joon, Kumar and Parle (2021: 1255) define ASD as social and relationship difficulties, verbal and non-verbal communication difficulties, and a tendency to engage in repetitive behaviour. The cause of ASD is unknown, although genetic links are strongly suspected. All children with ASD experience either a hyper or hypo sensitivity to sensory input. This hyper or hypo sensitivity can be very painful and debilitating for the child.

As stated above, the prevalence of ASD has increased alarmingly worldwide and ASD is now the number one neurodevelopmental disorder in children (Maenner *et al.* 2020: 1). The incidence and prevalence of ASD in Africa is not known due to lack of research, however, the Centre for Disease Control (CDC) has estimated the prevalence in Africa to be 1 in 100 children (Maenner *et al.* 2020: 1). The South African statistician general reported that there was just over 1 million births in South Africa in 2020 (Statistics South Africa 2021), so, based on the CDC estimation, this means there were over ten thousand children born with ASD in South Africa in 2020 alone.

Worldwide studies such as those conducted by Chiarotti and Venerosi (2020: 274) and Ndubaku (2018: 1) reported that the increased prevalence of ASD has led to nursing staff in hospitals caring for more children with ASD. According to Straus *et al.* (2019: 1), children diagnosed with ASD have an increased utilisation of health care facilities compared to children without ASD. This author further explains that the reason for this is that many children with ASD also have many medical comorbidities that require frequent hospitalisation.

A child with ASD cannot be nursed like any other paediatric patient because of their difficulty with communication and sensory processing.  states that the noises heard in a hospital setting can be very overwhelming for children with autism, such as having many people inside a room or area all talking at once, and noises also coming from various pieces of hospital equipment can cause sensory overload for children with

ASD. The author further explains that children with autism have heightened sensory abilities that are hard to ignore: they may experience increased sensitivity to auditory, tactile and visual stimuli, especially in a crisis situation like admission to hospital. When children with autism are overwhelmed, they may flap, scream, rock or use other calming methods to cope with the sensory overload (Garrick *et al.* 2022: 2047). Hospitalisation for children with ASD can be very stressful because of sensory overload which, according to Garrick *et al.* (2022: 2047) , can provoke difficult behaviour in these children and increase stress for the family. This behaviour can be very difficult for the nurse to manage on their own and they therefore require the assistance and knowledge of the family in order to assist the child in overcoming this sensory overload and soothing the child.

Ndubaku (2018: 1) and Corsano, Cinotti and Guidotti (2019: 1) indicated that nurse's lack knowledge of ASD, which makes nursing these children extremely difficult for them. In a recent study Ndubaku (2018: 1) identified two major challenges to providing high quality in-hospital care for children with ASD. Firstly, a general lack of knowledge regarding ASD, and secondly a lack of individualised care for children with ASD.

Studies such as those conducted by Taghizadeh *et al.* (2019: 927), Russell and McCloskey (2016: 21) and Muskat *et al.* (2015: 482) corroborate the poor nursing care received by children with ASD during hospitalisation in South Africa and worldwide.

In an Italian study done by Corsano, Cinotti and Guidotti (2019: 486), which aimed to investigate he knowledge of paediatric nurses about ASD and their experience with children with ASD, the authors found that paediatric professional nurses lack knowledge of ASD and therefore find it very challenging to nurse hospitalised children with ASD. Paediatric professional nurses therefore need to work closely with the child's family to develop a plan on how best to treat the child and to interpret the child's behaviour. Many studies, including those conducted by Nicholas *et al.* (2020: 93) and Muskat *et al.* (2015: 482), have discovered that family involvement has been linked to

the overall satisfaction of the family with the health care received by their children with special needs. These authors further explain that collaborative problem solving between health care workers and the family has shown to improve parent confidence, personal control and empowerment and result in improved child behaviour and health outcomes.

Mimmo *et al.* (2019: 1200) found that family members are the first people to notice and monitor signs and symptoms of ASD and are the biggest allies of the medical team who are treating these children. In order to achieve successful hospitalisation of a child with ASD, professional nurses need to listen to family members and encourage their active involvement. Family members can assist the nurses and doctors in providing the best care for the special needs of this child (Mimmo *et al.* 2019: 1200). By informing the professional nurses of the child's sensory triggers and needs, the family can ensure that the child is more compliant with the hospital treatment plan (Mimmo *et al.* 2019: 1200). If the family informs the nursing staff of the factors that may lead to the child becoming aggressive and injuring themselves, the staff can avoid these factors and ensure their own safety and safe nursing care for the child (Morris, Greenblatt and Saini 2019b: 2338).

All children in South Africa have a right to family care and support during hospitalisation; this right is afforded to them in terms of section 28 (1)(b) of the South African Constitution and may not be infringed upon by anyone including nursing staff (Mahery 2021: 1). The Children's Act No. 38 of 2005 section 1 further gives the parents and families the right to ensure that their child receives the best care while hospitalised and this includes making decisions on their child's medical and surgical treatment (Mahery 2021: 1). The World Health Organisation (WHO) encourages hospitals to develop policies that encourage the involvement of families in the care of their child while in hospital, as this improves the quality of care for the child (Mahery 2021: 1).

### 1.3 Research problem

Hospitalisation for children with ASD can be very stressful because of sensory overload, their impaired ability to communicate, disruption of routine, a new unfamiliar environment, and the illness the child was admitted for. These factors can provoke difficult behaviour in ASD children such as uncontrolled crying, screaming, biting, scratching and other self-injurious behaviour. It is for this reason, that a nurse, who is

not knowledgeable about ASD, will find it very difficult to nurse a child with ASD in hospital (Gautam 2020: 17). This lack of knowledge has resulted in many professional nurses mismanaging children with ASD in hospital (Bono *et al.* 2022: 377) due to their ignorance of the fact that ASD is a spectrum disorder, which means that each child is an individual who has their own special needs and manifestations of the disorder. According to Mimmo *et al.* (2019: 1200), the family are the most dependable, knowledgeable and stable people in a child's life and can contribute greatly to the hospital nursing care of their children. Furthermore, research on families of children with disabilities has found that when families are included in the nursing care of their children, both family and children benefit from improved family function (Berglund 2017: 89).

Nobody knows a child better than their parents or care givers, especially children with ASD, who have much more special needs than a neurotypical child. Family members of a child with ASD have learnt how to calm and sooth their child when he or she becomes anxious or aggressive. The parent has spent years learning what sensory stimulus will trigger a meltdown in their autistic child. They have given this child medical care at home successfully for years and have the much-needed knowledge, time and patience needed to care for their child with ASD. They are experts on their child and therefore they are the people that need to be included in the nursing management of their children while in hospital. Many children with ASD are non-verbal or have difficulty communicating and therefore rely on their parents to be their voices in many situations, including when they are hospitalised. Many children with ASD lack the maturity to make independent decisions on their healthcare and therefore the parent becomes the person that must make these decisions.

Research conducted in the USA has shown that even though family involvement in their child's treatment is recognised as critical to positive treatment outcomes, there are still many professional nurses that do not include the families in their child's nursing care (Fraatz and Durand 2021: 1). Shaibu *et al.* (2019: 1616) conducted a study in Ghana which corroborates this perceived lack of family involvement. The authors suggest that more research is needed to determine the most effective way that families can be included in care of their hospitalised child. Poor family inclusion in nursing care of their hospitalised child with ASD is a recognised problem in the USA, but there are very few studies that have been conducted in Africa and none could be found by the

researcher in the South African context. It is therefore evident that research is required to better understand if families of children with ASD are being involved in their in-hospital nursing care and how these families could be better involved in the South African context. This view was corroborated Pillai, Makhetha and Aldous (2021: 125), who found that in South Africa and KZN knowledge regarding ASD was lacking, resulting in a lack of resources for treatment.

Morris, Greenblatt and Saini (2019: 2374) state that there is a gap in knowledge concerning the nurse-patient relationship of children with ASD in healthcare facilities and that it is possible that nurses themselves may have awareness of the barriers and promoters of this relationship and therefore their perceptions should be researched.

The background of this study has clearly demonstrated that children with ASD have received poor nursing care in hospitals worldwide. It has also been shown that this poor nursing care can be resolved by effectively involving families in their children's nursing care, however this is not being done by many professional nurses in the USA. In South Africa generally, and in KZN in particular, there have been no studies performed to corroborate these findings and therefore a gap exists in the literature which may help improve the nursing care of children with ASD in hospitals. This gap exists not only in understanding the experience of parents but also of professional nurses as well. Pillai, Makhetha and Aldous (2021: 125) found poor knowledge of ASD in South Africa and KZN. There is therefore a gap in knowledge regarding the involvement of families in the nursing care of their children with ASD in the South African context.

## 1.4 Research questions

The research questions for this study were:

1 What are the perceptions of professional nurses and families regarding the involvement of families in the hospital nursing care of a child with ASD?

2 What do professional nurses and families perceive as challenges to the involvement of families in the hospital nursing care of a child with ASD?

3 What corrective interventions and actions can be developed to overcome these challenges and promote effective family involvement in the hospital nursing care of

a child with ASD?

## 1.5 Aim of the study

The study aimed to develop in-depth insights into family involvement in the provision of in-hospital nursing care for children with ASD in the South African context, in order to develop a framework for the improvement of family involvement in the hospital nursing care of a child with ASD.

## 1.6 Research objectives

The objectives of this study were to:

1 Critically explore the perceptions of professional nurses and families regarding the involvement of families in the hospital nursing care of a child with ASD.

2 From the perceptions, identify and describe the challenges perceived by professional nurses and families in the involvement of families in the hospital nursing care of a child with ASD.

3 Explore nurse and family participant perceptions on the range of corrective interventions and actions to overcome challenges and promote effective family involvement in the hospital nursing care of a child with ASD.

4 Develop a framework for the improvement of family involvement in the hospital nursing care of a child with ASD.

## 1.7 Significance of the study

This study has contributed to the closing the knowledge gaps identified by the objectives on the study.

The framework developed from the findings of this study is the first framework developed for the improvement of family involvement in the hospital nursing care of a child with ASD in KZN and in South Africa. If the framework is implemented correctly, it can contribute to improving nursing practice for paediatric ward professional nurses in South Africa as well as improve the in-patient experience of children with ASD and their families. The framework can ensure that families are meaningfully involved in the

treatment of their children which will lead to improved health outcomes for children with ASD and increased positive work experience for professional nurses in South Africa.

The newly developed framework can assist nurses to improving family involvement in the hospital nursing care of children with ASD. The findings and the framework will be reported to the Department of Health in KZN, private hospital groups and autism support groups that assisted during data collection and will hopefully be adopted by all these groups and included in their policies.

If the framework is successfully implemented, it will lead to a more pleasant in-hospital experience for the child with ASD and his/her family members and potentially better health outcomes for the child.

## 1.8 Theoretical framework

The researcher created a conceptual framework based on the following theories: Betty Neuman's systems model, Murray Bowen's family systems theory and the theory of family care during critical Illness. A detailed description of the above theories and the conceptual framework developed can be found in Chapter 3 of this thesis.

## 1.9 Research design and methodology

The research design for this study will be a qualitative design based on interpretative phenomenological analysis (IPA). Phenomenological research is a research design that describes the lived experiences of the participants from their perspective (Gray and Grove 2021: 95). IPA is a research design utilised to understand and interpret intricate and emotional lived experiences such as ill health. IPA explores the deep meaning attributed to the lived experience, by the participant, through in-depth reflection (Peat, Rodriguez and Smith 2019: 7). Admitting a child with ASD to hospital is a highly stressful situation for the child, the family and the professional nurses. It is an experience that can only be described by those that have lived through it; it is for this reason the IPA research design was chosen for this study. The Delphi technique was used to validate the developed framework.

IPA studies the meaning attributed to a lived experience by a participant and the researcher's interpretation of this lived experience, which is a process called double hermeneutics (Peat, Rodriguez and Smith 2019: 9). This double hermeneutic process

enabled the researcher to interpret the meaning attributed by families to the lived experience of having their autistic child admitted to a hospital and how that experience can be improved for other families. Likewise, the researcher interpreted the meaning attributed by paediatric professional nurses to the lived experience of nursing a child with ASD. This information was utilised to triangulate the information received from the family.

## 1.10 Research setting

The study setting can be any place where the research is executed. With qualitative research it normally happens in the participants' natural setting (Gray and Grove 2021: 439). The current study was conducted in the form of online interviews with families of children with ASD and professional nurses who work in paediatric wards at selected private and public hospitals in the eThekwini District of KZN. The interviews took place in their respective homes which was a safe and comfortable place for both, ensuring a relaxed and conducive environment for all.

## 1.11 Recruitment of participants

### 1.11.1 Family

Ahmed *et al.* (2020: 1) found that social media was much more successful than traditional advertising in the recruitment of participants for ASD related research. The researcher developed an advert (Annexure 5) to recruit family participants for this study and circulated that advert on social media, namely, Facebook® and WhatsApp®. The researcher also sent this advert to two autism support groups in the eThekwini region of KZN. Most of the participants responded to the advert circulated by one of the autism support groups. When the researcher was contacted by a parent who was responding to the advert, the researcher explained his research to the parent, and verified if they met the inclusion criteria. The researcher then set up a one-on-one interview with the family members at the most convenient date, time and method of communication.

### 1.11.2 Professional nurses

The researcher communicated with the nursing service managers of each selected hospital via emails and telephone calls and asked for their permission and assistance in setting up interviews with paediatric ward professional nurses who met the inclusion

criteria. The nursing services managers and unit managers circulated the information letter to their professional nurses working in their paediatric wards. The professional nurses were fully informed about the research by the researcher who sent the information letter (Annexure 3) to them via email or WhatsApp and asked them to participate in an online interview at a convenient date and time. On the date and time of the one-on-one interview the consent and information letter (Annexure 3) were handed to the participant and verbal consent was obtained and recorded, and the participants' permission was obtained in order to record the interview.

### 1.12 Research population

Gray and Grove (2021: 411) defined research population as "all members of a defined group, the population contains elements that share at least one common characteristic and consists of an entire group of people or type of element that is the focus of the study." There were two populations for this study, to ensure triangulation of information: the first population were permanently employed professional nurses working in paediatric wards in all private and public hospitals in the eThekwini region of KZN. The researcher was allowed access to five Paediatric wards of five different hospitals with a total of 42 professional nurses. The second population was families of children with ASD whose autistic child had been hospitalised in a paediatric ward in the eThekwini region of KZN.

### 1.13 Sampling

Gray and Grove (2021: 410) defined sampling as a process of choosing a small group that represents the entire population of the study.

#### 1.13.1 Sampling technique

Qualitative research is conducted to gain insight and discover meaning about a particular experience or situation. In qualitative research, the researcher attempts to select participants who can provide extensive information on the topic being studied, (Gray and Grove 2021: 429). Purposive sampling is a strategy which is commonly implemented in phenomenological studies because it permits the selection of participants that have in-depth knowledge of the phenomenon under study (Frechette *et al.* 2020). Table 1.1 sets out the sampling techniques employed in this study.

**Table 1.1: Sampling techniques**

| Participants | Sampling Method | Inclusion Criteria | Exclusion Criteria | Sample Size |
|---|---|---|---|---|
| Professional Nurses | Maximum variation purposive sampling | • Professional nurse permanently working in the paediatric ward in a hospital in eThekwini Region of KZN<br>• History of nursing a child with ASD | • Professional Nurses who do not want to share their experience nursing a child with ASD.<br>• Professional nurses who can not attend an online interview.<br>• Enrolled nurses and Enrolled nursing auxiliaries working in paediatric ward<br>• Professional nurses working in adult wards.<br>• | Achieved when data saturation is reached. In IPA small sample sizes are used because of in depth data collection. |
| Family | Maximum variation purposive sampling | • Family member of a child with ASD.<br>• Child admitted to a hospital paediatric ward in eThekwini region of KZN | • Family member of a child not previously admitted to a hospital paediatric ward in eThekwini.<br>• Family member who is unable to attend an online interview for whatever reason. | Achieved when data saturation is reached. In IPA small sample sizes are used because of in depth data collection. |

### 1.13.2 Sampling of participants

A non-probability maximum variation purposive sampling technique was utilised as the sampling method for the selection of nurse and family participants for this study. Gray and Grove (2021: 429) state that the focus of purposive sampling is to choose specific participants who will represent a particular population and provide in depth insight on a particular phenomenon. These authors further explain that maximum variation

sampling is a purposive sampling method that is implemented to obtain extensive viewpoints in order to gather in-depth understanding of a phenomenon by examining it from different perspectives.

Maximum variation purposive sampling was ensured in this study by sampling families and professional nurses with different characteristics such as occupation, sex, age, in order to capture a wide range of perspectives. Sampling both families and professional nurse participants in order to investigate this phenomenon from different angles led to greater insight and helped the researcher to identify common themes that were evident across the samples.

#### 1.13.2.1 Sample size

IPA is suitable for small samples who are purposively chosen because of their in-depth experience of a particular phenomenon (Peat, Rodriguez and Smith 2019: 8). Typically, in Qualitative researcher a sample size is not predetermined but based on data saturation, that is sampling to the point when no new information is obtained and redundancy is achieved, (Polit and Beck 2021: 502)

Recruitment of participants for this study continued until the achievement of data saturation. The sample size reached was ten family participants (one parent from ten different families) and ten nurse participants, which was a total of 20 participants.

## 1.14 Data collection

### 1.14.1 Data collection instrument

Peat, Rodriguez and Smith (2019: 8) explain that data collection for an IPA study can be any of the qualitative data collection methods, however the most frequently utilised data collection method is the semi-structured interview. The aim of the semi- structured interview in IPA is to encourage the participant to share their experience of the phenomenon of interest, while the researcher's role is to guide the discussion to explore this lived experience; this can be achieved by using an interview guide (Peat, Rodriguez and Smith 2019: 8). Data was collected in this study by means of semi-structured interviews of nurse and family participants. The questions in the semi-structured interview guides facilitated an in-depth interview of the participants and achieved the research objectives.

The interview guide for professional nurses (Annexure 1) and family participants (Annexure 2) were filled in by the interviewer during the interview and had three sections. Section 1 elicited information such as date and time of the interview, the type of institution the participant was working at and the participant code. Section 2 gathered the participants' demographic data such as marital status, age, sex, level of education and years of service and section 3 was made up of 6 open ended questions that were formulated by the researcher in order to realise the research objectives. The researcher also used probing questions when required to gather more data from participants.

### 1.14.2 Data collection method

Data for this study was collected utilising extensive semi-structured interviews with both family and nurse participants. Gray and Grove (2021: 326) explain that interviews are attentive discussions involving the qualitative researcher and the participants that generate in-depth knowledge in the form of words. Alase (2017: 14) agrees with Peat, Rodriguez and Smith (2019: 8) that the best way to collect data for an IPA is by conducting in-depth semi-structured interviews, therefore this method was chosen for this study.

Data were collected in December 2021 and January 2022. Due to the COVID-19 restrictions, the researcher conducted the in-depth semi-structured interviews with participants utilising electronic means, such as telephonic interviews, using the "WhatsApp" voice calls, using an online meeting programme called Microsoft Teams. To mitigate the data costs incurred by the participants, the researcher reimbursed the participants for data used for interview, in the form of a one gigabyte data voucher, that was sent via "What's app" message.

The following principles, which have been highlighted by Alase (2017: 15), were followed by the researcher:

- According to Alase (2017: 15) an IPA research study should conduct semi-structured interviews with between two to 25 participants. In this study the researcher sampled participants until data saturation was reached, data saturation was reached at nine family participants and eight nurse participants but a further two nurse participants and one family participant were interviewed to ensure that data saturation had indeed being reached. Thus, there were therefore 10 parents

and 10 professional nurses interviewed which made a total of 20 participants. According to Faulkner and Trotter (2018: 1) data saturation denotes the instant in the data collection process when no new information is being collected, and is a sign that data collection can terminate.

- Alase (2017: 15) further notes that the duration of each interview typically ranges from 30 to 90 minutes. The shortest interview was 20 minutes and the longest 60 minutes, with the average interview taking 30 minutes.

- Ideally each participant is only interviewed once unless a follow-up interview is needed (Alase 2017: 15). In this study only one interview per participant was conducted.

- The participant should select the venue, date, time of the interview, to ensure the participants comfort (Alase 2017: 15). In this research the date and time was decided by the participant but the interviews were mainly telephonic while three were on-line.

- Finally, the research should use different technological devices such as voice recorders, video recorders, etc. to collect data (Alase 2017: 15). The data was collected by the interviewer recording on the interview schedule, audio and video recordings. The researcher personally conducted all the interviews.

### 1.15 Data analysis

Data analysis in IPA commences immediately after the first interview with in-depth analysis of the first interview, which results in the formulation of the initial themes and these themes are considered in the analysis of subsequent interviews (Peat, Rodriguez and Smith 2019).

The researcher utilised the following step-by-step approach for IPA analysis as formulated by Peat, Rodriguez and Smith (2019: 8):

1. Reading and intense analysis of the first transcript.
2. As the researcher reads the transcripts, he/she makes observational notes in the margins
3. The researcher then takes these observational notes and forms groups of data and themes start to emerge.
4. The researcher looks at these groups of data and tries to find how they relate

or connect to each other.

5. The researcher then moves on to the next transcript, “bracketing” the themes that emerged in the previous transcript.

Steps 1–4 are repeated for each transcript.

6. Once all the transcripts have been analysed, as described above, the researcher then looks for common themes across all the transcripts and these are highlighted.
7. The researcher then looks at the themes across all the transcripts and makes a deeper interpretation, to find the meaning of these experiences.

Finally, the researcher looks at existing literature in an effort to further interpret and analyse the themes.

The IPA data analysis is reported as a comprehensible logical explanation with appropriate direct quotes from the participants with the researcher’s interpretation thereof in the light of the relevant literature.

Lastly, the data is interpreted in such a way as to meet the research objectives and aims.

A detailed account of data analysis is presented in Chapter 4 of this thesis.

### 1.16 Triangulation of data

According to Polit and Beck (2021: 154) data source triangulation involves collecting data from different sources to ensure trustworthiness of the information. The researcher ensured data source triangulation by collecting data from two sources, namely: professional nurses working in paediatric wards and families of children with ASD, admitted to paediatric wards. The researcher also used existing literature to validate the finding of the data analysis, which is a method used in qualitative research to ensure validity of the data, as this data converges from different sources. An independent coder was not used but Qualitative Data Analysis software (Nvivo pro12) was used to analyse the data.

### 1.17 Trustworthiness

Trustworthiness refers to the integrity of the researcher, the legitimacy of the results and the methodical precision and appropriateness of the research design and method

(Rose and Johnson 2020: 434). Trustworthiness of this study was achieved by adhering to the four criteria of trustworthiness as described by Lincon and Guba (1985: 301), namely, credibility, transferability, dependability and conformability.

### 1.17.1 Credibility

Polit and Beck (2021: 569) explain credibility as being confidence in the certainty of the research findings. Credibility is accomplished when the research findings are an accurate understanding of the data derived from the participants' true perceptions. Interviews that were conducted with nurse participants and family participants were recorded and notes were written on the interview guide verbatim, to ensure capture of the participants' original views. Probing questions were used to ensure data saturation. These notes and recordings will be kept for a period of five years after production of the final report, should they be required for verification purposes.

### 1.17.2 Transferability

Transferability is simply the measure to which the research can be reproduced in different settings with different participants, to test if it will yield similar findings. Transferability can be ensured by the researcher providing a detailed description of the research (Polit and Beck 2021: 570). Transferability was ensured by the researcher through providing a thick description of the entire research process, including the data collection, analysis and the context of data collection, so that this study can be conducted in other settings, context or with other respondents. The research process as published in the form of this research report so that it can be repeated if necessary.

### 1.17.3 Dependability

Dependability is defined by Polit and Beck (2021: 569) as the longevity of findings. Dependability can be achieved by the participants' assessment of findings regarding authenticity. The researcher ensured dependability by asking the participants to evaluate the findings prior to submitting the research report to the examiners, to ensure their views have not changed over time. The data collection tools were also pretested prior to data collection. The entire research process was made transparent so that the dependability of the findings could be tested later.

### 1.17.4 Confirmability

Confirmability is defined as the measure to which the research findings and interpretations can be endorsed by other researchers in order to determine the accuracy (Polit and Beck 2021: 570). To ensure confirmability the researcher shared recordings and verbatim field notes with the research supervisors to ensure that data had been correctly interpreted.

## 1.18 Ethical considerations

To ensure that this study adhered to all the relevant ethical principles, it was subjected to review and approval by the research ethics committees of 1) The Durban University of Technology, 2) The KZN Department of Health and 3) The research/ethics committees of the various private hospitals.

### 1.18.1 Beneficence and non-maleficence (right to protection from discomfort and harm)

Beneficence encompasses the duty of researchers to prevent harm and increase the advantages to the participants, and non-maleficence means doing no harm (Polit and Beck 2021: 133). In this study no known risks of physical harm to participants were identified, since the participants were only required to attend a voluntary interview which held on-line in order to minimise the risk of contracting Covid19. With regard to beneficence, the participants may benefit from the framework that was developed by the researcher. The participants were interviewed from the comfort of their homes, so that they had a familiar and therapeutic environment at all times. Even though the participants did not experience any physical harm, the participants were also protected from emotional harm because the participants were informed that at any time during the interview if the participant experienced any discomfort from the questioning they could inform the researcher who would not proceed with that line of questioning. None of the participants reported any discomfort from the questioning.

### 1.18.2 Respect for human dignity and right to self-determination (informed consent and disclosure of information)

Respect for human dignity is related to the participants' entitlement to autonomy and complete truthfulness. The right to self-determination encompasses the participants right to choose whether they want to participate in the research or not, without any fear or coercion. Full disclosure means the researcher must provide all pertinent information about the study to the participant so that they can make an informed

decision about whether or not to participate. This includes information about the nature of the study, risks and benefits of participating, and the researcher's responsibilities (Polit and Beck 2021: 133). The researcher ensured full disclosure by providing a detailed description of the nature of the research, the dangers and advantages of participation in the study and the researcher's obligations. Participants' right to self-determination was communicated in writing in the letter of information and the consent form (Annexure 3 and Annexure 4) which were given to all participants prior to their interviews. The researcher conducted the interviews and obtained consent personally so was available to answer any questions the participants may have had.

### 1.18.3 Justice and veracity

Polit and Beck (2021: 135) assert that justice comprises of the participants' entitlement to impartial behaviour, confidentiality and ethical selection. All participants were always treated fairly and equally by the researcher during this study. Veracity or truthfulness was always maintained by the researcher who answered all participant questions honestly and truthfully. The participants' right to privacy was always maintained because their names were not used in any way in this thesis, and they were given participant codes so only the researcher could link their interviews to their names.

### 1.18.4 Right to privacy and confidentiality

Privacy can be described as the participants right to determine how, when, and with whom, their personal information is disclosed (Polit and Beck 2021: 135). In this research each participant and institution were assigned a code to protect their personal information, and only the researcher knows who was assigned to which code. All information including recording and field notes have been locked away by the researcher and will not be made available to anyone, except to supervisors if necessary. The participants may access their own information if they wish to do so and are fully aware that their information will only be used for this research only.

## 1.19 Unique contributions

This thesis has added to the body of knowledge on ASD in KZN and South Africa. This research has added the following areas to nursing knowledge: 1) the perceptions of professional nurses and families, regarding the involvement of families in the hospital

nursing care of a child with ASD in KZN and South Africa; 2) the challenges perceived by professional nurses and families regarding the involvement of families in the hospital nursing care of a child with ASD in KZN and South Africa; 3) the corrective interventions and actions to overcome challenges and promote effective family involvement, in the hospital nursing care of a child with ASD in KZN and South Africa and 4) a framework for the improvement of family involvement in the hospital nursing care of a child with ASD in KZN and South Africa. There has never been such a study carried out previously and the areas above were gaps in the nursing body of knowledge, which has been filled to a degree, utilising an IPA study.

## 1.20 Chapter Summary

In this chapter a brief overview of the study was given by first discussing the introduction, background and then the research problem, aim, objectives and significance, methodology, data collection, trustworthiness, ethical considerations, scope and limitations, and the unique contribution of the thesis. In the ensuing chapter a comprehensive review of relevant available literature will be presented. To improve the hospital nursing care of children with ASD, this research aimed to develop in-depth insights into the influences that contribute to promoting family involvement in the provision of in-hospital nursing care for children with ASD and develop a framework to address these findings.

# CHAPTER 2: LITERATURE REVIEW

## 2.1 Introduction

The literature review of a thesis is a comprehensive and structured written report of most recent and relevant literature pertaining to a specific phenomenon. It presents the current comprehensive information on a particular topic. The literature review may take the form of an overview, description or synthesis of research findings (Gray and Grove 2021: 156).

Literature review is an interpretative, organised, and written presentation of literature the researcher has analysed. The reason for conducting a literature review is for in-depth exploration of the most recent, and relevant, information pertaining to the phenomenon of interest (Gray and Grove (2021: 157). The literature review allows the researcher to discover what is known and unknown (gap) about a particular phenomenon. In order to perform an effective literature review, the researcher has to find all recent, relevant literature on the phenomenon. The researcher then read through all the literature and organises it according to themes, subthemes and codes. The researcher then evaluates, interprets, and synthesises the sources read (Gray and Grove 2021: 156).

In this chapter the researcher provides a thick description of the literature review process in a thematic style, utilising the research objectives as the themes for this literature review. The chapter ends with a summary of the chapter.

## 2.2 Purpose of the literature review in this study

The purpose of the literature review in this study was to:

1. Gain insight into the most widely accepted literary perspectives regarding nurse and family perceptions of family involvement in nursing children with ASD.
2. Identify the challenges perceived by nurses and families regarding involvement of families in the hospital nursing care of children with ASD.
3. Discover strategies to promote effective family involvement in the in-hospital nursing of children with ASD.

4. Discover theories and frameworks associated with family involvement in the hospital nursing care of a child with ASD.
5. Identify the context of family involvement in the hospital nursing care of a child with ASD.
6. Gain new perspectives regarding holistic strategies to support families and nurses in the in-hospital nursing care of children with ASD.
7. Identify and explain the importance of involving families in the in-hospital nursing care of children with ASD.

## 2.3 Literature search strategy

Initially Google Scholar was used to search for literature using the key words highlighted below and then if articles were not available in full text from Google Scholar then the title of the article, author and date was copied and pasted into one of the data bases available through the University of Zululand or Durban University of Technology.

Keywords were identified prior to conducting the searches. To get the keyword the researcher brainstormed all relevant words in the form of a mind map. These keywords were then converted into search phrases. This was done prior to conducting the search in order to ensure that the searches were more focused and yielded appropriate results.

The following keywords and phrases were used:

- Autism spectrum disorder (ASD)
- Children with ASD admitted to hospital
- Nursing children with ASD in hospital
- ASD and paediatric ward nurses
- Involving families/parents in the nursing care of a child with ASD
- Experiences/ perceptions of families/parents and nurses with children with ASD
- Perceptions of families of a child with ASD
- Perception of nursing in involving families in nursing care
- Challenges/ barriers of involving family in the nursing care of child with ASD
- Promoting family involvement in paediatric ward
- Promoting parent involvement in nursing care of child with ASD
- Framework on family/parent involvement in nursing care of child with ASD

The researcher utilised electronic books and electronic journals from electronic databases. The researcher accessed the electronic databases available to students on the Durban University of Technology (DUT) library website and the University of Zululand Library website available to staff. The databases listed below were used most frequently:

- EBSCO-host database that contained hundreds of electronic Journals and books
- Medline
- CINAHL – The Cumulative Index of Nursing & Allied Health Literature
- Cochrane Database of Systematic Reviews
- Google Scholar

## 2.4 Inclusion and exclusion criteria

The search procedure recorded above yielded hundreds of thousands of articles; in order to limit the number of articles and find the most appropriate articles that would add value to this literature review, the following inclusion and exclusion criteria were utilised:

### 2.4.1 Inclusion criteria

- Only literature published in the year 2018 to current (five or less years old) were used in this review, in order to ensure that all information presented was as current as possible. Some seminal works older than 2018 were utilised as necessary.
- Only peer reviewed articles, published books and thesis and dissertations published by universities were utilised, to ensure that only credible literature was used. Grey literature was kept to the minimum.
- Most of the literature used were primary sources to keep the literature as authentic as possible, and free of the bias or misinterpretations that come with secondary sources.
- Articles that were available in English were utilised as this is a universally utilised academic language and the researcher's first language. This was done in order to prevent any misinterpretation when translating articles to English.
- Only articles where full text was available to the researcher were included.

### 2.4.2 Exclusion criteria

- Articles older than five years.
- Grey literature and unpublished works because these works have not been peer reviewed.
- Secondary sources of information because these are reports on primary research and therefore may contain opinions and misinterpretations of the original research.
- Articles not published in English to prevent any misinterpretation when translating articles to English.
- Articles where only the abstract was available.

## 2.5 Steps in the literature review

The literature was reviewed according to the steps promulgate by Machi and McEvoy (2021: 1), namely:

Step 1: Choose and identify the topic

Step 2: Search all available literature

Step 4: Examine the literature

Step 5: Evaluate the literature

Step 6: Compose the literature review

Once the topic was approved, the researcher performed many literature searches utilising on-line data bases via the DUT and University of Zululand library websites. As each article that was found the abstract was scanned to evaluate its relevance and if relevant the article was saved in an electronic folder. The articles where then re-read and categorised. The literature review was written up in sections according to the themes listed in the body of the literature review.

## 2.6 Literature review method

The narrative review method was used for this literature review. In this method all relevant literature was identified that was relevant to the topic being studied. The literature was then analysed and synthesised to provide a comprehensive

understanding of the multifaceted topic. Utilising this analysis allowed the researcher to identify themes and theoretical concepts and perspectives (Snyder 2019: 335).

A narrative review process is similar to the process of qualitative data analysis, namely: thematic or content analysis (Snyder 2019: 336). In this literature review the author used thematic analysis.

### 2.6.1 Literature mapping

Literature mapping is a strategy used when conducting a literature search, being a graphical representation of a research topic (Bhosale 2022: 1). A literature map is a reputable technique for conveying the researcher's thinking processes.

According to Bhosale (2022: 2) mapping can be either from keywords or experts in the field / authors. In this study the researcher chose to map by key phrases. The literature map used for this study is depicted in Figure 2.1.

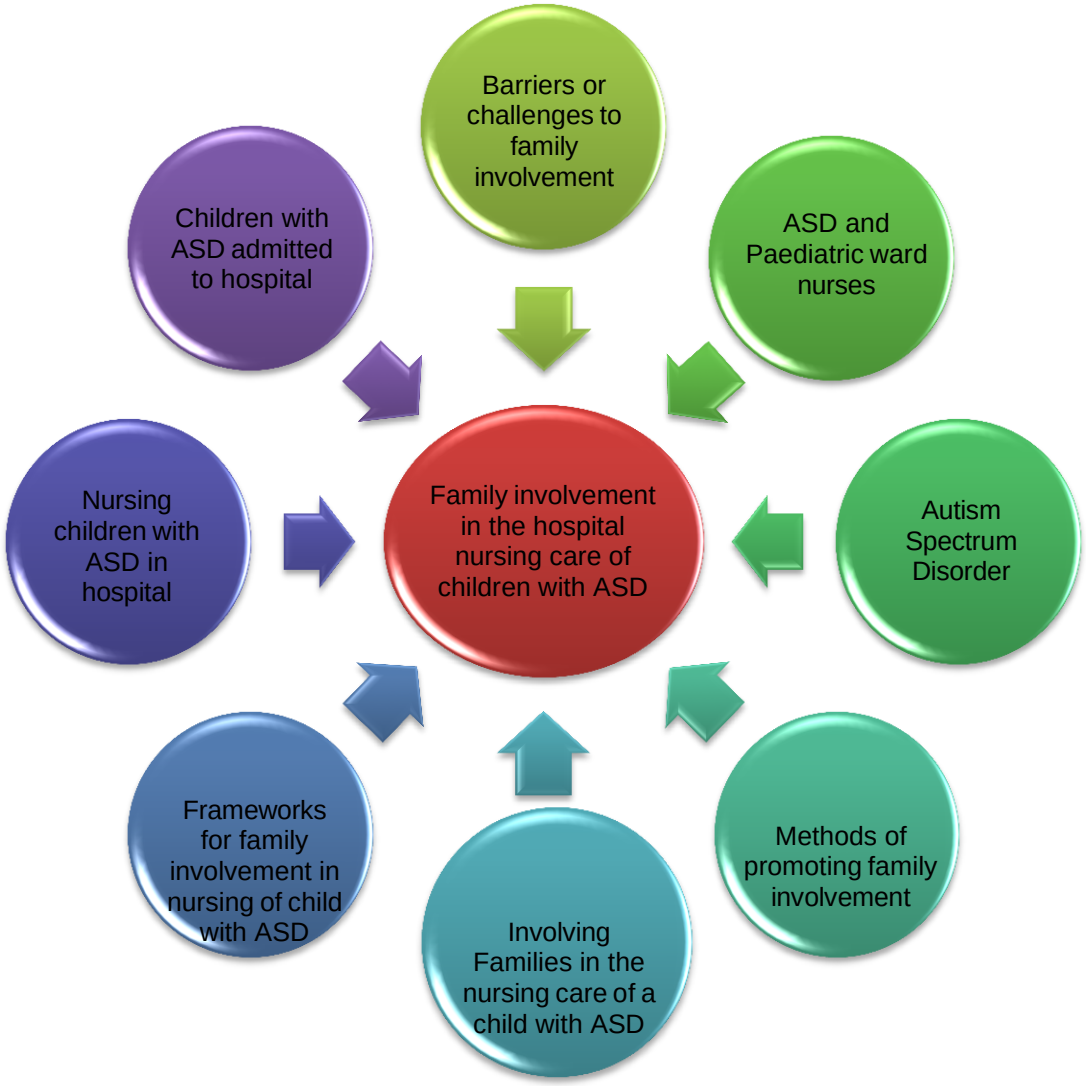


**Figure 2.1: Literature search map**

### 2.6.2 Searching techniques

Scanning technique involves a rapid surveying of an article for key words (Machi and McEvoy 2021: 50). This technique was utilised in this study by scanning sourced articles for the keywords listed above such as: parental involvement, nursing care, hospital care, child with ASD.

Skimming technique is the researcher swiftly reads just the title and abstract and a few headings to determine if this article can be included in the literature review (Machi and McEvoy 2021: 50). This technique was utilised in this review because all articles were initially skimmed.

Intensive reading is the technique that was utilised on the articles selected. This is a thorough and meticulous appraisal of the article in order to decide if it should be included in the literature review (Machi and McEvoy 2021: 51). In this study, articles that had been scanned and skimmed and appeared to be relevant were then intensively read to determine if it met the inclusion criteria for this review.

### 2.6.3 Evaluation of selected articles

Molly Beestrum developed the CRAP Test as a means of determining credibility and valid of a source. The CRAP Test evaluates each source against four principles namely: currency, relevance, authority and purpose (CCCOnline Library 2021). The researcher used these four principles when evaluating the articles included in this literature review.

#### 2.6.3.1 Currency

In an effort to ensure that only current information was utilised in this literature review, the researcher only utilised articles, literature and sources of information that were five years old or less, meaning articles that were published no later than 2018. Some exceptions were made for seminal pieces of literature that were important to this study.

#### 2.6.3.2 Relevance

All sourced articles were scanned, skimmed and intensively read for the purpose of this literature review. If the article contained the key concepts and met the inclusion criteria for this review, it was deemed to be relevant. Relevance of the article was also determined by gauging whether the information in the article could be used to answer the main research questions, aim or objectives.

#### 2.6.3.3 Authority

When evaluating the authority of each article the researcher had to determine the credibility of the author by checking the author’s background and credentials, and ascertain if the publisher or sponsor had any special interest in the article (CCCOnline Library 2021).

### 2.6.4 Databases Used

An academic database is defined as an anthology of academic journals, electronic books and other information which is frequently utilised for academic activities such as research and writing (Your Dictionary 2022). See Table 2.1.

**Table 2.1: Databases used**

| Database | Subject coverage | Number of articles found | Number of articles used |
|---|---|---|---|
| Google Scholar | An index of various databases, journals and articles | 29 000 | 54 |
| EBSCO Host | Covers all subjects | 192 800 | 26 |
| CINAHL Plus | Allied health information | 10 668 | 2 |

### 2.6.5 Literature sources

In order to ensure that the literature review for this study was comprehensive, the researcher utilised literature in many forms divided into the following categories as per Frederiksen and Phelps (2020)

**Primary Sources** – Primary sources are sources of information that originate from the person that conducted the research or compiled the statistics. In other words, the information stems from the author of that information. Examples of primary sources can be original research reports / articles, statistics, diaries, autobiographies, letters, etc. (Frederiksen and Phelps 2020).

**Secondary Sources** – Secondary sources of information interpret, discuss, summarise primary sources. Since a secondary source is an interpretation of a primary source, it may contain the opinions or bias of the secondary author and is therefore not as authentic as a primary source. Examples of secondary sources are qualitative reviews, integrative reviews, meta-analysis, biographies, etc. (Frederiksen and Phelps (2020).

### 2.6.6 Studies included in this literature review

As shown in Figure 2.2 the researcher entered the key words in EBSCO host data base via the University of Zululand online library and found 16 800 articles. The researcher also entered the same key words in the Google Scholar index and came

up with 28 739 articles, and the CINAHL Plus data base which yielded 300 articles, on the Scopus data base which yielded 312 articles, and on the OVID database which yielded 1 156 articles. All these articles were then subjected to the inclusion and exclusion criteria, and only those that satisfied the inclusion criteria were retained.

The abstracts of the remaining articles were read and evaluated by the researcher to see if the articles were relevant to this study and if the information contained in the article would add value to the literature review. Those articles that were not relevant to this literature review were then excluded, leaving the researcher with a total of 82 articles to review.

The themes that emerged from these 82 articles will be discussed in the next section of this chapter and for a detailed explanation of each article, please refer to the table in Annexure 15 at the end of this document.

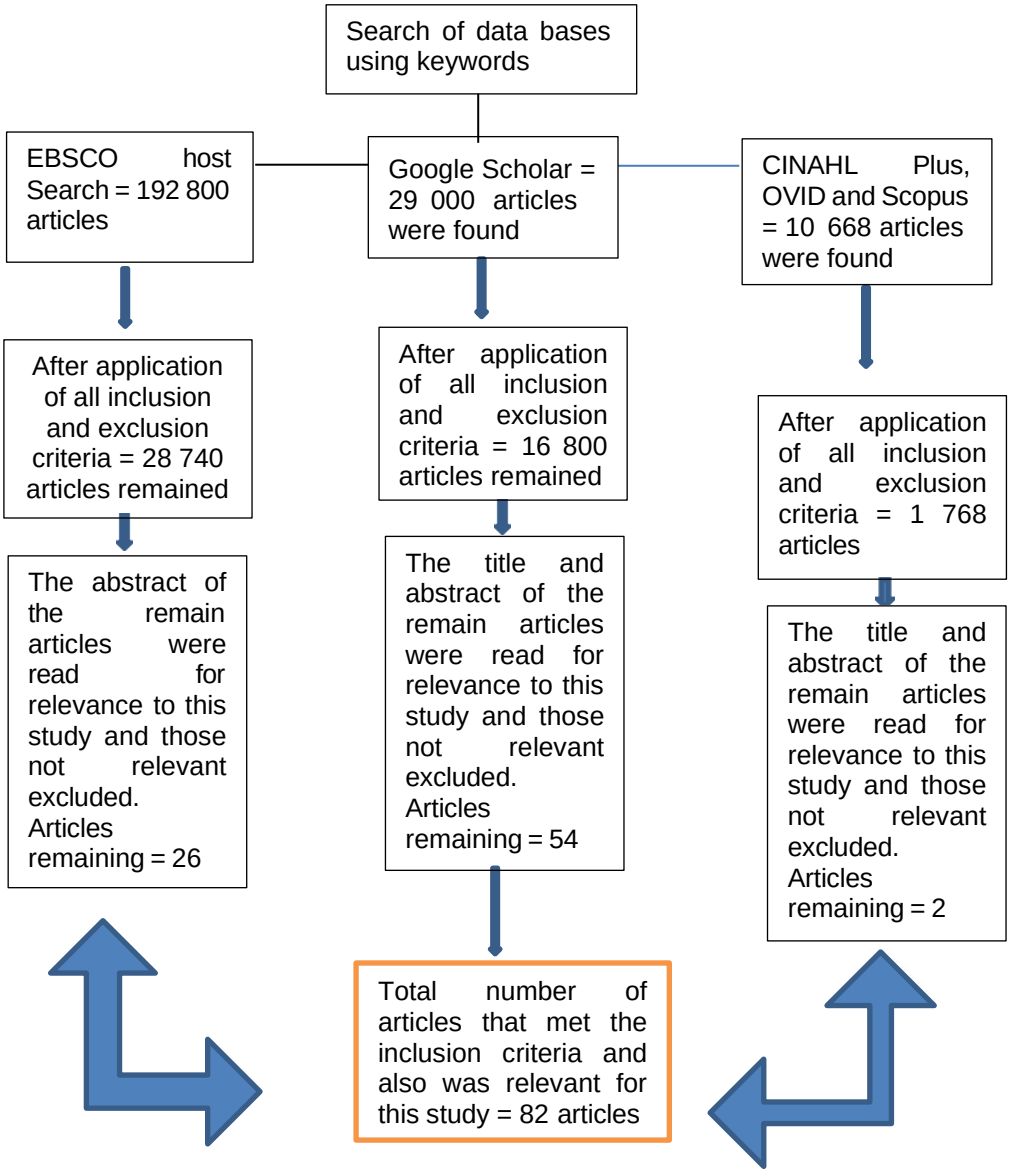


**Figure 2.2: Number of articles included in the literature review**

## 2.7 Themes that emerged relevant to this study

The researcher critically read and analysed all the selected articles and identified the themes below that were specifically relevant for this study.

### 2.7.1 Nurses supporting families of children with ASD

Parenting a child with ASD is a very highly stress experience for most parents and they need as much support from family and healthcare providers (HCPs) as possible. The most stressful time for a parent is when they receive their child's diagnosis of ASD

for the first time; at this time and throughout their journey as a parent that they need support from the family and especially the nursing staff they encounter. The kind of support that parents expect from nurses is education on ASD and how to care for their child as well as information about the available ASD resources in the community. They also require access to information and materials on ASD. When in hospital, they need to be informed by the nurses of their child's treatment plan, they need to be listened to, and they need to feel that the nurse is caring and supportive to them and their child. They also require material/ financial resources and help from family members. Parents want to be involved in the decision making with regards to their child's care and be supported in making these decisions. Family want physical, emotional and social support (Nygård and Clancy 2018: 3188; Oh *et al.* 2018: 274; Aarthun, Øymar and Akerjordet 2019: 55; Brødsgaard *et al.* 2019: 3134; De Beer and Brysiewicz 2019b: 22; Phiri, Kafulafula and Chorwe-Sungani 2019: 236; Gautam 2020: 15; Krajnc and Berčan 2020: 365; Magalhães *et al.* 2020: 557; Goh *et al.* 2021: 3269; Shibily *et al.* 2021: 133; Weissheimer *et al.* 2021: 2; Abukari, Acheampong and Aziato 2022: 4; Thi Lan Anh and Nujjaree 2022: 63).

### 2.7.2 Definition of family

Only one definition of family was discovered in this literature review and that definition was from Cranley *et al.* (2022: 69) who defined family as comprising people who play an important role in a patient's life for example parents, relatives, siblings, etc. Cranley *et al.* (2022: 69) went on to say that family interacts with and has a relationship with the patient and the healthcare team and that family members are key care partners in the task of providing quality patient care.

### 2.7.3 Definition of family involvement

Family centred care, family and patient centred care, parental participation and family/parent involvement are all very similar terms and are sometimes used interchangeably, however in this study we will differentiate between them. 'Family centred care' and 'family and patient centred care' can be used interchangeably. 'Parental participation' and 'family involvement' can also be used synonymously. However, 'family centred care' and 'family involvement' are different terms.

Family centred care (FCC) is a model developed in the 1990s and was mainly influenced by the research of James Robertson and John Bowlby. Prior to their work the general belief was that the health professional was the expert on clinical treatment and the patient and family were passive recipients of this clinical wisdom. FCC has been defined by the American Academy of Paediatrics as an approach to healthcare, in which the HCPs acknowledge the significance of family in the patient's healthcare and partners with patient and family in the planning, implementation and evaluation of healthcare (Coats *et al.* 2018: 52). The Institute for Patient and Family Centred Care describes four key constructs related to FCC, namely: dignity and respect, information sharing, participation and collaboration (Mol, Argent and Morrow 2018: 50).

Family Involvement (FI) or family participation is thus a component of FCC. FI is described as a component of FCC by many authors. FI can be defined as a method which involves the family as a component of the health care team by actively allowing them to assist with the planning and implementation of health care decisions and thus empowering the patient and family to take accountability for the patient's health.

Parental participation is defined as effective participation of parents in specific, agreed upon, stages of their child's health care facilitated by an exchange of information and increased parental skills (Coats *et al.* 2018: 52; Mol, Argent and Morrow 2018: 50; Shimizu and Mori 2018: 1590; Smith 2018: 57; Clark, Whitt and Lyons 2019: 890; Hsiao, Lu and Tsai 2019a: 681; O'Connor, Brenner and Coyne 2019: 3362; Phiri, Kafulafula and Chorwe-Sungani 2019: 232; An, Chan and Kaukenova 2020: 30; Krajnc and Berčan 2020: 357; Acar, Chen and Xie 2021: 2; Alexanian *et al.* 2021: 258; Williams *et al.* 2021: 436; Abukari, Acheampong and Aziato 2022: 1; Mohammed and Sunghee 2022: 14).

### 2.7.4 The components/principles of family involvement

As described above, the four key constructs of FI are: collaboration, respect/dignity, participation and communication. The practice of (FI and its components have been accepted by many countries in the world, however the implementation of FI has differed because many countries have chosen to implement certain components of FI. Collaboration mutual trust, support, information and partnerships were the components implemented in Asia (Shimizu and Mori 2018; Uhm and Kim 2019; Hassankhani *et al.* 2020). Shared decision-making, information sharing, respect and

dignity and participation were implemented in USA and Canada (Discenza 2018; Clarkson *et al.* 2019). Swedish researchers ran a training programme to improve parental support (Kjellsdotter, Lantz and Ottosson 2018). Norwegian researchers implemented the components of empathy and respect (Hagen *et al.* 2019). Family support was implemented in Ghana (Abukari, Acheampong and Aziato 2022). In Tanzania the participation component of FI has been implemented by allowing parents flexible visiting hours (Saria, Mselle and Siceloff 2019). All four of the key constructs were implemented in Europe, (Abukari, Acheampong and Aziato 2022: 1).

No studies could be found on the implementation of FI in the context of South Africa and therefore the need for this current study.

### 2.7.5 Benefits and importance of family involvement

FI in the care of patients (adults and children) is the gold standard of care in many countries that have embraced and even regulated FI under the umbrella of FCC. All the studies cited in this section agree that there are major benefits to FI for the patient, the family, and the nurse. Some studies have noted that the nurse's perception of FCC depends on her/his attitude towards FCC. Nurses that see FCC as an important part of their nursing duties and see the family member and patient as a unit, report very good experiences and perceptions of FCC and those nurses that have a negative attitude towards FCC and FI have a less positive perception on it. The recognised benefits for the nurse are: 1) Practically the nurse can assign some of the basic care of the child, to the parent, such as changing and feeding the child and thus freeing up time for the nurse to focus on delivering good quality nursing care, 2) FI helps to improve the nurse-family relationship, which helps with gaining mutual respect and co-operation, 3) If family are continuously present then they can make quick decisions on care of the child and this speeds up treatment, 4) Especially for children with ASD, family can help to calm the child if he/she becomes agitated or aggressive and help to individualise the nursing care plan to this specific child. Implementing FI for hospitalised ASD children has proven to be physically and emotionally beneficial for the parent and child. For the child (patient), having their family close to them gives them a sense of security and therefore reduces fear and anxiety and increases their co-operation with the nurses and medical staff. Effective FI and FCC have been linked with better health outcomes of the patient and higher levels of patient satisfaction. The

benefit for the family is that the family feels less anxiety and stress when they are involved in their family members care. Family members report greater family satisfaction with the nursing care when they have been involved in the care and have a better buy-in of the care. Family members feel more respected by the nurse and health team when they are involved. In summary, FI benefits the patient, the family and the HCPs (Argumedes, Lanovaz and Larivee 2018: 2588; Coats *et al.* 2018: 52; Dahav and Sjöström-Strand 2018: 364; Hetland *et al.* 2018: 68; Oh *et al.* 2018: 274; Shimizu and Mori 2018: 1590; Smith 2018: 57; Clark, Whitt and Lyons 2019: 899; Clarkson *et al.* 2019: 3978; Phiri, Kafulafula and Chorwe-Sungani 2019: 232; An, Chan and Kaukenova 2020: 30; Dunlap and Filipek 2020: 40; Gautam 2020: 17; Nicholas *et al.* 2020: 97; Maaskant *et al.* 2021: 2; Martinez-Torres *et al.* 2021: 2; Naef, Schmid-Mohler and Ernst 2021: 328; Van De Graaff *et al.* 2021: 64; Williams *et al.* 2021: 440; Cranley *et al.* 2022: 69; Mohammed and Sunghee 2022: 13; Thi Lan Anh and Nujjaree 2022: 64).

The researcher could not find any literature on family involvement in the nursing care of a child with ASD in South Africa, which shows a gap in knowledge, which this current research has addressed.

Even though FI has been proven by the above authors to be beneficial for the nurse, family and child, Mimmo *et al.* (2019: 1203) found that parents reported that they felt that they were overly involved and treated like another member of staff and not as parents, they felt that the nurses had abdicated all their responsibilities to the parents and therefore created much more stress and guilt for the parents and therefore in this case FI was not beneficial to the family. This increased stress of the family lead to increased stress in the child and therefore also was not beneficial to the child.

### 2.7.6 Nurses are important for family involvement

Successful FI is dependent on the nurse, as she/he is the most important role player in the hospital setting because she/he has the most contact with the patient and family. The nurse can identify the patients' and families' need for FI and advocate for them. During hospitalisation the nurse plays a crucial role in teaching the family about the patient's ailment, and including them in the patient's care promotes FI. Nurses should involve the family and patient in the nursing care to ensure that the patient's preferences are incorporated, which will lead to healthier patients and a positive

hospital encounter for all. Nurses can become change agents by educating and supporting and involving their patients' families. The nurse is the one member of the healthcare team that communicates with the entire team and the family and therefore their beliefs and attitude towards FI can be very important in assisting or blocking the implementation of FI, (Coats *et al.* 2018: 52; Hetland *et al.* 2018: 68; Smith 2018: 57; Clark, Whitt and Lyons 2019: 899; Phiri, Kafulafula and Chorwe-Sungani 2019: 232; Dunlap and Filipek 2020: 40; Gautam 2020: 17; Maaskant *et al.* 2021: 2; Van De Graaff *et al.* 2021: 64; Cranley *et al.* 2022: 69; Mohammed and Sunghee 2022: 17).

As described in the above paragraph nurses play a vitally important role in the implementation of FI; nurses' attitude and perceptions of FI can help or hinder FI therefore it is vitally important to explore their perception of FI. This has not been conducted in the South African context, therefore this is a gap in the literature that this current study has filled.

### 2.7.7 Nurses perception of family involvement

Studies conducted in Sweden, Malawi, Canada, Netherlands, Saudi Arabia and the USA have found that nurses have a positive perception of FI in the nursing care of patients. These studies found that nurses saw the value of FI for themselves as nurses, for the families, and for the patients. Even though the nurses in these studies experienced some barriers to FI, they focused on the benefits of FI such as building a positive and trusting relationship between the families (parents) and the nurses, helping deliver good quality nursing care, helping to comfort the patient, answering questions from the medical team thereby providing important clinical and care related information, and the family carrying out some nursing tasks for the nurses (Coats *et al.* 2018: 54; Phiri, Kafulafula and Chorwe-Sungani 2019: 236; Alexanian *et al.* 2021: 258; Fraatz and Durand 2021: 4; Maaskant *et al.* 2021: 2; Mason *et al.* 2021: 563; Shibily *et al.* 2021: 133; Konradsen *et al.* 2022: 1).

Although the studies cited above found that most nurse participants had positive perceptions, some of the participants had negative perceptions of FI. Negative perceptions were related to a differences in culture, unrealistic expectations from the family, the family demanding nurses' attention and time, and the nurses' beliefs that family are not important in patient care. Some studies found that newly qualified nurses had poor perceptions of FI, while other studies found that older more experienced

nurses had a negative perception of FI. Due to the conflicting reports arising from the above studies regarding how demographics of the nurses affected their perception of FI, the researcher has disregarded these factors, (Hetland *et al.* 2018: 73; Hsiao, Lu and Tsai 2019a: 684; Phiri, Kafulafula and Chorwe-Sungani 2019; Alexanian *et al.* 2021: 258; Mason *et al.* 2021: 564; Shibily *et al.* 2021; Konradsen *et al.* 2022: 1).

From the above two paragraphs we can see that some nurses have a positive perception of FI while other nurses have a negative perception of FI. There have been no studies conducted in the South African context to elicit South African nurses' perception of FI and therefore there is a gap in the literature. This study addressed this gap by exploring the perceptions of nurses with regard to FI.

### 2.7.8 Families' perceptions of family involvement

Studies conducted in Iran, Ghana, Australia, China, Norway and the USA all found that family members reported that FI was not being implemented correctly. Examples of this were: the nursing staff did not support them, there was a lack of information from the nursing staff that caused them anxiety, pain in their children was not managed well, nursing and medical staff had bad attitudes, nurses ignored them which caused them stress, staff were not available, and poor communication with them, (Dahav and Sjöström-Strand 2018: 366; Nygård and Clancy 2018: 3189; Clarkson *et al.* 2019: 3978; Hsiao, Lu and Tsai 2019a: 681; Mimmo *et al.* 2019: 1208; Mahoney *et al.* 2021: 2; Mason *et al.* 2021: 563; Abukari, Acheampong and Aziato 2022: 4).

Only one study, conducted in Japan by Shimizu and Mori (2018: 1598), found that parents were happy with the level of FI in the nursing care of their child.

From the above we can see that the majority of studies on family perception of the implementation of FI found that there was poor implementation of FI. It is important to note that none of these studies were conducted on families of children with ASD specifically, and none of the studies were conducted in South Africa, again showing a gap in literature that this current research has addressed.

## 2.8 Factors that challenge or promote family involvement

### 2.8.1 Communication

All the studies cited below reported that poor communication was a major challenge to the implementation of FI for their child with ASD in hospital. This poor communication took on two very different meanings: firstly, for the nurses and other HCPs, poor communication meant that the child with ASD could not adequately communicate the problem or medical care needed. This was mainly due to the fact that most of the children with ASD were nonverbal, and families also reported that even if their child could talk, they experienced stress induced mutism during hospitalisation. This meant that nurses and other HCPs could not accurately examine the child and get to the correct diagnosis. Secondly the families of children with ASD reported that there was poor communication and information sharing from the nurse or HCPs, in that they did not communicate their findings or treatment plan with the parents. They did not take time to explain to the families and child, the actual plan of care or treatment. Furthermore, families also reported that many nurses and HCPs did not communicate with the child at all, even though the child could understand speech very well; this caused dissatisfaction from the parents and behavioural outburst from the child. The families reported that there was just one-way communication where the nurses' issued orders to the families and child. Some families reported a language barrier, where the nurses' and families did not speak the same language and it was also reported that nurses and HCPs interpreted the child's difficult behaviour as being naughty or as a result of bad parenting, whereas the parents interpreted the child's behaviour as a communication of the child's anxiety. In summary, poor communication has been identified as a challenge to correctly implementing family involvement in the nursing care of the child with ASD (Mol, Argent and Morrow 2018; Wilson and Peterson 2018: 812; Hogan 2019: 2; Morris, Greenblatt and Saini 2019b: 2381; Phiri, Kafulafula and Chorwe-Sungani 2019: 232; Taghizadeh *et al.* 2019: 934; Krajnc and Berčan 2020: 934; Walsh *et al.* 2020: 422; Mahoney *et al.* 2021: 7; Mason *et al.* 2021: 563; Myers *et al.* 2021: 3073; Abukari, Acheampong and Aziato 2022: 4; Garrick *et al.* 2022: 2046; Mohammed and Sunghee 2022: 13; Mukhamedshina *et al.* 2022: 6).

The authors cited below found that the most prominent facilitator of FI was effective communication between families and nurses or HCPs. For FI to be successful nurses

need to work together and communicate effectively with the family members in a courteous manner. Research indicates that consistent and organised nurse communication is a fundamental component of FI, and that early communication by nurses with family members is a great enabler of family involvement. Unrestricted, truthful, polite communication with sufficient time to communicate has been found to enable the development of a valuable cooperative relationship between the nurse and family members. Efficacious communication amongst nurses and family members reduces discord and family anxiety levels and increases reciprocal confidence and family contentment and is therefore necessary for FI (Benich *et al.* 2018: 38; Dahav and Sjöström-Strand 2018: 364; Hetland *et al.* 2018: 73; Mol, Argent and Morrow 2018: 53; Morris, Muskat and Greenblatt 2018: 490; Wilson and Peterson 2018: 814; Aarthun, Øymar and Akerjordet 2019: 55; Brødsgaard *et al.* 2019: 3118; Clark, Whitt and Lyons 2019: 899; Hogan 2019: 3; Mimmo *et al.* 2019: 1209; O'Connor, Brenner and Coyne 2019: 3362; Phiri, Kafulafula and Chorwe-Sungani 2019: 231; Taghizadeh *et al.* 2019: 927; Krajnc and Berčan 2020: 364; Nicholas *et al.* 2020: 94; Maaskant *et al.* 2021: 1; Mahery 2021: 2; Mahoney *et al.* 2021: 6; Myers *et al.* 2021: 3074; Weissheimer *et al.* 2021: 2; Bevan *et al.* 2022: 1; Garrick *et al.* 2022: 2047).

Children with ASD have difficulty with all forms of communication. Wilson and Peterson (2018: 811) discovered that a mere 23% of children afflicted with ASD could speak and even fewer could express the symptoms they were feeling, in hospital. Children with ASD find it difficult to understand commands and communication from nurses. Some children with ASD feel isolated and angry because nursing staff assume they cannot communicate and only communicate with the family; this is as an obstacle to the nurse developing bonds with the family and the child. Not surprisingly families appreciated nurses who took time to speak directly to the child which helped to establish a bond between the nurse and child.

The authors cited below have discovered useful techniques for conversing with ASD children, such as using visual aids, increasing the time for communication and comprehension, and noticing non-verbal types of communication. It is very helpful if nurses are conversant in the varieties of nonverbal communication, namely: technological devices, sign language and body language including facial changes. For a child with ASD, one of the most important nursing interventions to plan for is communication. Alternative communication methods should be tried by the nurse such

as basic sign language, using pictures and ascribing meanings to colours such as red to indicate pain, (Wilson and Peterson 2018: 811).

The authors referenced below note the importance of nurses creating a well-defined mode of communication with children afflicted with ASD promptly – failure to do so may result in intensified irritation and violent behaviour which is harmful to the safety of the child and nurses, (Wilson and Peterson 2018: 811; Mimmo *et al.* 2019: 107; Morris, Greenblatt and Saini 2019a: 2375; Thom, McDougle and Hazen 2019: 439; Nicholas *et al.* 2020: 95; Owen, Gary and Schnetter 2020: 35; Fraatz and Durand 2021: 2; Jakimowicz, Perry and Lewis 2021; Mahoney *et al.* 2021: 2; Garrick *et al.* 2022: 2057).

### 2.8.2 Nurses' knowledge of ASD

Eighteen articles in this literature review highlighted that healthcare workers (including nurses and doctors) lacked knowledge of ASD and therefore lacked knowledge of how to care for a child with ASD. Some studies highlighted that healthcare workers also had a lack of knowledge on involving the family in the care of their children. This lack of knowledge was highlighted as a challenge to FI. This challenge was mainly identified by families but also identified by the healthcare workers themselves. Linked to this lack of knowledge, many families also reported that healthcare workers did not share information on their child with them, which was a further challenge to FI (Morris, Muskat and Greenblatt 2018: 484; Aarthun, Øymar and Akerjordet 2019: 54; Brødsgaard *et al.* 2019: 3117; Hsiao, Lu and Tsai 2019b: 681; Mimmo *et al.* 2019: 1023; Morris, Greenblatt and Saini 2019b: 2374; Taghizadeh *et al.* 2019: 934; Thom, McDougle and Hazen 2019: 436; Naef *et al.* 2020: 328; Nicholas *et al.* 2020: 94; Fraatz and Durand 2021: 2; Myers *et al.* 2021: 3079; Pillai, Makhetha and Aldous 2021: 126; Abukari, Acheampong and Aziato 2022: 6; Cranley *et al.* 2022: 70; Garrick *et al.* 2022: 2046; Konradsen *et al.* 2022: 1; Mukhamedshina *et al.* 2022: 2).

The authors below see education and training on ASD as a facilitator of FI. The participants in the studies referenced below unanimously requested education and training on ASD. Doctors, nurses and other HCPs all reported very little to no training on ASD in their formal training programmes. Due to the rising number of ASD patients HCP participants requested education and training on ASD, particularly in relation to screening, diagnostic standards, communication approaches, management choices,

co-morbidities and available resources. Studies conducted in the UK and Canada have found that increased education and training on ASD for nurses and other HCPs leads to a greater understanding of the disorder, which leads to better quality nursing care and more FI in the nursing care of the child with ASD (Benich *et al.* 2018: 35; Wilson and Peterson 2018: 814; Morris, Greenblatt and Saini 2019a: 2380; Thom, McDougle and Hazen 2019: 436; Coughlan *et al.* 2020: 1930; Dunlap and Filipek 2020: 47; Gautam 2020: 17; Mazurek *et al.* 2020: 242; Nicholas *et al.* 2020: 94; Owen, Gary and Schnetter 2020: 34; Kouo and Kouo 2021: 2829; Mahoney *et al.* 2021: 2; Naef, Schmid-Mohler and Ernst 2021; Sohl *et al.* 2022: 4).

### 2.8.3 Time

Lack of time was reported to be an issue by all the authors cited below. This lack of time was experienced differently by the families of the child with ASD and the nurses. The families felt that the nurse or doctor did not spend enough time with their child and were rushed. The nurses and doctors in the studies reported that they did not have enough time to spend with families and the ASD child because of workload and inadequate staffing. They also commented that examining and treating a child with ASD required much more time than examining and treating a normal child. So the families and the nurses both agree that not enough time is spent with the child with ASD and their parents, however parents may attribute this to attitude whereas nurses attribute it to workload and staffing, (Oh *et al.* 2018: 284; Wilson and Peterson 2018: 811; Hsiao, Lu and Tsai 2019b: 684; Coughlan *et al.* 2020: 1929; Magalhães *et al.* 2020: 557; Mazurek *et al.* 2020: 241; Walsh *et al.* 2020: 421; Goh *et al.* 2021: 3275; Myers *et al.* 2021: 3080; Van De Graaff *et al.* 2021: 66; Cranley *et al.* 2022: 70).

The authors below found that spending enough time with the child and parents can be a method of promoting FI. Families appreciated nurses and doctors that were patient and spent time attending to their apprehensions. Building trust and relationships takes extra time, actively listening to the child and family takes extra time, providing personalised care takes extra time, caring for a child with ASD takes extra time, and negotiating care and decision making with families takes extra time. Families recognise that nurses and HCPs have limited time, but taking extra time to start with could save time in the future. Poor nurse-family communication wastes everyone's time as information needs to be repeated. It is evident from the literature that in order

to effectively involve families in the hospital nursing care of the child with ASD, the nurses need to spend enough time with family and the child. This has been established as another subtheme of the theme “Methods to improve family involvement” (Benich *et al.* 2018: 38; Dahav and Sjöström-Strand 2018: 366; Wilson and Peterson 2018: 814; Mimmo *et al.* 2019: 1210; O'Connor, Brenner and Coyne 2019: 3364; Myers *et al.* 2021: 3080).

From the above three paragraphs, it is apparent that time can be a challenge or facilitator of FI, however, this factor has never been researched in the South African context and therefore was a further motivation for the current study.

### 2.8.4 Nurses listening to parents

The authors cited below all found that families felt that they were not listened to by the nurses and HCPs. Many families in those studies reported that when they shared their concerns with the nurses and HCP, they were just ignored, which made them feel helpless and powerless with regard to their child’s care. The families were not treated as a valuable member of the healthcare team even though they were the expert on their child, instead decisions were often made without their input or consultation. Some families felt that if their concerns were listened to, their child would have been diagnosed earlier and received the correct treatment. The following authors agree that if nurses and HCPs do not listen to families’ concerns, this can be considered another challenge to FI. (Nygård and Clancy 2018: 3189; Wilson and Peterson 2018: 812; Aarthun, Øymar and Akerjordet 2019: 55; Brødsgaard *et al.* 2019: 3121; Nicholas *et al.* 2020: 96).

The authors cited below found that listening to family members was a promoter or facilitator to FI. Research shows that families appreciate nurses and HCPs that listen to them and elicit their concerns. Family members consider themselves as experts on their children with ASD; they believe that no one knows their child better than they do and therefore the nurses and HCPs should listen to them. Nurses who actively and purposefully listen to the opinions and concerns of family members are more likely to be trusted by the family members and gain their co-operation. When family members are listened to this decreases their stress and anxiety and increases their overall satisfaction with the care of their child and improves their FI in the hospital nursing care of their child with ASD (Aarthun, Øymar and Akerjordet 2019: 56; Brødsgaard *et*

*al.* 2019: 3121; Clark, Whitt and Lyons 2019: 897; Mimmo *et al.* 2019: 1207; Magalhães *et al.* 2020: 557; Nicholas *et al.* 2020: 95; Owen, Gary and Schnetter 2020: 35; Myers *et al.* 2021: 3074).

### 2.8.5 Nurses treating families as partners

Families of all children, but especially children with ASD, consider themselves to be experts on their child because they spend the most time with their child and know them best. In the five studies referenced below, families report dissatisfaction because they were not involved in making treatment decisions regarding their child in hospital. Families reported that at home they make all the decisions for their child but in hospital the HCPs and nurses make decisions without them. These HCPs and nurses do not know their children like their families do. Not treating families as partners in the healthcare of their children has been acknowledged as another barrier to successfully implementing FI with a child with ASD in hospital (Nygård and Clancy 2018: 3180; Wilson and Peterson 2018: 812; Brødsgaard *et al.* 2019: 3134; Mimmo *et al.* 2019: 1206; Walsh *et al.* 2020: 422).

The authors cited below view treating parents as partners to be a method of improving FI. These authors found that families strongly desire a partnership with nurses and HCPs especially because of their lack of medical knowledge and objectivity. In order for this partnership to be successful they need to agree to work together in order to optimally care for the child, bearing in mind that the nurse is in control of this partnership and decides on the degree of FI. In order to form a real partnership, nurses should accept the family as exceptional experts and skilled partners in the care of their child. Families should be treated considerately and permitted to choose their intensity of participation in the child's nursing care. This level of partnership should be agreeable to both the family and the nurse. When nurses respect and treat families as partners in the care of their child, only then can families be truly engaged in the hospital nursing care of the child with ASD (Oh *et al.* 2018: 275; Aarthun, Øymar and Akerjordet 2019: 51; Brødsgaard *et al.* 2019: 3118; Mimmo *et al.* 2019: 1209; O'Connor, Brenner and Coyne 2019: 3362; Phiri, Kafulafula and Chorwe-Sungani 2019: 236; Fraatz and Durand 2021: 4; Mahoney *et al.* 2021: 2; Myers *et al.* 2021: 3079).

### 2.8.6 Environment

Unfamiliar people, unfamiliar environment, noisy machines and intense lights can make the hospital environment excruciating for the ASD child, leading to worsening of self-injurious and aggressive behaviours and to absconding. This difficult behaviour in turn will result in increased family stress, which will strain the family/nurse relationship and negatively affect FI. Thus, an environment that is not conducive for a child with ASD will negatively affect FI. (Wilson and Peterson 2018: 811; Thom, McDougle and Hazen 2019: 437; Nicholas *et al.* 2020: 94; Garrick *et al.* 2022: 2047)

As described above, children with ASD experience major sensory overload in the hospital environment, which can cause them to display difficult and self-injurious behaviour. This behaviour in turn causes stress for the family and the nurses. This leads to a negative hospital experience for the child, family and nurse. In order to counteract this negative, experience the authors referenced below all agree that the child with ASD must be cared for in a conducive hospital environment. A suitable environment would be a quiet, private room, and would have some form of distraction such as music which many children with ASD enjoy, sensory toys, articles of interest to the child, television, laptop or tablet computer, etc. These items can be provided by the hospital, or the parents can be encouraged to bring these items from home. These items would distract the child from the sensory overload or unfamiliar environment and keep them child and happy, which in turn will reduce the family's stress levels and ensure a positive hospital experience for all. These items may even be used as motivation to ensure the child adheres to the needed medical treatment. Other items can be brought from home like pillows and blankets, etc., which make the hospital environment more familiar to the child and make the child less anxious. Many of the studies cited below have created a conducive environment with sensory toys for children with ASD in hospital and have found that this has contributed to them having a very positive hospital experience. Other ways of creating a conducive environment for the child would be putting child in a private room, minimising noise, providing the child with noise-cancelling headphones, black-out curtains in the room, switching off bright lights, etc. A positive hospital experience will be more conducive to promoting FI in the nursing management of the ASD child in hospital (Benich *et al.* 2018: 38; Wilson and Peterson 2018: 814; Morris, Greenblatt and Saini 2019a: 2381; Selvey, Stypulkowski and Waisbren 2019: 92; Taghizadeh *et al.* 2019: 927; Thom, McDougle

and Hazen 2019: 438; Wood *et al.* 2019: 423; Magalhães *et al.* 2020: 557; Nicholas *et al.* 2020: 96; Fraatz and Durand 2021: 2; Bevan *et al.* 2022: 2; Litwin and Sellen 2022: 2).

## 2.9 Challenges to family involvement

The biggest theme to emerge from this literature review was challenges to family involvement. Under this major theme there are many subthemes namely: parental stress, lack of policies and guidelines for family involvement, constrained resources, rigid hospital policies, family dynamics, power and control, and long waiting times. All these subthemes are seen as separate, exclusive challenges to family involvement and are explained below.

### 2.9.1 Parental stress

Parental stress was mentioned in 26 articles and has come up very often in this literature review. Many authors have reported that raising children diagnosed with ASD is additionally demanding and taxing in comparison to a neuro typical child. Parenting an ASD child is associated with elevated degrees of psychological and mental health difficulties, namely poor quality of life, anxiety and depression. Parental stress is related to many factors such as social seclusion, insecurity about the child prognosis, inadequate access to crucial amenities, and intensified financial obligations, amongst others. The social consequences of ASD for the family is devasting and include the following: quality of life, occupation, familial and societal interactions, and individual functioning. The more severe the child's behaviour, the more stress the parents experience. For example, if the child is aggressive and hits other children or themselves or destroys property, then the parents experience more stress. Raising a child with ASD includes many tribulations, such as inadequate resources, few knowledgeable health professionals, no support system, and general ignorance about ASD. Studies have shown that parents experience the most stress immediately after diagnosis and as time goes on. As the parents become more aware of the ASD and learn more about their child, and if they receive adequate support from others, their stress levels do decrease. Parents experience additional stress when taking the child out into other social settings like church or the shopping mall etc. However parents experience the most stress when their child is in hospital. Parents appreciate nurses that acknowledge this increased stress in hospital and try to educate and support the

parents in hospital. The additional support for the child from specialists, occupational therapists, nurses, doctors et al., can reduce this stress in hospital. Likewise poor communication and poor attitudes of nurses et al. can increase parental stress and impede effective family involvement in the nursing care of the child with ASD (Argumedes, Lanovaz and Larivee 2018: 2585; Dahav and Sjöström-Strand 2018: 363; Hetland *et al.* 2018: 72; Morris, Muskat and Greenblatt 2018: 488; Nygård and Clancy 2018: 3180; Wilson and Peterson 2018: 810; Clark, Whitt and Lyons 2019: 890; De Beer and Brysiewicz 2019b: 19; Mimmo *et al.* 2019: 1203; Reddy, Fewster and Gurayah 2019: 43; Coughlan *et al.* 2020: 1929; Gautam 2020: 14; Morsy *et al.* 2020: 140; Owen, Gary and Schnetter 2020: 32; Goh *et al.* 2021: 3269; Mahoney *et al.* 2021: 2; Myers *et al.* 2021: 3074; Pillai, Makhetha and Aldous 2021: 126; Simpson, Schneider and Zlomke 2021: 184; Weissheimer *et al.* 2021: 5; Abukari, Acheampong and Aziato 2022: 4; Garrick *et al.* 2022: 2056; Matin *et al.* 2022: 2; Ruthes *et al.* 2022: 2; Thi Lan Anh and Nujjaree 2022: 64).

### 2.9.2 Lack of policies and guidelines for family involvement

Another challenge to FI found in the literature is the lack of FI policies or guidelines. All of the authors cited below reported that healthcare workers mentioned the lack of a policy or guideline on FI as one of the challenges with implementing good FI. When there is a lack of FI policies and guidelines, FI ends up being implemented at the discretion of the nurse or HCP. HCP and nurses reported that there should be a policy and guideline on FI so that adequate or additional resources can be allocated such as more staff. HCP managers noted that without a proper FI policies or guidelines, they could not enforce FI. The researcher could find no examples of policy on the implementation of FI in hospital for a child with ASD in the literature, demonstrating how important the current research is, as it will provide a framework upon which a policy can be developed in future, (Coats *et al.* 2018: 53; Brødsgaard *et al.* 2019: 3135; Hogan 2019: 3; O'Connor, Brenner and Coyne 2019: 3364; Krajnc and Berčan 2020: 365; Magalhães *et al.* 2020: 558; Nicholas *et al.* 2020: 95; Walsh *et al.* 2020: 421; Mahoney *et al.* 2021: 7; Shibily *et al.* 2021: 133; Mohammed and Sunghee 2022: 20).

### 2.9.3 Constrained resources

The lack of resources was cited by all the authors below as another challenge to FI for the child with ASD in hospital. The overall finding is that if FI is to be implemented

correctly the healthcare system will have to provide the nurses and HCPs with all the necessary resources. These resources include: (1) More space in the units and wards to accommodate the constant presence of a family, maybe even private rooms so that each family and patient would have their own room, 2) A place for family to sleep, 3) Policies, guidelines and protocols on FI that staff can follow, 4) Training on correct implementation of FI, 4) More nurses and HCPs and 5) Demonstration material such as videos and FI literature that can be used to educate the family. Research such as this current study is vitally important to help motivate for more resources (Coats *et al.* 2018: 54; Hetland *et al.* 2018: 67; Phiri, Kafulafula and Chorwe-Sungani 2019: 237; Krajnc and Berčan 2020: 365; Walsh *et al.* 2020: 421; Kouo and Kouo 2021: 2829; Abukari, Acheampong and Aziato 2022: 6; Sohl *et al.* 2022: 2).

### 2.9.4 Rigid hospital policies

Hospitals are extremely inflexible and do not accommodate for the unique requirements of children with ASD. Many rigid policies exist in hospitals to ensure its effective operation but which are inimical to FI. Across the literature cited below both HCPs and families have noted that rigid hospital policies and a rigid environment are challenges to FI and the care of a child with ASD. Nurses and families both reported that inflexible adherence to hospital protocols can cause behavioural worsening of the ASD child. An example of an inflexible adherence is inflexibility with taking of routine vital signs even when the child is vitally stable as this may cause the child extensive behavioural anguish. The lack of FI policies and inflexibility of existing hospital policies are yet another challenge to FI of child with ASD in hospital, necessitating the need for this research and the framework it has developed (Wilson and Peterson 2018: 812; De Beer and Brysiewicz 2019b: 22; Morris, Greenblatt and Saini 2019a: 2384; Taghizadeh *et al.* 2019: 933; An, Chan and Kaukenova 2020: 34; Walsh *et al.* 2020: 422; Kouo and Kouo 2021: 2829).

### 2.9.5 Family dynamics

In the studies cited below the nurse participants all mentioned that they assessed the family member that is with the patient first before involving them in the patient's nursing care. The nurses assess whether the patient is comfortable with that family member and whether the family member is willing and able to participate in the nursing tasks. While involving the family in the care of the patient, the nurses are always cognisant

of the patient's entitlements and dignity which trumps family's rights at all times. The emotional state and co-operation of the family member is also assessed by the nurse before allowing the family member to assist with the nursing care. Thus, family dynamics such as if the patient does not want the family member involved, or the family member does not want to involved, can be a challenge to FI (Hetland *et al.* 2018: 70; Alexanian *et al.* 2021: 257; Goh *et al.* 2021: 3274; Shibily *et al.* 2021: 134).

### 2.9.6 Power and control

Traditionally nurses and HCPs are regarded as the experts when the child is admitted to hospital and as being the ones in control of their working environment. Nurses and HCPs are seen as the gatekeepers, allowing only certain people at certain times to enter the unit or ward and visit the patient/child in hospital. Traditionally the nurse and doctors decide on the treatment for the child and tell the parents what treatment will be administered to their child and the family. The family member is as a passive participant in the care of their child. This traditional view of the nurse/family relationship is a challenge to FI, because FI is the complete opposite to this traditional view. In FI the family are the experts on the child and need to be consulted and involved in the decision-making process. The family member/parent needs to decide what is the best treatment for their child guided by the nurse and HCPs. In the studies cited below many nurses have reported that they are reluctant to give up this power and the control they have to the family of the child and still believe that they are the experts and will make the correct decision for the child, which is another challenge to FI in the nursing care of a child with ASD while in hospital (Dahav and Sjöström-Strand 2018: 367; Aarthun, Øymar and Akerjordet 2019: 54; Brødsgaard *et al.* 2019: 3118; Morris, Greenblatt and Saini 2019a: 2374; Alexanian *et al.* 2021: 259).

### 2.9.7 Long waiting times

Long waiting times include in the emergency department to see the doctor, waiting for a planned procedure, waiting to get admitted to hospital, waiting to go to theatre for an operation, waiting for pain and other medication, waiting for the nurse or doctor, waiting to be discharged from the hospital. A particular kind of long waiting time is a child starving and thirsty because they not allowed to eat because they are waiting to go to the operating theatre. These long waiting times can cause sensory overload in a child with ASD and result in difficult behaviour. This difficult behaviour in turn causes

the families of the child to experience stress and be very unhappy with the nursing care they have received. This unhappiness leads to a strained family/nurse relationship which in turn affects FI. Thus, long waiting times affects negatively affects FI of a child with ASD while in hospital (Wilson and Peterson 2018: 811; Taghizadeh *et al.* 2019: 927; Nicholas *et al.* 2020: 94; Goh *et al.* 2021: 3275; Garrick *et al.* 2022: 2047).

## 2.10 Methods to improve family involvement

One of the major themes that emerged from this literature review was methods to improve family involvement. Subthemes were: developing a personalised plan of care, respect for parents, creating a conducive environment for the child with ASD, building a good nurse-family relationship, provide knowledgeable information, involve parents in nursing tasks, respect culture and religion, in-service education for nurses on family involvement, power and control, parents always present with the child even in theatre. All these subthemes are seen as separate and important subthemes/methods to improve family involvement as described in the literature.

### 2.10.1 Developing a personalised plan of care

All the authors cited below agree that a very important facilitator of FI is personalising the care received by the child with ASD in hospital. Nurses and HCPs need to recognise ASD as a spectrum disorder and therefore the acuteness of behaviours, symptoms and capabilities vary according to the child. No two children with ASD are the same, they are all different with a spectrum of difficulties. The nurse or HCP needs to interview the family of the child with ASD and obtain a detailed history of the child, including all the important information needed to personalise the child's care. The child should then be assessed and examined, after which a very personalised nursing care plan can be developed. An individualised ASD plan of care can be created by the multidisciplinary team in order to enhance the hospital encounter of the ASD child. The nursing care plan for the child with ASD needs to be flexible and individualised and should plan for every part of the hospital stay from admission, ward, operating theatre, to discharge. It should include all the preferences of the child and avoid all the child's triggers. This personalised care plan has been proven to increase the family's and child's contentment with the care received in hospital. Such a plan reduces the family stress and improves the FI in the nursing care of the child with ASD in hospital (Benich

*et al.* 2018: 35; Dahav and Sjöström-Strand 2018: 368; Clark, Whitt and Lyons 2019: 890; Mimmo *et al.* 2019: 1208; Selvey, Stypulkowski and Waisbren 2019: 95; Taghizadeh *et al.* 2019: 932; Thom, McDougle and Hazen 2019: 440; Magalhães *et al.* 2020: 557; Nicholas *et al.* 2020: 94; Walsh *et al.* 2020: 414; Fraatz and Durand 2021: 2; Mahoney *et al.* 2021: 7; Bevan *et al.* 2022: 2; Mohammed and Sunghee 2022: 19)

### 2.10.2 Respect for family

Mutual respect is important for creating a good professional partnership between the nurse and family and promoting FI. Nursing staff and literature have both identified respect as a vital component in promoting FI. Respect is demonstrated by displaying kindness, empathy, and compassion, recognising the uniqueness of each patient, and upholding their human rights. Nurses should also respect the child's family and endeavour to appreciate and respect their thoughts on the nursing and medical care. Respecting the family helps develop a nurse-family affiliation based on trust which results in better health outcomes and happiness with the nursing care. Nurses possess nursing expertise and families are specialists on their children; if both these experts share knowledge and work together they can ensure that the child has optimal health outcomes. The literature quoted below has highlighted that when a respectful nurse-family association occurs, family members are inspired to contribute to their child's treatment and in-hospital management choices. Thus, respecting the family is important to promoting FI (Dahav and Sjöström-Strand 2018: 365; Brødsgaard *et al.* 2019: 3121; Mimmo *et al.* 2019: 1207; O'Connor, Brenner and Coyne 2019: 3362; Phiri, Kafulafula and Chorwe-Sungani 2019: 237; Nicholas *et al.* 2020: 95; Myers *et al.* 2021: 3081; Williams *et al.* 2021: 436; Abukari, Acheampong and Aziato 2022: 4; Mohammed and Sunghee 2022: 14).

The reality is that in many cases nurses are not respectful to families even though the families want to be respected by the nurses, as found by the authors cited below. In these studies, the families reported that they were not seen as experts on their children by the nurses and not seen as source of information on their child with ASD. Their experience of the care in hospital was negative due to being disrespected by the nurses. Families wanted to be involved in their child's care and to receive information from the nurses, however this was not done and the families felt disrespected. (Mol,

Argent and Morrow 2018: 53; Oh *et al.* 2018: 274; Morris, Greenblatt and Saini 2019a: 2375).

### 2.10.3 Building a good nurse-family relationship

Another method of improving FI in the hospital nursing management of an ASD child is for the nurses to build a good nurse-family relationship with family members. The authors cited below found that parents reported that they greatly appreciated when nurses and HCPs took the time to establish a rapport with the child and the family, which is so important in understanding the child's and family's needs and building a trusting relationship. It was found in the literature that nurses and HCPs built a trusting relationship with the child and the family by familiarising themselves with the child, agreeing together on nursing treatment responsibilities, and functioning in collaboration with family members. Partnering of the family and nurses in the care of the child allowed dividing of knowledge, where family members were not abandoned to totally care for their child and make all the therapeutic judgements alone, which resulted in the family members increased confidence in the abilities of nurse or HCP. In the literature it was found that communicating effectively with the parents, as well as clarifying the family's roles in care and the nurse's role, allowed the family and nurses to effectively work together in the child's nursing care and decision making. It was easier to build a trusting relationship with the family when the family members felt that their concerns were being heard and respected by the nurses, and when the nurses were empathetic as well as showing medical expertise. The literature also reports that when there is a good nurse-family relationship the family experience less stress and are more contented with the nursing care and have a positive hospital experience. (Dahav and Sjöström-Strand 2018: 364; Hetland *et al.* 2018: 73; Brødsgaard *et al.* 2019: 3132; Mimmo *et al.* 2019: 1207; Morris, Greenblatt and Saini 2019b: 2374; O'Connor, Brenner and Coyne 2019: 3362; Naef *et al.* 2020: 328; Mahoney *et al.* 2021: 7; Williams *et al.* 2021: 436)

### 2.10.4 Knowledgeable and gives information

The studies cited below found that the nurse participants were knowledgeable about the child's condition, treatment and care. The nurses shared this knowledge with the family of the child admitted. Sharing of this knowledge and explaining the treatment to the family made the family feel included in their child's treatment and increased the

their confidence in the nurse's knowledge and abilities. This information sharing also made the family feel respected and created trust in the nurse's competence to nurse their child and therefore increased the trust relationship between the nurse and family. This created a positive hospital experience for the families and decreased family stress. It is therefore very evident that being knowledgeable and sharing information with the family can improve FI in the hospital nursing care of the child with ASD (Dahav and Sjöström-Strand 2018: 364; Oh *et al.* 2018: 274; Brødsgaard *et al.* 2019: 3133; De Beer and Brysiewicz 2019b: 22; Mimmo *et al.* 2019: 1207; O'Connor, Brenner and Coyne 2019: 3362; Phiri, Kafulafula and Chorwe-Sungani 2019: 232; Mahoney *et al.* 2021: 6; Myers *et al.* 2021: 3079).

### 2.10.5 Involve family in nursing tasks

Involving the parents in important nursing responsibilities can assist in the alleviation of fear and tension, and prime them to attend to their child at home. Including family in their admitted child's care is a chance for distributing knowledge and can help in the continuity of care at home. Nurses can include parents in two ways, namely, passive or active. The passive approach is when parents initiate involvement in care. The active approach is when nurses encourage family members to contribute to nursing activities. Nurses stated that commencement of family involvement is very necessary and helpful but requires careful consideration of the abilities and needs of the family and patient. Nurses were anxious for the parents and children when allocating tasks for parents because they did not want the parents to feel compelled to perform these tasks and be discouraged. It is very apparent from the literature review that when family members are meaningfully involved in care and are allowed to perform some nursing tasks which they are comfortable with, this benefits the child, the family and the nurse and promotes family involvement (Dahav and Sjöström-Strand 2018: 364; Hetland *et al.* 2018: 72; Brødsgaard *et al.* 2019: 3134; Mimmo *et al.* 2019: 1208; Selvey, Stypulkowski and Waisbren 2019: 92; Naef *et al.* 2020: 328; Martinez-Torres *et al.* 2021: 1; Van De Graaff *et al.* 2021: 64; Mohammed and Sunghee 2022: 14).

### 2.10.6 Respecting culture and religion

Children are located in families which are located in particular cultures. Therefore,

nurses and HCPs cannot exclude culture and religion when nursing a child and their family. Culture influences FI in the care of their child, especially in non-Western cultures. The parental experience of in hospital nursing care is profoundly influenced by their culture and religion. Researching the role of the family in many cultures is crucial in developing personalised support approaches pertinent to each setting. Currently most of the literature is from the West and research concentrating on children with ASD and their families in Africa is minimal. This emphasises the importance of the current study. In addition to this nurses that are nursing children and their families are expected to learn about and respect the cultural and religious beliefs of the family and child. If this is done correctly it will promote FI in the hospital nursing care of a child with ASD. Tied into culture is language and a language barrier can have a negative effect on a family's satisfaction with the nursing care of their child. Nurses and HCPs should be aware of the culture and religion of their patient and the family during their admission. The cultural and religious context of the child and their family should be recognised and respected in all aspects of the care provided by the nurse and HCPs. The HCP and nurse should not impose their own cultural or religious beliefs on the child or family, as this may lead to conflict and have a negative influence on FI (Mol, Argent and Morrow 2018: 55; Morris, Muskat and Greenblatt 2018: 2382; De Beer and Brysiewicz 2019b: 23; Acar, Chen and Xie 2021: 1; Goh *et al.* 2021: 3269; Abukari, Acheampong and Aziato 2022: 4; Mohammed and Sunghee 2022: 20).

### 2.10.7 Inservice education for nurses regarding family involvement

All the authors referenced below agree that the nurses' and HCPs' implementation of FI cannot be done on an ad hoc basis but must be a deliberate process guided by knowledge and skills. Therefore, ongoing education and training of nurses and HCPs on FI needs to be conducted in hospitals. The nurses and HCPs need to learn the definition, components, principles and implementation of FI. They also need to learn the skills inherent in FI such as effective communication, active listening, and role negotiation. Training nurses in FI can change attitudes and care practices and improve FI in nursing care. (Hetland *et al.* 2018: 68; Brødsgaard *et al.* 2019: 3135; O'Connor, Brenner and Coyne 2019: 3364; Nicholas *et al.* 2020: 94; Mason *et al.* 2021: 568)

### 2.10.8 Parents present with child always, including in theatre

All the authors cited below found that from the family members point of view, being

present with their child at all the times, including going into the operating theatre, was calming and beneficial for the child and the family members. The nurses however had mixed feelings in that some of the nurses preferred having the family members present all the time to help care for and calm the child down, while other nurses preferred not to have family members present with the child all the time and found this practice counterproductive. The studies cited below found that when the parents where present with the child all the time, the child and family member were less anxious and stressed and were more involved in the care of their child and thus this is a method of improving FI (Benich *et al.* 2018: 40; Mol, Argent and Morrow 2018: 53; Selvey, Stypulkowski and Waisbren 2019: 92; Van De Graaff *et al.* 2021: 64).

## 2.11 Knowledge gap

The literature review reveals the scarcity of research conducted on ASD in South Africa regarding the nursing care of children with ASD while in hospital and on FI, which was the gap in knowledge that this study has addressed. Specifically, there have been no studies conducted in South Africa on family involvement in the hospital nursing care of children with ASD. Furthermore there are no South African studies that: 1) Critically assess the perceptions of nurses and families, regarding the involvement of families in the hospital nursing care of a child with ASD, 2) Identify and describe the challenges perceived by nurses and families regarding the involvement of families in the hospital nursing care of a child with ASD and 3) Explore participant perceptions on the range of corrective interventions and actions available to overcome challenges and promote effective family involvement in the hospital nursing care of a child with ASD. An exhaustive search of the literature revealed that there is no framework for the improvement of family involvement in the hospital nursing care of a child with ASD in South Africa. Therefore, the framework developed in this study makes a unique contribution to the literature.

## 2.12 Chapter Summary

Table 2.2 summarises the three major themes with their subthemes found in this literature review:

**Table 2.2: The three major themes with their subthemes of the literature review**

| Factors that Challenge or Promote Family Involvement | Challenges to Family Involvement | Methods to Improve Family Involvement |
|---|---|---|
| Communication | Parental stress | Developing a personalised plan of care |
| Nurses' knowledge on ASD | Lack of policies and guidelines for family involvement | Respect for family |
| Time | Constrained resources | Building a good nurse-family relationship |
| Nurse listening to parents | Rigid hospital policies | Knowledgeable and gives information |
| Nurses treating families as partners | Family dynamics | Involve family in nursing tasks |
| Environment | Power and control | Respecting culture and religion |
| | Long waiting times | Inservice education for nurses on regarding family involvement |
| | | Parents present with child always, including in theatre |

This chapter reviewed 82 current articles which met the inclusion criteria for this review. The chapter started with a thick explanation of the methodology utilised to source and analysis the literature which was followed by a presentation of the major themes that emerged from the literature review. The major themes that emerged from the literature review were: nurses supporting families of children with ASD, definition of family, the components/ principles of family involvement, benefits and importance of family involvement, nurses perception of family involvement, families perceptions of family involvement, factors that can be challenges or promoters of family involvement, challenges to family involvement and methods to improve family involvement.

# CHAPTER 3: THEORETHICAL AND CONCEPTUAL FRAMEWORK

## 3.1 Introduction

In this chapter the researcher discusses the theoretical frameworks that guided the study and presents the conceptual framework developed in the study. A theory comprises a collection of delineated concepts and relational statements that offer an organised way of reflecting on a phenomenon (Gray and Grove 2021: 170). The theories chosen to guide this research were Betty Neuman's systems model, Murray Bowen's family systems theory and the theory of family care during critical illness. A theoretical framework is a theory that directs the advancement of an investigation and allows the investigator to relate the conclusions to existing nursing research (Gray and Grove 2021: 170)

In research, ideas are called concepts and a conceptual framework is a grouping of concepts which explains the connection and relationship amongst the concepts (Gray and Grove 2021: 172). A conceptual framework is created by classifying concepts, describing them, and suggesting a relationship amongst them (Brink, van der Walt and van Rensburg 2018: 21). A conceptual framework is the theoretical structure guiding a specific study (Gray and Grove 2021: 182). Such a framework provides lucidity in the research in the following areas: 1) Detects and underpins the knowledge gap in established postulations; 2) Supports the notion that the study will add to the body of knowledge in a particular area; 3) Establishes a base for the analysis of data; and 4) Defends the research decisions made. The purpose of having a conceptual framework is to help contextualise and structure the research (Brink, van der Walt and van Rensburg 2018: 21).

A theory can exist by itself, but a framework is associated to a particular study, since it defines concepts specific to that research and how they relate to each other which assists the researcher and the reader of the study (Gray and Grove 2021: 170).

In this study, due to the complexity of the research, no one theory was sufficient to guide this study, so three theories were used as described below, and certain concepts from each theory were utilised to develop a conceptual framework. In this chapter the researcher describes the three theories and presents the conceptual framework developed from these theories.

## 3.2 Betty Neuman's systems model

Betty Neuman was born in 1924 and grew up in Ohio in the USA. She became a nurse in 1947 after attending the Peoples Hospital School of Nursing in Ohio. She attained a double honour at this school of nursing. Neuman then relocated to California, where she served in many nursing roles for numerous years. Neuman obtained her Bachelor's degree in Psychology and Public Health in 1957, in 1966 she completed a Master's Degree, and in 1985 a Doctorate. Neuman went on to have many nursing and academic achievements. In 1982 Newman's systems model (NSM), applicable to nursing practice and nursing education, was first published. After further development and revision, it was published again in 1989, 1995, 2002 and 2011 (Lawson 2021: 231).

NSM has an extensive theoretical basis, incorporating both general systems theory and gestalt theory (Lawson 2021: 232). Neuman also drew on the philosophies of Marx and de Chardin, which suggest "that the properties of the part are determined largely by the larger wholes within a dynamic organised system" (Lawson 2021: 232). De Chardin named this the 'wholeness of life' philosophy. This model also incorporated Selye's concept of stress. NSM also adapted Caplan's conceptual model and related it to the levels of prevention in nursing. Neuman used the above theories deductively, and her own philosophies from her experience as a mental health nurse inductively, to develop this model.

According to the NSM, nursing takes place in a milieu where there is an ever-changing interaction and relationship between the environment and the human being, health and society. With this in mind, the nurse endeavours to ensure that the client's health status is maintained or improved based on their requirements (de Almeida *et al.* 2018: 2).

The NSM is applicable to nursing a child with ASD because the NSM regards the ASD child as a complex entity, who is an open system continuously in contact with the

environment. The NSM asks the nurse to investigate the influence of stressors when caring for a child with ASD. The NSM allows all health care providers to synchronise treatment of the ASD child. Nurses must be aware of factors that influence the child's reaction to stressors. The NSM also promotes changes in nursing practices to deliver wholistic, synchronised and personalised treatment for a child with ASD (Ndubaku 2018: 3).

### 3.2.1 The main definitions of Neuman's system model applicable to this study

The NSM has four major assumptions regarding nursing, human beings, the environment, and health. These assumptions and their relevance to the current study are discussed below.

#### 3.2.1.1 Nursing

NSM regards nursing as a unique vocation concerned about the entire patient and all the variables in the clients' environment which may impact them. The nurse's perception influences the care given (Lawson 2021: 234). This model is applicable to this study as it investigated the perceptions of nurses regarding the involvement of families in the hospital nursing care of a child with ASD. This perception affects the nurse's willingness to involve the family in the child's care. This concept of a nurse is also reflected in the framework developed by the researcher, where the professional nurse is a prominent feature of the developed framework.

#### 3.2.1.2 Human beings

In NSM the 'human being' can be a person or a family. This human being made up of the physical, emotional, social, growth-related, and religious factors (Lawson 2021: 236). This is applicable to the current study as the 'client system' is the child with autism and their family. The study elicited the perceptions of the family participants regarding the involvement of families in the hospital nursing care of a child with ASD. The perceptions of the family participants covered the physiological and psychological needs of their children. The framework developed in this study also proposes that the nurse meets the child's physiological and psychological needs.

#### 3.2.1.3 Environment

Neuman defines environment “as the internal and external forces surrounding the client, influencing, and being influenced by the client” (Lawson 2021: 236). Furthermore, stressors are defined as “environmental forces that interact with and potentially alter system stability”.

In NSM the internal environment is intrapersonal factors which factors within the patient or family. The external environment is interpersonal factors that arise outside the child or family, which is unconsciously created to protect the child and family and help them cope with stressors. In this study the researcher recognises that a child with ASD being admitted to hospital is an external stressor to the child’s and the family’s normal environment and as such they need to create an environment to protect their normal environment. The parent in this case will draw on his or her internal environment to help regulate the environment and protect the child, therefore the parents’ or families’ perceptions of hospitalisation and being involved in their child nursing care is very important as it exposes their internal environment. The parents’ or family’s suggestions on how to improve the care experience and their involvement in nursing care is also very important in ensuring that the nurse creates an environment for the families and the child with ASD that has as few stressors as possible. This study examined the interpersonal relationship between the professional nurse and families and child with ASD, which the NSM refers to as the external environment. The framework developed in this research provides suggestions on how to improve the external environment for the families and the child with ASD, by making suggestions to strengthen the nurse-patient and nurse-family relationships, as well as the actual physical environment of the paediatric ward.

In this research, stressors are the barriers to family involvement and were identified from the perceptions of both the family and nurse participants and a framework was developed inductively by the researcher to prevent these stressors or barriers, and therefore protect the internal environment of the family and child with ASD.

#### 3.2.1.4 Health

Neuman considers the NSM to be a wellness model where health is regarded as a dynamic continuum from good health to poor health. Newman states that the best

possible state is good health or wellness (Lawson 2021: 236). In this study the researcher also proposes that health is a continuum and when the child is in a state of illness in this continuum, they require hospitalisation. The nurse's responsibility is to ensure that the child with ASD returns to a state of wellness on this health continuum and all nursing care is directed toward achieving this purpose. The nurse can minimise stressors to the child's internal environment by meaningfully involving the family in the child's care and thus return the child to the optimal state of wellness as soon as possible with as little disruption of the child's normal environment as possible.

### 3.2.2 Theoretical assertions

Lawson (2021: 236) explains that theoretical assertions are relationships among the essential concepts of a model. Newman's model illustrates the nurse as an active participant in a mutual association with the patient and the nurse is responsible for keeping the client's system stable. In this study this theoretical assertion is adopted, in that the nurse is seen as a functioning contributor in a mutual association with the child with ASD and their family, and it is the nurse that should ensure meaningful family involvement in the nursing care of their child in hospital. It is the nurses' responsibility to minimise stressors to the child's internal and external environment, and this is done by promoting family involvement.

### 3.2.3 Critique of Neuman's system model

The NSM has been criticised for having insufficient clarity, lack of simplicity, insufficient generality and lack of accessibility. In response to this criticism Lawson (2021: 239) responded as follows:

- **Lack of Clarity**: Neuman's model was criticised for having lack of clarity when it comes to the concepts. Neuman then published definitions of concepts in later editions of Neuman's model. The concepts of client, health, nursing and environment are all concepts understood by nurses and form part of the nursing metaparadigm and therefore are clear concepts in nursing.
- **Lack of simplicity**: at first glance the NSM appears to be a very complex model, and indeed it is a complex model because of the multiple links between concepts. However, as demonstrated by the many midrange theories and frameworks developed from it, it appears to be simple for nurses to interpret and utilise.

- **Lack of generality**: the NMS has been criticised for having lack of generality but as demonstrated by its use in various nursing disciplines and other health disciplines, this model can be generalised to many situations in nursing and other disciplines.
- **Lack of accessibility:** the NSM has been assessed and applied extensively to direct research in nursing. Continuous analysis and improvement conducted by research organisations and individual nursing scholars has increased the NSM's research accuracy and therefore improves the accessibility of this model.

### 3.2.4 The use of Neuman's systems model in this study

Parts of the NSM were utilised in the conceptual framework, which acted as the guiding framework for the study. The NSM also had an influence on the framework that was developed as a result of this study.

Application of the main assumptions of the NSM:

1) Human being: also known as 'client system' could represent a patient, family, group, community or social issue. This client system is made up of physiological, psychological, sociocultural, developmental, and spiritual factors. In this study the child with ASD and their family is seen as the client system, which is the centre of the NSM and the centre of this research.

2) Nursing: NSM defines nursing as a unique vocation that is concerned with the whole patient and each of the variables in the client's environment that may influence them, therefore the nurse's perception affects the care given. Nurses are involved in caring for children with ASD while admitted in hospital. In this study they have volunteered to provide data on family involvement in the care of a child with ASD in hospital, i.e., their perceptions regarding the involvement of families in the hospital nursing care of a child with ASD because their perception affects the care they provide.

3) Environment: NSM describes environment as the inner and outer influences encompassing the patient, affecting and being affected by the client. In NSM the internal environment is intrapersonal factors which are factors within the patient or family. The external environment is interpersonal factors that arise outside the child or family which is unconsciously created to protect the child and family and help them

cope with stressors. For this reason, the researcher focused on the interpersonal relationship between the nurse and the family of the child with ASD, as this external environment or interpersonal relationship affects the child's intrapersonal or internal environment and influences his/her behaviour. Therefore, family involvement and the relationship between them and nurses is important to the in-hospital care of the child with ASD.

4) Wellness and Health: Neuman considers the NSM to be a health model, with health being regarded as a dynamic continuum from good health to poor health. Newman states that the best possible state is good health or wellness (Lawson 2021: 236). In this research it is also acknowledged that the continuum of health and wellness for the child with ASD should involve the family in their care while they are admitted in hospital. This helps the child in that routines are maintained whether in hospital or at home due to the common factor in both places being the family as represented by the caregiver. When children are unwell, the purpose of nursing and hospital care is to return them to a state of wellness again, but in doing so the researcher recognises that the admission to hospital will present the child with many stressors and it is the family of the child and the nurses who are the first and second lines of defence against these stressors. The researcher regarded the challenges to family involvement as the stressors in this case and therefore looked to identify these challenges to family involvement and to propose methods to improve family involvement and thereby reduce environmental stressors.

In this research the nurse is seen as a functioning contributor in a mutual association with the child with ASD and their family, and it is the nurse that should ensure meaningful family involvement in the nursing care of their child in hospital. It is the nurses' responsibility to minimise stressors to the child's internal and external environment, and this can be accomplished by promoting family involvement.

NSM is a theory that addresses the relationship of the nurse and the patient, but does not address the relationship between the family and the patient therefore the Bowen's family systems theory (BFST) addresses this aspect of the study. The theory of family care during critical illness addresses the relationship between the nurses and the family, which is not addressed by the NSM and BFST. In summary NSM addresses the nurse-patient relationship, the BFST addresses the patient family relationship and

the theory of family care during critical illness addresses the nurse-family relationship. Thus, these three theories were incorporated into a conceptual framework which allowed the researcher to address all aspects of the research.

## 3.3 Bowen's family systems theory

In 1950s, Dr Murray Bowen established the notion of 'family' as a system. He undertook an exclusive research study from 1954 to 1959 in which he housed young adults diagnosed with schizophrenia, initially with their mothers and then later with other family members, as they lived in psychiatric ward. Continuous scrupulous surveillance by qualified professionals uncovered architypes of behaviour which resulted in the formulation of Bowen's family systems theory (BFST) (The Murray Bowen Achieves Project 2019: 1). It took Bowen 10 years to develop the BFST after working in various psychiatric and academic institutions (Keller and Noone 2019: 1).

### 3.3.1 Main concepts of Bowen's family systems theory

BFST comprises eight main constructs namely: family projection process, differentiation of self, triangles, multigenerational transmission process, nuclear family, emotional process emotional cut-off, societal emotional process and sibling positions. These concepts are presented below in summary form.

#### 3.3.1.1 Triangles

Pfeiffer and In-Albon (2022: 186) explain that in BFST a 'triangle' is the smallest unit of a family system that consists of three people. A relationship with two people is too small and tension builds easily, therefore a three-person relationship is more stable. When there is a third individual in the relationship, the friction is transferred amongst the three individuals in order to ensure stability of all relationships. One of the two closest members, known as the 'insiders' can decide to become more intimate with the third member, known as the 'outsider' if pressure between the two insiders increases. Any conflict or tension that develops between any two people in a triangle tends to change the dynamics of that triangle (Pfeiffer and In-Albon 2022: 186).

Bowen identified this when he invited fathers to family sessions and personally watched the impact of triangling; children would frequently serve as the triangle between the two parents to alleviate tension within the marital subsystem, indicating

that triangles tend to arise during times of stress and when family members feel the need to minimise anxiety or conflict (Thompson, Wojciak and Cooley 2019: 236).

In this current research this triangle relationship is formed by the child, nurse and family member, because hospitalisation is experienced as a time of anxiety and stress. The parent can help reduce stress on the nurse and vice versa in the case of hospitalisation. This relationship is illustrated in Figure 3.1.

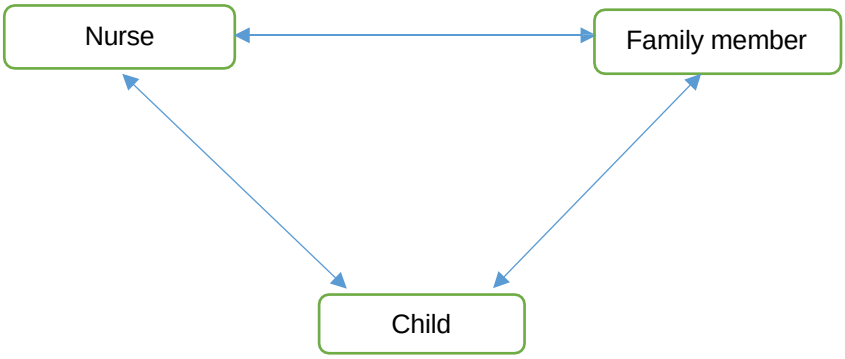


**Figure 3.1: BFST triangle applied to this study**

#### 3.3.1.2 Differentiation of self

Bowen (1978), cited in Thompson, Wojciak and Cooley 2019: 235) asserted that the concept 'differentiation of self' refers to one's ability to maintain a strong sense of one's self-identity or self-concept while interacting with others.

Thompson, Wojciak and Cooley (2019: 235) asserted that individuals who are well differentiated are more likely to cope with interpersonal challenges such as conflict with others and high levels of anxiety as a result of and within the context of these interactions. Bowen (1978) also argued that while all persons can cope with acute levels of worry, it is during heightened or chronic anxiety that individuals' level of differentiation is most visible (Thompson, Wojciak and Cooley 2019: 235).

According to Pfeiffer and In-Albon (2022: 186), every individual inside a triangle or family structure is unique, which is known as 'differentiation of self'. The less established the sense of self, the more likely one is to be influenced by others and to strive to influence others. Someone with a greater sense of self, on the other hand, is less likely to be affected by others and does not try to impose their personality on others.

Pfeiffer and In-Albon (2022: 186) further explain that the extent to which a person develops a sense of self is influenced by familial interactions during childhood and adolescence. There will always be a mix of persons with poor and strong self-differentiation in all families and society at large. Families differ in their levels of emotional interconnectedness dependent on the degree to which family members differentiate themselves. The more emotionally intertwined a family is, the less distinct the individuals' identities are. In such cases adapting to stressful events will be more difficult for a family unit, because an individual's problem affects the entire family unit emotionally (Pfeiffer and In-Albon 2022: 186).

In the current research it is apparent that if a child is admitted to hospital that emotional situation affects the entire family, especially because the child is still to develop his or her sense of self and is dependent on the family, therefore, the inclusion of family members in the nursing care of their child is important.

#### 3.3.1.3 Nuclear family emotional process

The term 'nuclear family emotional process' refers to certain relational processes within a single generation of a nuclear family that can lead to conflict and hence issues within the family system (Thompson, Wojciak and Cooley 2019: 237). Causes of conflict may be found in several subsystems of the family (such as the marriage or people within the family) which all impact the greater family system. When one family member experiences anxiety, whether via open disagreement or emotional distance, this always impacts other family members who must absorb that worry (Thompson, Wojciak and Cooley 2019: 237).

The emotional process of the nuclear family comprises four connection patterns that produce familial problems: marital conflict, one spouse's dysfunction, one or more children's impairment, and emotional distance (Pfeiffer and In-Albon 2022: 186).

In the current research, impairment (hospital admission) of the child results in anxiety of that child which must be absorbed by other family members, therefore, involving family members in the care of their child is vitally important.

#### 3.3.1.4 `Family projection process

'Family projection process' describes how parents may transmit their emotional problems onto their children (Pfeiffer and In-Albon 2022: 190). Children may inherit various flaws as well as strengths from their parents, but interpersonal sensitivities such as a high need for acceptance from others or feeling responsible for other people's pleasure are likely to be the most influential. The projection procedure is divided into three steps: (1) The parent pays special attention to a youngster out of concern that something is wrong with the child. (2) The parent notices something in the child's behaviours or behaviour that confirms their fears, and (3) the parent treats the child as if there is something really wrong with him/her (Pfeiffer and In-Albon 2022: 190). By concentrating so much emphasis on the child's perceived flaws, parents frequently end up forcing the youngster to embody the things that they dread, creating a self-fulfilling prophesy (Pfeiffer and In-Albon 2022: 190).

The family projection process was not considered in the current research.

#### 3.3.1.5 Multigenerational transmission process

Bowen identified multigenerational transmission methods by which emotional processes are carried down through generations (Thompson, Wojciak and Cooley 2019: 241). Bowen hypothesised that one's own degree of differentiation or anxiety is reliant on one's biological family as well as the processes at work to sustain that level of differentiation or stress. The child with the highest emotional cohesiveness or anxiety in the family, for example, will have the least amount of differentiation. Bowen argued that people will marry someone with same the amount of differentiation process, hence they will tend to raise a child in that milieu, thereby maintaining the differentiation or anxiety transmission process (Thompson, Wojciak and Cooley 2019: 241).

Pfeiffer and In-Albon (2022: 190) explain that people tend to seek partners who have comparable levels of self-differentiation as themselves, which means that their offspring will tend to follow in their footsteps. This means that tiny disparities in parental and child differentiation will become greater over time. For example, the child who is more differentiated from their parents will produce offspring that are likely to be somewhat more differentiated than themselves (Pfeiffer and In-Albon 2022: 190). As the trend

continues, the generational disparities might become dramatic. Many aspects of one's life and relationships are affected by one's level of differentiation, including health, marital stability, career success, and others. As a result, various generations of the same family may have very different lives (Pfeiffer and In-Albon 2022: 190).

This concept of multigenerational transmission process was not considered in the current study.

#### 3.3.1.6 Emotional cut-off

'Emotional cut-off' happens when people attempt to settle unsolved issues with family members by cutting off emotional contact totally. In order to become more emotionally independent, it is sometimes necessary to cut off emotional contact with family members (Pfeiffer and In-Albon 2022: 190).

This concept was not considered in the current study.

#### 3.3.1.7 Sibling positions

According to Thompson, Wojciak and Cooley (2019: 235) Bowen used 'sibling position' profiles, terminology, and concepts from Walter Toman, who theorised that an individual's birth order, that is, eldest, middle, and youngest, determines how they handle conflict with their spouse. Bowen claimed that a person's birth order was connected to predicted behaviours and attitudes and therefore was one of the most crucial pieces of knowledge that you could have about them. Bowen argued that sibling birth order profiles were so robust that he could use them to rebuild family emotional dynamics in previous generations (Bowen, 1978). However, this is one of the most contentious aspects of Bowen's theory (Thompson, Wojciak and Cooley 2019: 241).

This concept was not considered in the current study.

#### 3.3.1.8 Societal emotional process

Societal emotional process as arises from Bowen taking his conceptualisations of families and applying these to society. Bowen (1979) proposed that human society is frequently anxious, and that depending on the level of anxiety, society might develop or regress. Long-term anxiety leads to societal deterioration. Decisions in a situation of social deterioration are frequently made based on excessive anxiety, emotion, and

reaction, which diminishes the logical ability to make decisions (Thompson, Wojciak and Cooley 2019: 241).

This concept shows that Bowens Family Systems Theory can also be applied outside the family, in this current research we are looking at the relationship between the nurse and the parent and this concept shows that Bowens Family Systems Theory, therefore applies to this current study as well.

### 3.3.2 Testing and validation of Bowen's family systems theory

Miller, Anderson and Keala (2004) conducted a narrative review of 50 articles on the BFST and found that BFST concerning the positive association between more differentiation and reduced psychological discomfort and chronic anxiety, as well as increased marital satisfaction, had empirical validity as demonstrated in the included research. Calatrava *et al.* (2022: 2) also conducted a similar study and confirmed the tenets of BFST

Lampis *et al.* (2019: 457) conducted an empirical study on 1 807 individuals and found that BFST had cross-cultural validity. Neophytou *et al.* (2021: 185) conducted an empirical study with 717 participants and found that BFST was valid and culturally sensitive. Willis *et al.* (2021: 1) conducted a study on 332 married couples over five years and found parts of the BFST to be valid.

Many studies such as the ones noted above have empirically proven that BFST is a valid theory which is why BFST was chosen as one of the theoretical frameworks for this study.

### 3.3.3 Critique of the Bowen's family systems theory

The researcher searched and could not find many critiques of the BFST, the only one noted was from Calatrava *et al.* (2022: 2) who noted a lack of longitudinal or causal study designs to examine the stability of the construct 'determination of self' (DoS), the intergenerational transfer of DoS, and the efficiency of therapeutic treatments in altering DoS to achieve optimal well-being.

### 3.3.4 The use of the Bowen's family systems theory in this study

In this study Bowen's concept of triangle relationships comprises the child, nurse and family member. Because hospitalisation is experienced as a time of anxiety and stress, a parent or family member can help reduce the stress on the nurse and vice versa. This relationship is illustrated in Figure 3.2.

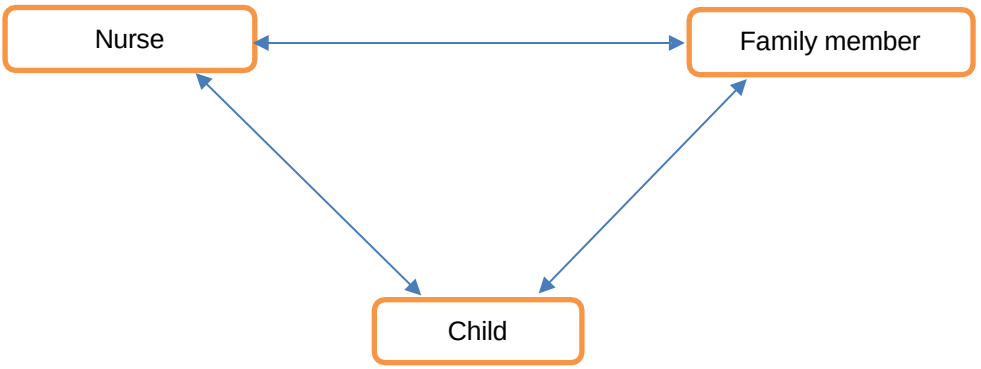


**Figure 3.2: BFST triangle as applied to this study**

Regarding Bowen's DoS concept, this study assesses that when a child is admitted to hospital this emotionally affects the entire family, especially because the child has not yet developed his/her sense of self and is dependent on the family. Therefore, the inclusion of these family members in the nursing care of their child is important.

With regard to the concept of nuclear family emotional process, the assumption is that impairment (hospital admission) of the child results in anxiety of that child which must be absorbed by other family members, therefore involving family members in the care of their child is important. The above three concepts will be utilised in this current study and the other concepts of the BFST are not considered in this study.

## 3.4 Theory of family care during critical illness

The theory of family care during critical illness was developed by de Beer and Brysiewicz (2019a), this theory was developed from a grounded theory study, based on Strauss and Corbin's philosophy. The theory's central notion is empowerment guided by the underlying principles of information sharing, proximity, resource gathering, and cultural and religious collaboration (de Beer and Brysiewicz 2019: 19).

This theory describes family care as a cooperative endeavour characterised by

teamwork and trust between HCPs and Family Members (FMs). This concept places family care in the context of a culturally varied environment. The paradigms of this theory enable HCPs to provide appropriate family care to fulfil the requirements of FMs, resulting in a less stressful critical care experience for patients' families (de Beer and Brysiewicz 2019: 23). The description of the theory Figure 3.3 depicts the notion of family care during critical illness, demonstrating how crisis and stress connected with a family member's illness can lead to a condition of disequilibrium. Other family members exhibit emotional upheaval and disrupted physical functioning as a result of this imbalance. HCPs enabling FMs' access to the patient, sharing information about the patient with the family, aiding FMs to obtain resources and assistance, and being aware of FMs' cultural and religious norms and beliefs all help to reduce family disharmony. These variables give FMs and HCPs more strength. This process is made possible by HCPs who, by making time to interact with a patient's family, foster a sense of cooperation and respect for the individual and the situation (de Beer and Brysiewicz 2019: 23).

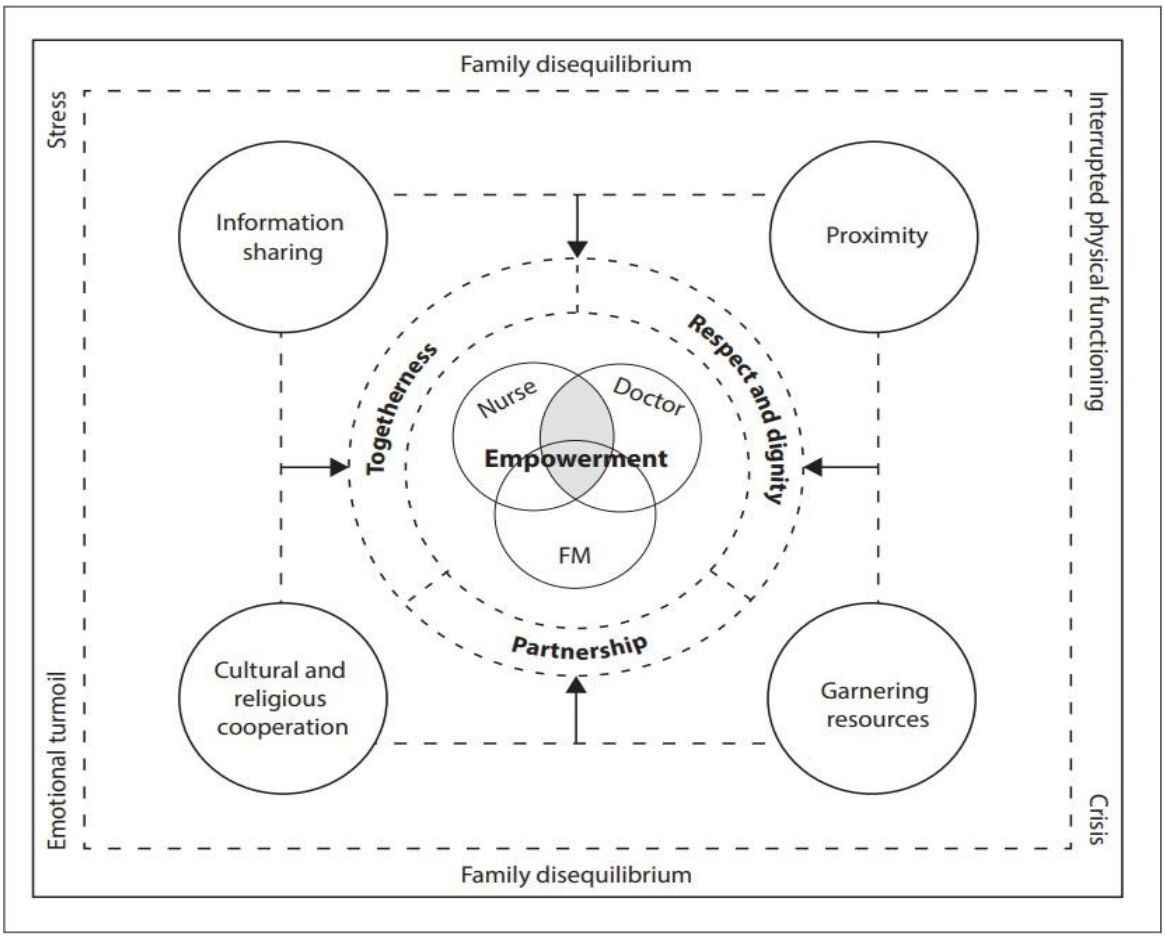


**Figure 3.3: Theory of family care during critical illness**

### 3.4.1 Major concepts

The theory of family care during critical illness' comprises one central idea of empowerment and four sub-concepts: information sharing, proximity, resource gathering, and cultural and religious collaboration. These ideas and sub-concepts are discussed below.

#### 3.4.1.1 Core concept: Empowerment

According to de Beer and Brysiewicz (2019: 21), ‘empowerment’ refers to the process through which FMs progress from helplessness to increased personal ability, allowing them to deal effectively with the psychological, intellectual, physiological, and physical problems connected with a loved one’s critical illness. HCPs help FMs mobilise resources (emotional, cognitive, physical, and environmental) to handle the crisis effectively. In this perspective, empowerment also refers to the empowerment of HCPs who engage and create connections with FMs while providing family care, and so acquire knowledge and skills that help in effectively mobilising resources both for themselves and for FMs. Information exchange, closeness, resource gathering, and cultural and religious collaboration all contribute to empowerment.

#### 3.4.1.2 Sub-concept 1: Information sharing

Information sharing is the communication of truths about the patient and major illness among both HCPs and FMs, which increases everyone’s wisdom. Receiving information on a family member’s status, care, progression, and results, broadens FMs’ understanding, allowing them to best deal with a family member’s severe illness (de Beer and Brysiewicz 2019: 22).

Sharing knowledge adds to FMs' psychosocial support and minimises anxiety connected with the new critical care setting (de Beer and Brysiewicz 2019: 22).

#### 3.4.1.3 Sub-concept 2: Proximity

According to de Beer and Brysiewicz (2019: 22) ‘proximity’ refers to the HCP’s willingness to accommodate the family’s access to the patient. The HCP should facilitate FMs’ physical and emotional closeness to the patient, permitting them to monitor the situation, follow the treatment given to the patient and establish confidence and trust in the care received by the patient. When FMs' entry to their family members

is limited, unpleasant feelings like dread, worry, and powerlessness are exacerbated. Permitting FMs to be near to their loved ones lessens these bad feelings since they may give assistance without sacrificing closeness (de Beer and Brysiewicz 2019: 22).

#### 3.4.1.4 Sub-concept 3: Garnering resources

Garnering resources refers to FMs gaining both material and non-material resources for themselves. FMs' material resources include their requirements for contentment, relaxation, rest, and sustenance, while their non-material resources include their ability to maintain hope. Non-material resources also include FMs' sharing of their pain with others, such as relatives, friends, or HCPs. It is critical for FMs to get enough rest and sleep, therefore to have comfortable furniture in the waiting area or, if feasible, a specific place that has been made homely and relaxing. FMs frequently feel compelled to remain close to the patient; therefore, it is critical to have easy access to water and food in the waiting room (de Beer and Brysiewicz 2019: 22).

#### 3.4.1.5 Sub-concept 4: Cultural and religious cooperation

De Beer and Brysiewicz (2019: 23) state that 'cultural and religious collaboration' refers to HCPs displaying knowledge, regard, comprehension, and acknowledgement of FM perceptions, principles, religious views, and practices relating to a family member's major illness. HCPs must acknowledge patients and FMs as people from a social and spiritual and perspective and provide contextually appropriate treatment. HCPs should also be sensitive to their own stereotypes and assumptions in order to avoid imposing them on others (de Beer and Brysiewicz 2019: 23).

### 3.4.2 Assumptions

According to de Beer and Brysiewicz (2019: 23), the following are assumptions of the theory of family care during critical illness:

- Family care is a joint effort of nurses, doctors, and family members, all of whom play important roles in delivering family care in the hospital.
- Family care capitalises on the family's strength and connectivity; the family and patient are treated as a unit rather than as individual persons.
- Family care necessitates a shift from the professional knowledge paradigm of the HCP to one that promotes knowledge interchange.

- The hospital atmosphere is stressful for both HCPs and FMs, requiring them to devote time and energy to dealing with moments of uncertainty and dread.
- Family care fosters trust by encouraging a therapeutic interaction between HCPs and FMs.
- Family care fosters compassion in a diverse setting.

### 3.4.3 Context

The theory of family care during critical illness was developed as a descriptive approach to the practice of family-centred care in critical care units (CCU) in the South African milieu, a country distinguished by a disparate multiethnic socio-political landscape (de Beer and Brysiewicz 2019: 23).

This theory's backdrop is the physical environment of the CCU, which is frequently viewed as a ‘hostile’ setting characterised by highly technological equipment, bright lights, unexpected loudness, restricted visiting permission, and a hurried pace, with continual activity aimed at preserving the lives of critically sick patients. This theory’s backdrop includes family disequilibrium, which includes emotional turbulence, disrupted physical functioning, stress, and a crisis system (de Beer and Brysiewicz 2019: 23).

### 3.4.4 Purpose

The overall purpose of this theory is to improve family care during the critical illness of a loved one. This idea pushes HCPs to move away from a biological model of care towards one that emphasises caring for the patient within a family setting, with the family viewed as a member of the health team. The family is seen as having competence that, when combined with the healthcare team, helps the patient achieve the best possible outcome. Because the South African health sector is so culturally varied, the theory’s second goal is to improve family care by integrating culture-specific healthcare and adopting ubuntu (solidarity and collaboration) concepts (de Beer and Brysiewicz 2019: 23).

The theory’s third goal is to enable both FMs and HCPs to cope successfully with a patient’s severe illness, based on their respective strengths rather than their deficiencies. The idea was created in the setting of critical care, however it is not limited to this field. The principles are broad enough to be extended to other areas of

healthcare where empowerment of FMs and HCPs is desired (de Beer and Brysiewicz 2019: 23).

### 3.4.5 Evaluation

The theory was successfully evaluated against the following principles of rigour in terms of grounded theory: (i) appropriate; (ii) comprehensible; (iii) general; and (iv) regulated, as stated by (Chiovitti and Piran 2003) and described in de Beer and Brysiewicz (2019: 23). This theory was also evaluated and published in two peer reviewed journals namely; the South African Journal of critical care (de Beer and Brysiewicz 2019a: 19) and Health SA Gesondheid (De Beer and Brysiewicz 2017).

### 3.4.6 Critique

The major critiques of this theory are: it is a relatively new theory that requires implementing and evaluation, and the study setting was confined to an urban area of eThekwini, South Africa.

The theory of family care during critical illness can be incorporated and utilised in this current study because the study setting of the eThekwini region of KZN, which is the same for both studies and the other similarity is that both studies are based in hospitals.

Even though the theory of family care during critical illness has never been tested as yet, its development did follow a rigorous process and has been peer reviewed and published. It was only developed recently which is the possible reason why it has not yet been tested.

### 3.4.7 Use of the theory of family care during critical illness in the current study

The core concept of empowerment and the four sub-concepts of information sharing, proximity, garnering resources, and cultural and religious cooperation are all applicable to the current study, because these are all concepts that can promote the involvement of family in the hospital nursing care of the child with ASD. These five concepts can be interpreted as promoting or hindering family involvement in the hospital nursing care of the child with ASD. These concepts were incorporated in a conceptual framework that will be developed for this study by the researcher.

De Beer and Brysiewicz (2019: 23) have stated that although this theory was created in the setting of critical care, it is not limited to this field. The principles are expansive enough to be extended to various fields of healthcare. It was therefore be incorporated into this study which deals with family involvement in the hospital nursing care of the child with ASD.

## 3.5 The conceptual framework developed for this study

In this doctoral study, the researcher incorporated several complex concepts that were derived from a variety of theoretical domains and frameworks. The researcher evaluated the three theories described above and found that no one theory encapsulated this study in totality, however certain concepts from each of the abovementioned theories did apply to this study. It was therefore necessary for the researcher to develop a conceptual framework for this study that incorporates concepts from each of the three above mentioned theories. This newly developed conceptual framework was the guiding framework for this study and is described in the sections below.

### 3.5.1 Concepts utilised from Neuman's systems model

Two concepts from NSM were incorporated in the newly developed conceptual framework for this study, namely, the nurse and the patient. These two concepts were described by the NSM as follows.

#### 3.5.1.1 Nursing

NSM views nursing as a unique profession that is concerned about the whole patient and all variables in the client's environment that may affect them. The nurse is a major element of this environment, therefore the nurse's perception affects the care given (Lawson 2021: 234). This model is applicable to this study as this study collected the perceptions of nurses regarding the involvement of families in the hospital nursing care of a child with ASD, as their perceptions affect their willingness to involve the family in the child's care. The concept of 'nurse' has been incorporated in the conceptual framework by linking the nurse to the patient/ child with ASD/ human being, because the nurse has a direct influence on the health and wellbeing of the patient, which, in this case, is the child with ASD admitted to hospital. It is the nurse who is there to

control the environment in such a way as to move the child to a state of wellness on the health continuum.

#### 3.5.1.2 Human beings

In NSM the 'human being', can be a person or a family. This human being is made up of the physical, emotional, social, growth-related, and religious factors (Lawson 2021: 236). This is applicable to the current study as the, client system' is the child with autism. The conceptual framework developed in this study incorporates the human being which in this case is the child with ASD. NSM demonstrates that the nurse has a direct impact on the child with ASD, because as described above, the child depends on the nurse to help move to a state of wellness through controlling the stressors in the hospital environment. The conceptual framework for this study shows a direct link / relationship between the nurse and the child with ASD, as illustrated in Figure 3.4

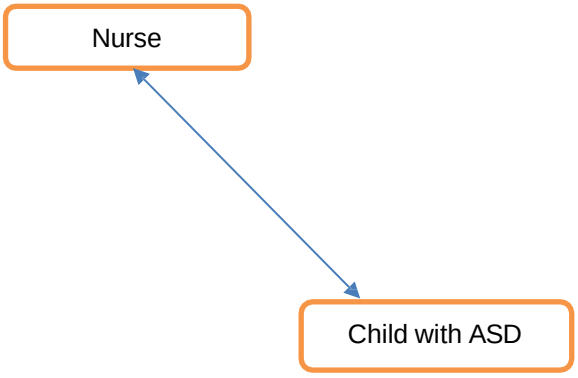


**Figure 3.4: Relationship of the nurse and child with ASD according to NSM**

### 3.5.2 Concepts utilised from Bowen's family systems theory

The main concept that was incorporated from the BFST was the concept of triangles, which has been explained in detail in section 3.3.1.1 above and therefore will not be explained again here.

In the current study Bowen's concept of triangle relationships relate to the child, nurse and family member. Because hospitalisation is experienced as a time of anxiety and stress the parent can help reduce the stress on the nurse and vice versa in the case of hospitalisation. This relationship is illustrated in Figure 3.5.

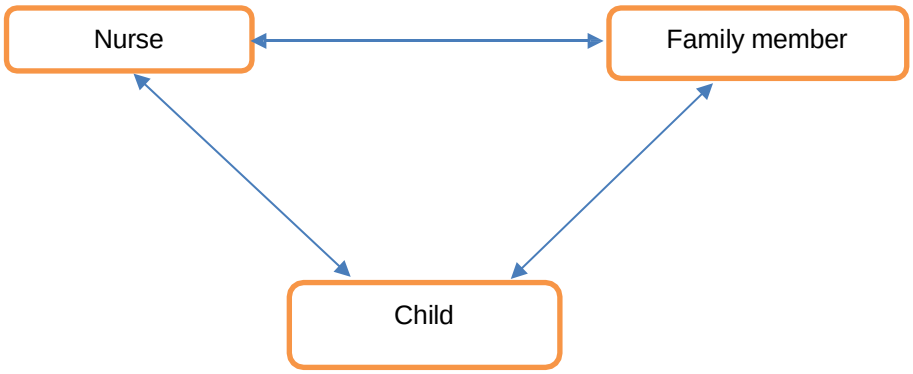


**Figure 3.5:** BFST Triangle applied in this study

### 3.5.3 Concepts utilised from the theory of family care during critical illness

The core concept of empowerment and the four sub-concepts of information sharing, proximity, garnering resources and cultural and religious cooperation are all applicable to the current study because these are all concepts that can promote the involvement of family in the hospital nursing care of the child with ASD. These five concepts can be interpreted as concepts that can promote or hinder the family involvement in the hospital nursing care of the child with ASD. These concepts were incorporated in a conceptual framework that will be developed for this study by the researcher.

## 3.6 Chapter Summary

In this chapter detailed explanations of the NSM, BFST and de Beer and Brysiewicz's theory of family care during critical illness were presented. These three theories were the guiding theoretical frameworks of this study and contributed to the development of a specific conceptual framework for this study.

The researcher explained the NSM in detail and how it is applicable to this study. In this research NSM's theoretical assertion is adopted, in that the nurse is seen as an active participant in a reciprocal relationship with the child with ASD and their family and it is the nurse that should ensure meaningful family involvement in the nursing care of their child in hospital. It is the nurse's responsibility to minimise the stressors to the child internal and external environment, and this is done by promoting family involvement.

BFST was described in detail. In this study Bowen's concept of triangle relationship

are formed by the child, nurse and family member. Because hospitalisation is experienced as a time of anxiety and stress, the parent can help reduce the stress on the nurse and vice versa in the case of hospitalisation. With regard to Bowens differentiation of self-concept, this research assesses that when a child is admitted to hospital this emotionally affects the entire family, especially because the child has not yet developed his/her sense of self and is dependent on the family. Therefore, the inclusion of family members in the nursing care of their child is important. Regarding the concept of nuclear family emotional process, this is reflected in the assessment that hospital admission of the child results in anxiety for that child which must be absorbed by other family members thus involving family members in the care of their child is vitally important.

The theory of family care during critical illness has one fundamental concept and four sub-concepts which are all applicable to the current study because these are all concepts that can promote the involvement of family in the hospital nursing care of the child with ASD. These five concepts can be interpreted as either promoting or hindering family involvement in the hospital nursing care of the child with ASD.

The researcher utilised the three theories above to develop a conceptual framework for this study which was described in this chapter with an explanation of how it was utilised in the research.

# CHAPTER 4: METHODOLOGY

## 4.1 Introduction

In this chapter an in-depth description of the research process and research methodology is presented, including: the research philosophy, research design, research type, research strategy, sampling strategy, data collection method, and data analysis method.

As explained in Chapter 1, the aim of this study was to develop in-depth insights into family involvement in the provision of in-hospital nursing care for children with ASD in the South African context, in order to develop a framework for the improvement of family involvement in the hospital nursing care of a child with ASD. In this chapter the researcher describes in detail the methodology used to achieve this aim.

## 4.2 Research method

Qualitative research is an approach that is used to understand and explore the meaning an individual or group attributes to a problem. The aim of qualitative research was to understand a phenomenon. Data in qualitative research is usually collected in the participants' setting normally by interviews or observation, and analysed inductively by forming themes from the data and presenting them in a narrative (Polit and Beck 2021: 472). The qualitative research method was utilised in this study as described below.

### 4.2.1 Qualitative method

The researcher chose to utilise the qualitative research method because it was in keeping with the researcher's relativist ontological paradigm, social constructivist epistemology, interpretivism theoretical perspective, and inductive research approach.

Qualitative research is an academic approach to describing life experiences, societies, and social dynamics through the eyes of those involved. Qualitative researchers help others understand a phenomenon from the perspective of those who are experiencing it. Qualitative researchers are interested in organically happening daily occurrences in natural settings. The deep, rich, and complex perspectives and experiences inherent

in human lives may be explored through qualitative research. This process generates nursing knowledge by encouraging awareness of patient needs and challenges, directing evolving theories, and defining cultural and social issues influencing health (Gray and Grove 2021: 75).

According to (Polit and Beck 2021: 473), qualitative research methods are an important aspect of nursing knowledge creation because they provide information that is needed for evidence-based practice. Qualitative research is commonly used by nurse researchers to explore issues that affect all elements of clinical practice and human existence. The sentiments and thoughts and feelings of persons with whom nurses engage are some of the most essential parts of holistic nursing practice, therefore qualitative research is vital in improving nursing care.

In order to accurately reach the aim of this study it was necessary to utilise the qualitative research method to gather data so as to fully understand the lived experience of families and nurses in order to identify the barriers and promoters of family involvement and develop an evidenced based framework.

### 4.2.2 Qualitative research approach

The qualitative research approach may be categorised into two sub-approaches: the deductive approach, and the inductive approach. The deductive approach is generally employed when the study emphases formulation of theories and assumptions and develops a research scheme to test hypotheses and is aligned with quantitative research. When gathering data and creating a theory as a result of data analysis, the inductive method is typically used. The deductive approach is more in line with the positivist philosophy, the inductive approach is more in line with the interpretivist philosophy, and it is crucial to match research philosophies and research approaches (Al-Ababneh 2020: 85).

In this study the researcher used the inductive research approach because inductive methodology helps bring meaning to the phenomena through the subjective views of participants (Ryder, Jacob and Hendricks (2019: 2646). The researcher did not have any preconceived hypotheses to test. The researcher used the information gathered from the research participants through interviews to formulate a framework, therefore the inductive research process was utilised but then moved to deductive reasoning in the consolidation of the findings to develop a framework. concept analysis did not

influence the analysis of the interviews

### 4.2.3 Qualitative research designs

Gray and Grove (2021: 95) explain that there are five qualitative research strategies frequently used in nursing. These five strategies are: 1) Historical research, 2) Ethnography, 3) Grounded theory, 4) Phenomenology, and 5) Exploratory- descriptive. Psychotherapists developed phenomenological research and social scientists created grounded theory research. Ethnography was developed by anthropologists to study ethnic groups and cultures. Exploratory-descriptive qualitative research is used to investigate and explain a topic of interest. Historical research is the method used by historians to examine historical documents, relics, and witness interviews to synthesise the information learnt from studying the past. To interpret the meaning of human experiences as created by the people involved is the aim shared by all of the above methodologies, the only difference being the context (Gray and Grove 2021: 96).

The research strategy used for this study was the interpretative phenomenological analysis (IPA) strategy, therefore a detailed description of phenomenology and then IPA will follow in order to describe and motivate its use in this study.

## 4.3 Research design

The research design is the heart of the research and regarded as the plan, framework, blueprint or road map. The research design helps link the researcher's chosen methods and techniques to the research question and problem (Polit and Beck 2021: 51). In this study the IPA design was utilised. This design falls within the qualitative research method. In the paragraphs that follow both the research design and method will be discussed in more detail, as well as the research paradigm.

### 4.3.1 Phenomenology

Phenomenology is the study of lived experiences of participants or the essence of the human experience of a phenomenon (Polit and Beck 2021: 477). The origins of phenomenology can be found in the works of Edmund Husserl (1960) and Merleau-Ponty (1962/ 1999). Initially phenomenology was based on philosophy and contributed greatly to it. Philosopher Martin Heidegger proposed changes to this approach, and phenomenology was further adopted as a method of inquiry in psychology.

Phenomenology is essentially a means of analysing the person and how that individual assigns meaning to an event. The premise that persons build their own realities, and that these realities, in turn, have a substantial impact on the creation of that individual, is a key basis of this study technique. This concept is known as co-constitution, and it describes the premise that individuals and their reality impact one other (Polit and Beck 2021: 477). The perception or significance that a person attributes to what they are undergoing has a significant impact on the individual's feeling of self and desire to share this personal experience with others. Even though all qualitative approaches are concerned with personal experiences and their own unique realities, the phenomenological researcher often goes further than the actual utterances stated by the participant in order to interpret these and discover hidden meaning. Hence, rather than being a descriptive approach, phenomenology is divided into two schools namely :descriptive and interpretive (Polit and Beck 2021: 479). A discussion of the major concepts or significant remarks obtained from analysis of the participant's utterances and interpretation of the meanings the phenomenon being researched has for the person, is the outcome of phenomenological research. The two schools of phenomenology also have different analytic procedures(Polit and Beck 2021: 477).

Phenomenology was utilised by the researcher in order to fully understand the lived experiences of parents who had their autistic children admitted to a hospital in the eThekwini Region of KZN. The researcher also interviewed nurses who cared for children with ASD in hospital, to fully understand their lived experiences of nursing such a child.

The origins of modern phenomenology may be attributed to the German philosopher Edmund Husserl who suggested a descriptive technique to determine the meaning of a phenomena. Husserl suggested that if one can bracket presuppositions, this essence can emerge from the things themselves (Frechette *et al.* 2020: 2). Heidegger, a Husserl protege, is regarded as the father of interpretative phenomenology or hermeneutics. Hermeneutics and interpretative phenomenology are sometimes used synonymously, despite the fact that hermeneutics focuses on the interpretive process more narrowly. There are two major types of phenomenology namely: 1) Descriptive

phenomenology derived from the work of Husserl and 2) Interpretive phenomenology derived from hermeneutic principles. The primary goal of interpretative phenomenology is to expose or reveal a phenomenon by stripping away layers of forgetting or hiddenness that occur in daily life (Frechette *et al.* 2020: 2). As evidenced by the hermeneutic definition of lived experience, phenomenology and, more particularly, hermeneutics are fundamental to interpretative phenomenological study. The researcher utilised interpretive phenomenology, which is discussed below.

### 4.3.2 Interpretative Phenomenology Analysis

IPA was initially established in psychology as a strategy for doing experiential research, but it has gained popularity in health and social sciences in an effort to comprehend and interpret issues that are nuanced and emotionally charged, such as disease experiences. The goal of IPA is to discover what a lived experience means to a person via a deep introspective investigation process. IPA also acknowledges that all are impacted by the world in which we live as well as our own experiences (Peat , Rodriguez and Smith 2019: 7). As a result, IPA is an interpretive process amongst researchers and participants. IPA is especially effective for comprehending things that have received little attention (Peat , Rodriguez and Smith 2019: 7). Unlike descriptive phenomenology, IPA provides instructions on approaching the phenomenon of interest, including sampling, data collecting, and analysis (Peat, Rodriguez and Smith 2019: 7).

### 4.3.3 The role of the researcher in IPA

According to IPA, the investigator is an essential component of the research process. IPA researchers regard their participants as authorities of their experience and that both the researcher and the participants must engage in a process of deep interaction and interpretation, a process known as the double hermeneutic; this process can be explained as the researcher interpreting and seeking meaning as the participants make sense and seek meaning of their experience (Peat , Rodriguez and Smith 2019: 7). In this study the participants will share their experience and attach meaning to that experience, the researcher will further analyse and interpret the participants meaning, thus the researcher will formulate their own meaning of the participants experience. To assist this process of seeking meaning, the researcher needs to engage with a Hermeneutic circle. The hermeneutic circle may be seen as a process which involves

the researcher moving between the smaller units of meaning and the larger units of meaning. It can also be described as the researcher moving between the pieces and the complete lived experience. In this research, the researcher followed the above-described process (shifting between smaller and bigger units of meaning) in the interpretation of the data.

Heidegger (2005: 35) stressed that instead of ignoring our presumptions before dealing with people and data, researchers must constantly monitor how they present themselves across the study. Peat , Rodriguez and Smith (2019: 8) go on to clarify that researchers in IPA must be aware of their self- views, preconceptions, and experiences in order to improve their interpretations to prevent these from becoming a barrier to understanding the participants' experiences, which can be accomplished through reflexivity. Reflexivity is the process of 'being aware' and revealing the researcher influences on the research process. There are five types of reflexive practices in qualitative research, namely: introspection, intersubjective reflection, mutual collaboration, social critique, and discursive deconstruction (Yao and Vital 2018: 196). IPA is based on intersubjective reflexivity. This method seeks to understand the evolution of the researcher-participant connection, (Peat , Rodriguez and Smith 2019: 8). Double hermeneutics is important to IPA because it is relevant when examining the researcher's and participants' viewpoints, opinions, and mindsets. Reflexivity improves the ethics of IPA research by allowing the researcher to recognise his or her own preconceptions and how they impact the research process.

In this study the researcher practised intersubjective reflexivity by acknowledging that the researcher is a nurse and a parent of a child with ASD, but the researcher did not allow this to impede the data collection and analysis process. The researcher did not allow any preconceived ideas to interfere with the research process in any way. The researcher did this by practicing mindfulness to bolster self-awareness, recorded any assumptions in the research plan, kept a reflexive journal and kept notes during data collection.

### 4.4 Research paradigm

According to Polit and Beck (2021: 7), the researcher's view of the world influences the approach the researcher will adopt to address the research problem. It is therefore, important for the researcher to define his or her own research paradigm. Botma *et al.*

(2022: 50) explain further that research paradigms are based on philosophical assumptions, namely ontology, epistemology and methodological assumptions.

### 4.4.1 Ontology

Ontology is a branch of philosophy that addresses the nature of reality. In research, ontology refers to the researcher's perception of reality, or the researchers view of the world (Creswell and Creswell 2018: 5). There are two major types of ontology, namely: realism ontology and a relativism ontology. Realism ontology holds that all reality operates independently of the knower and that environment has no impact on this reality. The premise of realism ontology is that the world's nature is disclosed by observing, measuring and classifying its many material aspects (Power 2020: 43). Relativists, on the other hand, believe that, one actual reality does not exist, but rather many realities and highlight the importance of dialect, heritage, experiences, and history in the building of these various realities. Relativists believe that comprehension of reality is via dialogue with the participants in order to comprehend their perception of the circumstance (Power 2020: 43).

In this research the researcher rejects the realism paradigm and adopts the relativist paradigm, in which the reality for the families of children with ASD can only be known through in depth interviews with them, to gain their lived experiences and this is also true with the nurses that have nursed a child with ASD in hospital.

### 4.4.2 Epistemology

Having chosen the relativist ontology, the researcher will now explain the epistemology chosen so as to be consistent with this ontology. Epistemology is concerned with the nature of knowledge, its possibilities, breadth, and overall foundation. Furthermore, epistemology is concerned with giving a philosophical foundation for the many types of knowledge that are attainable and how we might be sure that they are both sufficient and valid. Epistemology is concerned with the acceptability of knowledge in a particular field of study. In research, epistemology relates to the researcher's philosophy about how knowledge is understood (Al- Ababneh 2020: 77).

Constructionism, subjectivism, and objectivism are the three primary epistemic types. Objectivism holds that meaning and meaningful reality exist independently of awareness, which reflects the idea that social phenomena exist in a reality outside of

social actors. Constructionism suggests that meaning emerges through human interaction with the world's realities (Polit and Beck 2021: 10). Finally, subjectivism refers to the idea that meaning is derived from somewhere other than the item to which it is assigned, implying that the item itself does not contribute to the meaning placed on it by the subject. The subjectivist viewpoint holds that social phenomena are formed by the understandings and acts of social actors (Al-Ababneh 2020: 78).

#### 4.4.2.1 Constructivism

Constructivism is a learning model theory based on philosophical studies and psychotherapy. It posits that knowledge is socially formed and shaped by people's prior life experiences. There are three versions of the constructivist learning theory. The first is known as radical constructivism, and is considered the most radical version of constructivism since it believes that reality exists outside of the person, and that reality is mysterious (Abualhaija 2019: 2). Another milder type of constructivism is social constructivism, which maintains that social interaction, rather than individual intelligence, is a source of knowledge. Knowledge and reality are outcomes of people's social interactions. Jean Piaget created the final type, cognitive constructivism which presumes that knowledge is objective and exists outside of an individual's world (Abualhaija 2019: 2).

#### 4.4.2.2 Social Constructivism

According to social constructionists, everyone's knowledge of the world is formed as a result of daily encounters and diverse social practices, and it is through these social interactions that certain kinds of knowing emerges. People, according to social constructivists, seek to comprehend the world in which they live and work, therefore develop their own subjective meaning of an experience (Creswell and Creswell 2018: 8; Power 2020: 45).

In this study social constructivism epistemology was the basis of the research process. The researcher viewed the lived experiences and interactions between the families of children with ASD and nurses in hospital as a source of knowledge, that could lead to

the production of a framework that to guide nurses' interaction with the families of children with ASD.

#### 4.4.2.3 Social constructionism and epistemological reflexivity

The current study used social constructionism as its epistemological foundation. Power (2020: 45) invites social constructionist researchers to analyse their involvement in the research process, as well as how they are involved in the construction of research data and the interpretation of its conclusions. This researcher took the stance that the lived experience of nurses and parents of children with ASD during hospitalisation is a critical component of socially constructed knowledge, and that the information produced by the current study was co-built by the researcher and participants. This researcher recognised their role in the study process and admitted that they were the author, rather than a witness, in the construction of findings.

### 4.4.3 Research philosophy/ theoretical perspective

A theoretical viewpoint is a philosophical attitude that informs and determines research methods. A research philosophy is an important component since it guides the choice of which research design to use and why. The researcher's research philosophy is concerned with the advancement of knowledge. Based on researchers' perspectives on the research process, there are four forms of research philosophy: positivism, interpretivism, realism, and pragmatism. Paradigm refers to the advancement of scientific practice based on people's ideologies and assumptions about the universe and the nature of knowledge. In other words, people's worldviews influence research design and research methodologies (Creswell and Creswell 2018: 5; Al-Ababneh 2020: 79). The researcher adopted the interpretivism theoretical perspective / research philosophy for this study as discussed below.

#### 4.4.3.1 Interpretivism

Interpretivism was developed to provide a subjective alternative to positivism. Variables and context-related aspects are central to interpretivism. Interpretivism differentiates individuals from physical objects. According to interpretivists, humans cannot be researched in the same way that physical things can. This divide distinguishes social science research from natural science research. Interpretivism

analyses cultural, contextual, and historical disparities in the creation of multiple social realities. Instead of providing clear and universal principles that can be generalised and applied to everyone, interpretivism tries to accommodate the variety of participant views (Alharahsheh and Pius 2020: 41).

Interpretivism as discussed is more sensitive towards individual meanings and contributions. Using the interpretivism paradigm can provide in depth understanding of certain contexts. Adoption of the interpretivism paradigm leads to generation of high-level validity in data as it is based on personal contributions with consideration of different variables (Alharahsheh and Pius 2020: 41).

The interpretative paradigm, as described above, allows researchers to explore many characteristics such as behavioural features based on participant experiences, which aids in describing the participant's reality as interpreted by the researcher. The interpretivist theoretical approach allows researchers to treat the research environment and scenario as unique in considering the specific conditions and people involved. This research philosophy allows the research to be more focused on a single issue while avoiding the positivist paradigm's tendency to generalise research.

Considering the interpretivism paradigm, qualitative techniques are the most suitable approaches to gain in-depth insight into a specific context (Alharahsheh and Pius 2020: 41).

The researcher adopted the interpretivism theoretical perspective / research philosophy for this study, as it allowed the researcher to explore the in-depth lived experiences of parents and nurses, regarding hospitalisation of the child with ASD. It also allowed the in-depth investigation of their experiences and aided in the discovery of techniques for promoting family involvement in the nursing care of a child with ASD in Hospital. This in-depth understanding has also led to the production of a much-needed framework.

## 4.5 Research setting

The study setting is the site where the research was carried out, and it might be organic, slightly supervised, or strictly structured (Gray and Grove 2021: 439). This research was conducted in the form of online interviews with families of children with ASD and nurses who work in paediatric wards at the selected private and public

hospitals in the eThekwini District of KZN. The interviews were conducted online because the data was collected during the Covid 19 pandemic when face to face meetings were discouraged and online meeting encouraged in order to avoid exposing the participants to the pandemic and thus adhering to the ethical principle of non-maleficence. The interviews therefore took place while the interviewer and participants were in their respective homes, which were a safe and comfortable place for both, ensuring a relaxed and conducive environment for all.

## 4.6 Population

Research population is defined as the entire membership of a certain group (Polit and Beck 2021: 797). The population is made up of elements that have one common feature and consists of a complete group of individuals or a specific type of element that is the subject of the investigation. There were two populations for this study, to ensure triangulation of information; the first population was permanently employed professional nurses working in paediatric wards in private and public hospital in the eThekwini region of KZN. The second population was families of children with ASD, who have had their autistic child admitted to a paediatric ward at a hospital in the eThekwini region of KZN.

## 4.7 Recruitment of participants

This research consisted of two different sets of participants, namely family participants and nurse participants. In the following paragraphs, the researcher explains the recruitment of each of these groups.

### 4.7.1 Recruitment of family participants

Family participants were recruited for this study by means of an advert (Annexure 5). This advert was posted on the researcher's Facebook® page and WhatsApp® status. The advert was also posted by a non-profit autism organisation (Annexure 6) on their Facebook® page, their WhatsApp® group and their website (Annexure 5), was also emailed by a special needs school to parents of children with ASD in that school (Annexure 7). Parents that met the inclusion criteria and that wanted to participate in the study, called or messaged the researcher, who set up an appointment and interviewed the participant. This process was repeated until saturation of data was achieved. The researcher checked to see if the family member met the inclusion criteria

before making an appointment. The population of family participants is not known as there are no available statistic available on families of children with ASD, however 10 family members responded and all were included in the sample.

### 4.7.2 Recruitment of nurse participants

Nurse participants were recruited via their employers and via social media. The researcher recruited some nurses via social media by posting an advert (Annexure 8) on the researchers Facebook® page and WhatsApp® status.

The nurse participants were also recruited via their employers. Nurses in KZN are either employed by the KZN Department of Health in public hospitals, or by private hospitals. The researcher obtained permission from the KZN Department of Health (Annexure 9) and then wrote to all 11 Department of Health (DoH) hospitals in the eThekwini region of KZN, unfortunately only two hospitals replied. The one DoH hospital refused permission and access to their nurses even after an appeal by the researcher (Annexure 10). The other DoH hospital granted permission (Annexure 11) to the researcher from hospital management but when the researcher went to the hospital and asked the zonal matron in charge of the paediatric ward for permission to interview the nurses, she refused and asked the researcher to obtain the permission from the nursing services manager (NSM). The researcher then emailed the NSM on many occasions but did not receive any response. This meant that professional nurses that were working in the DoH hospitals were not accessible to the researcher, therefore this particular group did not form part of the research sample. Some of the nurse participants that were interviewed did previously work for the DoH or trained in one of their hospitals.

The researcher also wrote to the three major private hospital groups that have hospitals in the eThekwini Region of KwaZulu-Natal. Two of the three hospital groups responded and granted the researcher permission (Annexure 12 and Annexure 13) to access the nurse participants working in the paediatric wards in their hospitals in eThekwini region of KZN. Once permission was granted the researcher emailed the nursing managers of the private hospitals and asked them to share the advert (Annexure 8) with the staff working in their paediatric wards via the unit manager and this was done. The researcher did not receive many calls from nurse participants after the above recruitment process, so the researcher asked permission from the nursing service managers of three of the large private hospitals and went personally to the

paediatric wards in these hospitals. The researcher arrived at 7am in the morning during the handing over of patients from night to day staff, over five days to ensure all shifts were covered. The researcher personally spoke to the nurses and described the study to the nurses and handed the advert with contact details on it, to them. The researcher told the nurses that were interested in participating to contact the researcher and set up a date and time for interview. This appeal yielded many more participants in addition to those that responded to the advert on social medial. The researcher went to five different hospitals, each having one paediatric ward each and appealed to a total of 42 professional nurses. Of the 42 professional nurses ten nurses contacted the researcher, all of whom met the inclusion criteria and were therefore included in the study.

Once the researcher was contacted by a nurse participant, who met the inclusion criteria and responding to the advert (Annexure 8), the researcher set a date and time for the interview. The interview was then conducted at the stipulated date and time. This process was repeated until the saturation of data was reached.

## 4.8 Sampling method

In phenomenological research, the most commonly employed approach is purposive sampling. This is due to the fact that it enables the selection of individuals who have a thorough understanding of the phenomena under study (Polit and Beck 2021: 499). In contrast to quantitative research and descriptive qualitative designs based on topic or content analysis, sample sizes in interpretative phenomenology are lower (Polit and Beck 2021: 55). According to Frechette *et al.* (2020: 6), the intensity of the data collected is more important than the sample amount. A small sample size is not a barrier in phenomenological investigations because the primary goal is to highlight the lived experience. The reader can then assess the potential transferability to their own surroundings after thoroughly defining the context. A small purposive sample with rich lived experiences of the phenomena is most congruent with the primary goal of phenomenological investigations, which is to reveal the numerous layers of hiddenness of a phenomenon within its environment (Frechette *et al.* 2020:6).

IPA focuses on a narrow and homogenous sample; the research topic must be significant to participants who are purposefully chosen because of their personal knowledge of the phenomenon. IPA studies have a limited number of participants of

(usually less than ten) to allow for a deep micro level study of the participants' data. Each participant offers a detailed description of their lived experience. IPA does not seek to generalise the findings because participants are chosen for their unique lived experience rather than to represent the views of the general public (Peat, Rodriguez and Smith 2019: 8).

*Inclusion and exclusion criteria:* To ensure that the researcher recruited the appropriate participants for this study the following inclusion and exclusion criteria were used for the participants:

#### 4.8.1.1 Inclusion criteria for nurse participants

- Professional nurse permanently working in a paediatric ward in a hospital in eThekwini Region of KZN.
- History of nursing a child with ASD.

#### 4.8.1.2 Exclusion criteria for nurse participants

- Professional Nurses who do not want to share their experience nursing a child with ASD.
- Professional nurses who cannot attend an online interview.
- Enrolled nurses and Enrolled nursing auxiliaries working in paediatric ward
- Professional nurses working in adult wards.

#### 4.8.1.3 Inclusion criteria for family participants

- Parent or family members of autistic child.
- Child with ASD had been previously admitted to a hospital paediatric ward in the eThekwini region of KZN.

#### 4.8.1.4 Exclusion criteria for family participants

- Family member of a child not previously admitted to a hospital paediatric ward in eThekwini.
- Family member who is unable to attend an online interview for whatever reason.

### 4.8.2 Sampling process

Non-probability, maximum variation purposive sampling method, was utilised as the sampling method for the selection of nurse participants and family participants for this study. Polit and Beck (2021: 499) explain that the focus of purposive sampling is to

gain insight by describing and comprehending a phenomena, scenario, or process via the use of specifically selected research participants who are typical of the studied area. Polit and Beck (2021: 499) further explain that maximum variation purposive sampling is a strategy used to collect a large amount of viewpoints in order to get more insights into a phenomena by viewing it from various aspects, which may assist the researcher uncover common patterns that are visible across the sample.

Maximum variation purposive sampling was accomplished in this study by advertising widely on social media, through ASD support groups, Special needs schools and both public and private hospitals and is evident in family and nurse participants with different characteristics, such as age, race, gender, and socio-economic status, in order to capture a wide range of perspectives.

#### 4.8.2.1 Sample size of family participants

All the participants had to meet the inclusion criteria in the advert (as listed above); therefore, this was purposive sampling. The researcher validated that the family participants met the inclusion criteria by taking a detailed history from the participant. This was maximum variation sampling because the sample achieved a wide variety of parents for example the ages of the parents ranged from the late 20s to early 60s, there was a mix of single, married and divorced parents, some parents were working while others were unemployed, some parents only had one child while others had many children and some parents were on medical aid while others were not and lastly family participants were from African, Indian and White race groups. The samples of family participants were from a wide range of demographics making this a maximum variation sampling method of families. The final sample size of ten family participants was achieved, only ten family participants contacted the researcher and all ten met the inclusion criteria and therefore included in the study. In this study the researcher sampled participants until data saturation was reached; data saturation was reached at nine family participants and one further family participant was interviewed just to ensure that data saturation had indeed being reached there were therefore ten family participants in total. According to Faulkner and Trotter (2018: 1) The term ‘data saturation’ refers to the moment in the study process when no new information is being gathered, and this redundancy warns researchers that data gathering may be discontinued.

#### 4.8.2.2 Sample size of nurse participants

The sample size of nurse participants for this study was ten. In this study the researcher sampled participants until data saturation was reached. Data saturation was reached at eight nurse participants but a further two nurse participants were interviewed just to ensure that data saturation had indeed been reached. Ten professional nurses contacted the researcher, all of whom met the inclusion criteria and were therefore included in the study. There were therefore 10 family participants and 10 nurse participants interviewed which made a total of 20 participants. This was purposive sampling because all the nurse participants had to meet the inclusion criteria on the advert, as listed above. This was maximum variation sampling because the sample achieved a wide variety of nurse participants for example the ages of the nurses ranged from the 30 years old to 50 years old, the majority were married with one widow, the majority of nurses were female with one male nurse, participants were from African, Indian and coloured race groups and some nurses had diplomas while others had degrees and finally the years of service ranged from 6 years to 31 years.

### 4.9 Data collection

Data collection describes how data was collected in order to answer the research questions. In qualitative studies there are many data collection techniques (Polit and Beck 2021: 783).

Data for this research was gathered utilising semi-structured interviews with both family and nurse participants. (Polit and Beck 2021: 515) explain that interviews are intensive discussions among the qualitative researcher and the participants that produce in-depth knowledge in the form of words. Alase (2017: 14) agrees with Peat, Rodriguez and Smith (2019: 8) that the best way to collect data for an IPA is by conducting in-depth semi-structured interviews, therefore this method was chosen for this study.

IPA was carried out utilising a variety of qualitative data gathering approaches, allowing participants to offer a full description of their personal and lived experience. Diaries, interviews, and focus groups are examples of these approaches. In IPA, the in-depth semi-structured interview is the most commonly employed data gathering approach. The goal of the IPA interview is to encourage participants to offer their perspectives on the issue being examined. The researcher's function in the interview

is to steer the conversation toward the phenomenon's lived experience being researched and an interview guide will assist the researcher to do this (Peat, Rodriguez and Smith 2019: 8). It is because of the above motivation that the researcher chose to collect the data for this study by means of Semi-structured interviews.

Individual interviews elicit a personal account that allows the participant to recall a lived experience and communicate it in a significant way. This meaning is an essential component of lived experience. To uncover the lived experience, the interviewer must have committed listening skills. Committed listening is more than listening to the words, but also listening for their motivating opinions, conjectures and understandings. The interviewer should not to fall into the complacency of engaging in everyday small talk and not exploring the phenomenon being researched. Silence, probing inquiries, meditation on nonverbal clues, and integration of features acquired by other data collecting sources help the researcher to peel away at amnesia of a phenomena's everyday experience; these interviewing styles allow tearing down the veils hiding the phenomenon little by little (Frechette *et al.* 2020: 7). The above principles were followed to throughout the semi-structured interviews with the participants, in this current research. The researcher has been a nurse for 22 years, interviewing skills is taught during the nurse training, the researcher has already completed a Bachelors and Master's degree and is therefore academically trained; the researcher is also a parent of a child with ASD and a nurse and therefore can empathise with the participants, all these qualities, qualifies the researcher to conduct the interviews.

### 4.10 Data collection tools

Data was gathered using semi-structured interviews. Audio recording was used to capture the participant responses. Semi-structured interview guides (Annexes 1 and 2) were utilised for nurse and family participants respectively, and were designed to facilitate in-depth interviews with participants and achieve the research objectives. The interview guides were assessed for face validity and content validity by the research supervisor and co-supervisor. The tool was developed in English because the researcher, who conducted the interviews, and the interviewees, were proficient in English. The structure of each interview guide is described below.

#### 4.10.1 Data collection tool for nurse participants

The answers to the questions in the interview guide for nurses (Annexure 1) were filled

in by the interviewer during the interview. Section 1 elicited information such as date and time of the interview, the type of institution the participant was working at and the participant code. Section 2 gathered the participants' demographic information such as marital status, gender, level of education, age, and years of service. Section 3 comprised six open ended questions that were developed by the researcher based on the research objectives and the literature reviewed in chapter two. The researcher used probing questions, when required, to gather more data from participants. The Interviews were video recorded on MS Teams® software.

### 4.10.2 Data collection tool for family participants

The answers to the questions in the interview guide for family participants (Annexure 2) were filled in by the interviewer during the interview. Section 1 elicited information such as date and time of the interview and the participant code. Section 2 gathered the participants' demographic information such as marital status, age, sex, age of the autistic child, and relationship to the child. Section 3 comprised six open ended questions that were developed by the researcher to realise the research objectives. The researcher also used probing questions, when required, to gather more data from participants.

## 4.11 Pilot Interviews

Pilot interviews were conducted to find out if participants understood the questions and provide the lived experiences needed for this research. Pilot interviews were conducted on one nurse participant and one family participant prior to the commencement of data collection. The data obtained from the pilot interviews not used in this research. This pilot interviews were a requirement for full ethics approval from the DUT Institutional Research Ethics Committee (IREC). The pilot interview are also used to identify the need to refine the methodology or the data collection processes however in this case no changes were made to the interview guides and process after the pilot interview. The pre- testing data and results were not included in the main study

## 4.12 Data collection process

On the 5th October 2021 the researcher received provisional ethics approval pending gatekeeper approval. The gate keepers" approval (Annexure 6 to Annexure 14, excluding Annexure 8) was subsequently received and forwarded to the IREC for full

ethics approval. On 23 November 2021 the researcher received full approval from the DUT IREC (Annexure 14), Clearance Number 221/21. The researcher then immediately embarked on a process to recruit participants for this study. The recruitment procedure unfolded as described above (section 4.7).

Data was collected from the 30 November 2021 until the 21 January 2022 by means of individual or one-on-one semi-structured interviews with the participants. A total of 20 participants were interviewed, ten being family participants and ten being nurse participants. The time taken to interview each participant ranged from 30 to 60 minutes per interview. The interviews were conducted on the Microsoft® Teams software by the researcher in English. During the recruitment of participants and before confirming the dates for the interview, the participants were informed that participation was voluntary and that they could withdraw from the study at any time without penalty or prejudice. This disclosure was done in writing, in the letter of information and consent form (Annexure 3 and Annexure 4) which was given to all participants prior to their interviews. The researcher obtained consent personally in order to be able to answer any questions the participants may have had. This letter of information and consent form (Annexure 3 and Annexure 4) was emailed to the participants during recruitment and was completed and signed by the participants and emailed back to the researcher prior to the interviews being conducted. Even though consent was obtained in writing prior to the interview, the researcher still read out the information letter again to the participants at the beginning of the interview and asked them to confirm they had given consent for the interview.

Each one-on-one semi-structured interview followed the following process. At the start of the interview the researcher thanked the participant for participating in the research. The researcher then asked for the participants permission to record the session using Microsoft® Teams. The researcher then formally introduced himself and fully explained the research he was doing. The researcher also explained to the participants that the researcher would be taking field notes as they spoke. The researcher then asked the participants demographic information as per the interview schedule (Annexures 1 and Annexure 2). The researcher asked the first question and allowed the participants to exhaust the question before moving on to the next one. This process was followed until the interview ended naturally because there was no further information that the participant had to offer. The questions were not always followed in the order they

appear in the interview schedule, as the researcher used these as initiation questions and allowed the participants to share their lived experiences in the manner most comfortable form themselves. At the end of each interview the researcher thanked each participant and assured them that all information would remain confidential and that the notes and recordings would be coded so that only the researcher would be able to trace who they belonged to. At the end of each interview the researcher also asked for the participant's nominated cell phone number to which the researcher sent one Gigabyte of data to thank them for participating in the research and to reimburse them for any data they may have used during the interview.

### 4.13 Data analysis

Qualitative data analysis involves the examination of non-numeric data such as transcripts and recordings which contain a large amount of text. This large amount of text (data) is firstly managed and organised in a specific manner, following which the researcher immerses themselves in the data in order to analyse it. Thematic, content or construct analyses is used to find patterns in the data and help code the data in order to develop themes. This coding can be done manually or by means of software (Polit and Beck 2021: 541). The above explanation applies to qualitative research in general, however IPA has a specific method of analysis which is explained below. The information below was sourced from current articles that detail the IPA analysis process.

According to Frechette *et al.* (2020: 9), IPA research is distinguished from other forms of qualitative investigation by its hermeneutic approach to data processing. Because data analysis is an interpretative process, the hermeneutic cycle, which is a back-and-forth movement from part to whole, is continually linked with co-constructions. The researcher cycles from preconceptions to new understandings, which are then blended with future preconceptions as the study progresses, forming a circle.

Data analysis in IPA commences immediately after the first interview with in-depth analysis of the first interview, which results in the formulation of the initial themes and these themes are then considered in the analysis of subsequent interviews (Peat, Rodriguez and Smith 2019).

The researcher utilised the following step-by-step approach for IPA analysis as formulated by Peat, Rodriguez and Smith (2019: 8):

1. Reading and intense analysis of the first transcript.
2. As the researcher reads the transcripts, he/she makes observational notes in the margins.
3. The researcher then takes these observational notes and forms groups of data and themes start to emerge.
4. The researcher looks at these groups of data and tries to find how they relate or connect to each other.
5. The researcher then moves on to the next transcript, “bracketing” the themes that emerged in the previous transcript.

Steps 1–4 are repeated for each transcript.

6. Once all the transcripts have been analysed, as described above, the researcher then looks for common themes across all the transcripts and these are highlighted.
7. The researcher then looks at the themes across all the transcripts and does a deeper interpretation, to find the meaning of these experiences.
8. Finally, the researcher looks at existing literature in an effort to further interpret and analysis the themes.

The IPA data analysis is reported as a comprehensible logical explanation with appropriate direct quotes from the participants, the researcher’s interpretation, and with reference to the relevant literature.

Thus, data analysis is the process of translating the raw data into themes to meet the research objectives and aims.

Even though this process is described above as a linear process, data analysis occurs concurrently with data collection.

The researcher uses existing theory/concepts to further investigate the data in the last step of analysis. The IPA findings are given in the form of a cohesive analytical narrative that includes relevant participant quotations and a full interpretive commentary (Peat, Rodriguez and Smith 2019: 8).

The researcher followed the above steps in the analysis of the data for this study and also utilised the Nvivo version 12 pro software, which assisted in the qualitative data

analysis. A detailed explanation of the data analysis process and the results of this analysis is presented in Chapter 5. An independent coder was not used but Qualitative Data Analysis software (Nvivo pro12) was used to analyse the data.

### 4.14 Data management and storage

All data collection instruments, recordings and transcripts have been stored away safely in a lock cupboard by the researcher. These items will be kept under lock and key for a period of 5 years and then destroyed by the researcher. All data collection tools, recordings and transcripts are only identified with a code. This code is only known by the researcher.

### 4.15 Trustworthiness

In qualitative research trustworthiness refers to the integrity of the researcher, the legitimacy of the results and the methodical precision and pertinence of the research design and method (Rose and Johnson 2020: 434). Trustworthiness of this study was achieved by adhering to the four criteria of trustworthiness as described by Lincon and Gruba (1985: 301), namely: credibility, transferability, dependability and conformability.

#### 4.15.1 Credibility

Interviews that were conducted with nurse participants and family participants were recorded and notes written on the interview guide verbatim to ensure that the participants original views were captured. Probing questions were used to ensure data saturation. These notes and recordings will be kept for a period of five years after production of the final report, should they be required for verification purposes. Source triangulation was also used to ensure credibility as data was sourced from nurse participants, family participants, and literature. The researcher further ensured credibility by staying in the field until data saturation was reached, thus ensuring an in-depth understanding of the phenomenon.

#### 4.15.2 Transferability

Transferability was ensured by the researcher by providing a thick description of the entire research process, including the data collection, analysis and the context of data collection. This process is published in the form of this research report, so it can be repeated in other settings, or with other respondents. Purposive sampling was used in

this research as one of the methods of ensuring transferability because all participants were experts in the field of study. Data saturation is also a method of ensuring transferability according to (Polit and Beck 2021: 570).

### 4.15.3 Dependability

The researcher ensured dependability by asking the participants to evaluate the findings prior to submitting the research report to the examiners, to ensure their views had not changed over time. The data collection tools were also pretested prior to data collection. The entire research process was made transparent so that the dependability of the findings can be tested later by using stepwise replication or inquiry audits.

### 4.15.4 Confirmability

To ensure confirmability the researcher audio recorded the interviews and took verbatim field notes. These were made available to the research supervisors to ensure that data had been correctly interpreted, and will be kept for a period of 5 years. Conformability was further ensured through researcher reflexivity and triangulation, as explained previously.

## 4.16 Ethical considerations

To ensure that this study adhered to all the ethical principles, it was subjected to review and approval by the research ethics committees of 1) The Durban University of Technology, 2) The KZN Provincial Department of Health and 3) The research/ethics committees of the various private hospitals. The researcher adopted the ethical principle as presented in the model of the Belmont Report. Polit and Beck (2021: 133) describes the Belmont Report as a model for ethical research, which was developed in 1978 by the United Sates National Commission for the Protection of Human Subjects of Biomedical and Behaviour Research. The Belmont Report contains 3 broad principles of beneficence, respect for human dignity and Justice (Polit and Beck 2021: 133), these principles will be applied to this study below.

### 4.16.1 Beneficence and non- maleficence (right to protection from discomfort and harm)

There were no known risks of physical harm to participants involved in the study

because they were only required to attend a voluntary interview which was held on-line to minimise the risk of contracting Covid19. The participants will benefit from the framework that was developed by the researcher. The participants were interviewed from the comfort of their homes, so that they had a familiar and therapeutic environment at all times. Even though the participants did not experience any physical harm, the participants were also protected from emotional harm because the participants were informed that at any time during the interview if the participant experienced any discomfort from the questioning they could inform the researcher who would not proceed with that questioning. None of the participants experienced any emotional harm.

### 4.16.2 Respect for human dignity and right to self-determination (informed consent and disclosure of information)

The researcher fully disclosed to the participants the nature of the study, their right to decline participation, the researcher's obligations, and the risks and advantages of participating in the study. The participants were advised that their participation was entirely voluntary and that they could withdraw from the research at any moment without penalty or detriment. This disclosure was made in writing, in the form of an information letter and permission form (Annexures 3 and 4), which were distributed to all participants prior to their interviews. In order to answer any queries, the participants may have had, the researcher also performed the interviews and obtained consent in person.

### 4.16.3 Justice and veracity

All participants were treated fairly and equally by the researcher at all times during this study. Veracity or truthfulness was always maintained by the researcher who answered all participant questions honestly and truthfully. The participants' right to privacy was always maintained because they were given participant codes so only the researcher could link their interviews to their names, and their names were not used in any way in this thesis.

### 4.16.4 Right to privacy and confidentiality

In this research each participant and institution were assigned a code to protect their personal information; only the researcher knows who was assigned to which code. All

information including recording and field notes are kept under lock and key by the researcher and will not be made available to anyone, except to supervisors if absolutely necessary. The participants may access their own information if they wish to do so and were made fully aware that their information will only be used for this research only.

### 4.17 Chapter Summary

In this chapter the researcher described how the study was based on the relative ontology, social constructivism epistemology, an interpretivist research philosophy or theoretical perspective, with an inductive research approach. The methodology followed was the qualitative interpretative phenomenological analysis (IPA) strategy, utilising the maximum variation purposive sampling method to determine the sample who participated in a semi-structured, one-on-one interview to collect data. This data was analysed using the IPA data analysis method. The researcher also described how trustworthiness and ethical principles were maintained in the research. Chapter 5 presents the findings of the data analysis.

# CHAPTER 5: PRESENTATION AND DISCUSSION OF FINDINGS

## 5.1 Introduction

The study methodology and data gathering technique were detailed in the preceding chapter and this chapter presents findings and interpretation of data. This chapter presents and discusses findings from analysed data. The study aimed to develop in-depth insights into family involvement in the provision of in-hospital nursing care for children with ASD in the South African context. Research objectives, were to:

- Critically assess the perceptions of nurses and families, regarding the involvement of families in the hospital nursing care of a child with ASD.
- From the in-depth interviews an analysis, challenges perceived were identified and described by nurses and families regarding the involvement of families in the hospital nursing care of a child with ASD.
- Explore participant perceptions on the range of corrective interventions and actions to overcome challenges and promote effective family involvement in the hospital nursing care of a child with ASD.
- Develop and validate a framework for the improvement of family involvement in the hospital nursing care of a child with ASD.

## 5.2 Overview of data analysis process

The interviews were conducted on Microsoft (MS) Teams®, and were recorded and transcribed by MS Teams®. The researcher downloaded and saved the transcripts after each interview. After a transcript was downloaded, the researcher listened to the recording and verified that the transcript was correct. The transcript was imported into the NVIVO 12® pro software and saved there. Using the NIVIVO 12® pro software, the researcher went through the transcript line-by-line and coded the material. Once the researcher had coded the entire transcript, it was saved. After the ten family participant transcripts and the ten nurse transcripts had been coded, the researcher then grouped these codes within each group until themes emerged, starting with the family group. Please note that this was not a linear process but an iterative process, because the researcher had to go back and forth during the process. An independent coder was not used. Figure 5.1 is a graphical representation of the data analysis process followed.

An independent coder was not used, but Qualitative Data Analysis software (Nvivo pro12) was used to analyse the data.

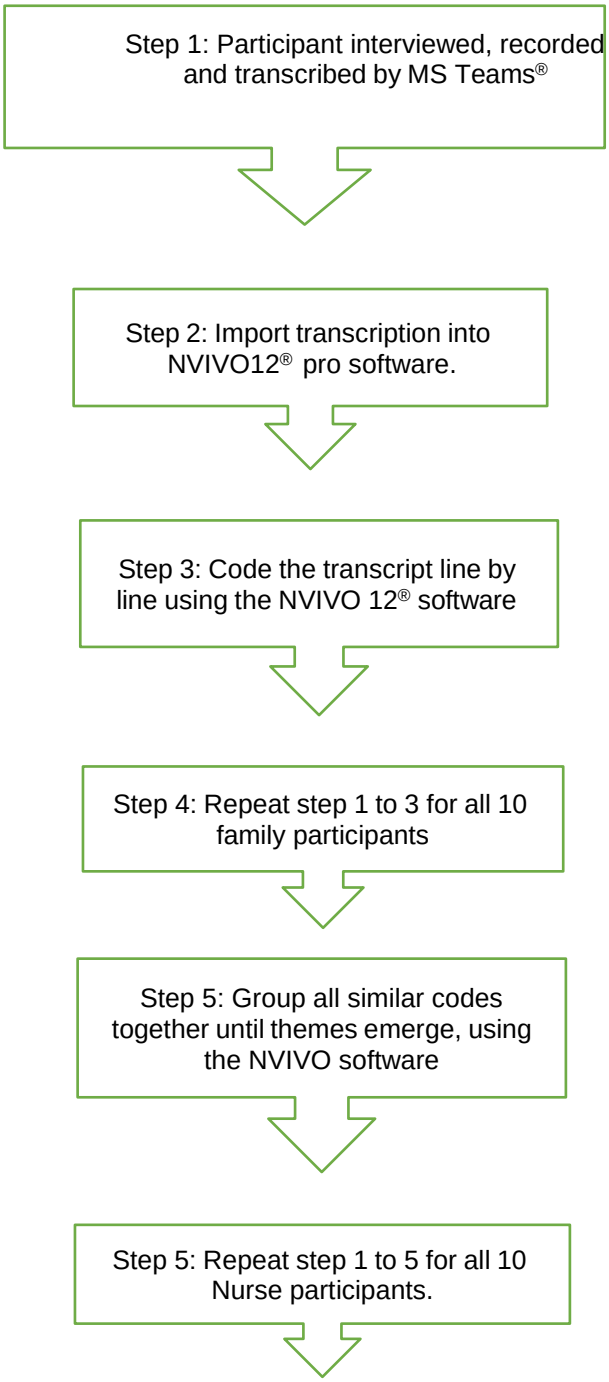


**Figure 5.1: Data analysis process**

## 5.3 Presentation of findings and interpretation

The demographic data of participants is presented first followed by themes and subthemes.

## 5.4 Demographic characteristics – family participants

The following demographic data is presented without interpretation of statistical significance as this was a qualitative study. Data is presented according to family participants, nurse participants and child demographics. Demographic data presented is; age, gender, marital status, age of child and relationship to the child.

### 5.4.1 Age

The age groups of family participants were as follows: three family participants were in the 41 to 50 and 20 to 30 age group; two in the 31 to 40 age groups; one in the 51 to 60 age group, and one above 60 years (Table 5.1). The results show that family participants were from a wide age range (20 years old to above 60 years old), therefore a wide range of experience. Considering that in this study all the family members were parents, this implies that the study included some new parents as well as much older parents. This is validation of maximum variation sampling, ensuring that data collected were representative of the views of a wide range of parents. As explained by Statology (2020: 1), a researcher can acquire a more comprehensive picture of a topic and analyse it from many different perspectives by selecting persons who are highly varied in age from one another.

**Table 5.1 Age of the family participants**

| Age Group | Number |
|---|---|
| 20 to 30 years old | 3 |
| 31 to 40 years old | 2 |
| 41 to 50 years old | 3 |
| 51 to 60 years old | 1 |
| Above 60 years old | 1 |

### 5.4.2 Gender

Gender was part of demographic information that was collected from parent participants. The researcher recruited participants via social media advertisements, but only female family members responded to the advertisements and therefore this sample of family participants was 100% female (unlike the nurse participants which is discussed below). This gender imbalance is consistent with other health research; Leach *et al.* (2019) and Cabrera, Volling and Barr (2018) state that males are underrepresented in social and health research, particularly studies on parenting experiences.

### 5.4.3 Marital status

According to data collected from family participants, eight participants were married, one was single and one was divorced (Table 5.2). The researcher, therefore has obtained data from a wide range of parents with different marital status, thus ensuring maximum variation sampling.

**Table 5.2: The marital status of the family participants**

| Marital status | Number |
|---|---|
| Married | 8 |
| Divorced | 1 |
| Single | 1 |

### 5.4.4 Relationship to child

All family participants were mothers and primary caregivers of children with ASD, which is a similar finding to a recent study conducted in KZN by Pillai, Makhetha and Aldous (2021: 126), who found that the mother was the primary caregiver for 83% of the children with ASD in their study. This also confirms the finding by Leach *et al.* (2019: 872) that men are minimally engaged in social and health research, including research about experiences of parenthood.

### 5.4.5 Current age of autistic child

The last part of demographic data collected from family participants was the current age (not age when admitted) of their child with ASD. Three children were from birth to 10 years old, four from 10 to 20 years old and four above 20 years old (Table 5.3). The

researcher interviewed family participants about the experience of their child with ASD when the child was admitted to the paediatric ward, as a child (not at the current age). The wide variation of the children's current age reflected that the researcher obtained data from a wide variety of participants, some parents with very young children and other parents that now have adult children. The numeric age of the child with ASD does not always correlate with the intellectual or physical abilities of a neurotypical child (Vyshedskiy *et al.* 2022: 99), hence the inclusion of older children who would normally be recognised as adults if they were neurotypical. All the children were under the age of 12 when admitted to the paediatric ward.

**Table 5.3: The current age of the child with ASD**

| The current age of the child | Number |
|---|---|
| 0 to 10 Years old | 3 |
| 10 to 20 years old | 4 |
| Above 20 years old | 3 |

### 5.4.6 Other demographic information about family members obtained during the interview.

The above five demographic questions were specifically asked at the beginning of the interview, however, during the interview the researcher discovered the following demographic information about the family participants: five participants were working mothers, five were housewives, eight were on medical aid. The above information showed that participants were evenly divided between working and not working, ensuring that the sample represented different socioeconomic groups.

### 5.4.7 Other demographic information about the child with ASD obtained during the interview.

Gender data about the child with ASD revealed during the interview with the family participants was that eight out of the ten children were male and two females. This empiric data is confirmed by Morsy *et al.* (2020), Owen, Gary and Schnetter (2020), Ndubaku (2018) and Pillai, Makhetha and Aldous (2021) who all note that ASD affects males more often than females.

### 5.4.8 Other information about the admission to hospital obtained during the interviews.

During the interviews of family participants, the researcher found that eight of the children were admitted to private hospitals and two of were admitted to government hospitals. The admitting diagnosis were as follows: accidental Risperdal overdose, attempted suicide, injured hand, magnetic resonance imaging (MRI) and hearing testing, whooping cough, dehydration, chest infection, aggressive behaviour, incision and drainage of abscess, seizures, Covid-19, tonsillectomy, circumcision and repair of injured knee. This wide array of diagnosis illustrates that data collected by the researcher was from a variety of medical and surgical admissions.

## 5.5 Demographic data – nurse participants

The semi-structured interviews gathered the following information from the nurse participants: age, gender, marital status, do you have children, level of education in nursing and years.

### 5.5.1 Age

The ages of the nurse participants were as follows; six (60%) of the nurse participants were in the 30 to 39 age group, two (20%) were in the 40 to 49 age group and two (20%) were in the 50 to 59 age group (Table 5.4). This empiric data demonstrates that the data was gathered from a wide age group of nurses thus ensuring maximum variation sampling. This age distribution was similar to the age distribution of professional nurses in the country for the year 2022, which, according to South African Nursing Council (2022: 1) was 21% for 30 to 39 age group, 26% for 40 to 49 age group and 27% for the 50 to 59 age group.

**Table 5.4: Age of nurse participants**

| Age of nurse participants | Numbers |
|---|---|
| 30 to 39 years old | 6 |
| 40 to 49 years old | 2 |
| 50 to 59 years old | 2 |

### 5.5.2 Gender

In this study, there were nine female nurse participants and one male nurse participant (Table 5.5). The sample illustrates that nursing is a female-dominated profession in South Africa. According to Health e-News (2021), “There is an overwhelming gap in our country–there are 28 000 males registered as nurses compared to 250 000

females". According to these statistics, the nursing staff in South Africa is made up of only 10% of male nurses, the researcher also has a 10% male nurse sample, making this an adequate representation of male nurses.

**Table 5.5: Gender of nurse participants**

| Gender of nurse participants | Number |
|---|---|
| Female | 9 |
| Male | 1 |

### 5.5.3 Marital

As depicted in Table 5.6, eight of the ten nurse participants were married, with one nurse participant being single and one a widow. The researcher therefore obtained data from a wide range of nurse participants with different marital status, thus ensuring maximum variation sampling.

**Table 5.6: Marital status of nurse participants**

| Marital status of nurse participants | Number |
|---|---|
| Married | 8 |
| Widow | 1 |
| Single | 1 |

### 5.5.4 Regarding nurse participants having children

Nurse participants were asked if they had children and nine of them responded yes to this question and one replied no, therefore many of the nurse participants were parents themselves.

### 5.5.5 Level of education

Table 5.7 shows that seven nurses had obtained a diploma in general nursing and three participants that had obtained a degree in nursing. In South Africa these are the two educational qualifications that allow a person to be registered as a nurse with the South African Nursing Council (South African Nursing Council 2023: 3). This sample therefore represented all educational levels of registered nurses in South Africa and again ensured maximum variation sampling.

**Table 5.7: Level of education for nurse participants**

| Level of education for nurse participants | Number |
|---|---|

| | |
|---|---|
| Diploma in Nursing | 7 |
| Degree in Nursing | 3 |

### 5.5.6 Years of service

As illustrated in Table 5.8, four nurses had less than 10 years of service, another four nurses had 11 to 20 years of service and two nurses had 31 to 40 years of service. This demonstrates that nurses interviewed had a wide range of nursing experience and therefore provide a wide variety of data thus ensured maximum variation sampling and a rich source of data derived from their years of lived experiences.

**Table 5.8: Years of service of the nurse participants**

| Years of service of the nurse participants | Number |
|---|---|
| 0 to 10 Years | 4 |
| 11 to 20 years | 4 |
| 21 to 30 years | 0 |
| 31 to 40 years | 2 |

## 5.6 Themes and subthemes

Table 5.9 illustrates the themes and subthemes that emerged from the data analysis.

**Table 5.9: Themes and subthemes**

| Objective | Theme | Subtheme |
|---|---|---|
| **Objective 1**<br>To critically assess the perceptions of nurses and families, regarding the involvement of families in the hospital nursing care of a child with ASD | **Theme 1:**<br>Perceptions of nurses and families, regarding involvement of families in hospital nursing care of a child with ASD. | |
| **Objective 2**<br>Identify and describe the challenges perceived by nurses and families, in the involvement of families, in the hospital nursing care of a child with ASD. | **Theme 2:**<br>The challenges perceived by nurses and families in the involvement of families in the hospital nursing care of a child with ASD. | **Subthemes:**<br>2.1 Lack of knowledge.<br>2.2 Nurses not listening to families.<br>2.3 Uncaring attitude of nurses.<br>2.4 Nurse's lack of time.<br>2.5 Shortage of nursing staff. |
| **Objective 3**<br>Explore participant perceptions on the range of corrective interventions and actions to overcome challenges and promote effective family involvement in the hospital nursing care of a child with ASD. | **Theme 3:**<br>Suggestions to promote effective family involvement and good quality nursing care | **Subthemes:**<br>3.1 Nurses must be trained to nurse children with ASD.<br>3.2 Nurses must have a caring attitude and patience.<br>3.3 Nurses must communicate with family.<br>3.4 Nurses must listen to family.<br>3.5 Nurses need to take a detailed history of patient<br>3.6 Nurses need to use child's likes to get co-operation |
| | | 3.7 Nurses need to involve the family more in care<br>3.8 Building a good relationship between the family and nurse<br>3.9 Child needs toys or some entertainment in hospital<br>3.10 Safety of child and other children |

| | | |
|---|---|---|
| | **Theme 4**<br>Families' perceptions of their child's experience in hospital | **Subthemes**<br>4.1 Bad hospital experience<br>Code 4.1.1: Forced treatment<br>Code 4.1.2: Problems with hospitalisation of child with ASD<br>Code 4.1.3: Food requirements for ASD child not met<br>4.2 Good hospital experience<br>Code 4.2.1: Quiet environment and private room helps<br>Code 4.2.2: If parent is a Doctor or Nurse child gets better care<br>Code 4.2.3: Nurses Listen to family. |

### 5.6.1 Theme 1: The perceptions of nurses and families, regarding the involvement of families in the hospital nursing care of a child with ASD

Theme 1 was formulated to address **Objective 1** of this thesis, which was: **To critically assess perceptions of nurses and families, regarding involvement of families in the hospital nursing care of a child with ASD.**

The unanimous responses from both the family and nurse participants were that the family is very involved in the basic nursing care of the child with ASD when they are admitted to hospital. The exception to this is the administration of medication and invasive procedures such as the insertion of intra-venous (IV) cannulas, although at times even the medication is administered by the parents.

Participants were asked "How involved were you in your child's care in hospital?". Participants answered:

> We told the nurses everything about him and us, and did not really need anything much from the nurses. The nurses were very good listeners, we had a private

> room, and I did everything for my son, they did some of the nursing care when necessary. (Family Participant 4)
>
> I did everything for her because I am a nurse in the same hospital; I was allowed to do everything for her. I even assisted when they took bloods from her, because she is very strong and fights back, I prepared the staff for the tantrum. (Family Participant 7)
>
> Absolutely involved. Telling the doctor what you do and the nurse, but then we parents tend to take over the nurse's duty. So, for example, the toileting and of course, my son is not going to allow somebody else to come near him if he doesn't know you. (Family Participant 9)

From all the responses above it is very apparent that the majority of the family participants agree that they did everything for their children whilst in hospitals and the nurses did very little. Clearly some parents were happy that they did everything for their children and wanted to do so. However, other parents were upset and unhappy that they had to do everything for their children in hospital and the nurses did very little:

> When he came back to the ward, there was no help from the nurses. All the children in that room were with their parents and the parents were doing everything for the children with no help at all from the nurses. (Family Participant 3)
>
> The nurse battled to give my son the medication because he would spit it out or vomit the medication. The nurse was complaining about my child and then gave me the medication to administer to my son. I did everything for my son**,** even assisting with the chest physio because he had a chest infection. (Family Participant 6)
>
> My son takes care of himself, but the nurses did not do anything for him. I had to feed him and change him. (Family Participant 6)
>
> My daughter was Covid 19 positive, so they put us in an isolation ward and the nurses did not do anything for us at all. The nurses and doctor did not want to even come into the room. The doctor stood at the door and just looked in and gave the nurses orders. He did not examine my daughter or even talk to me and her. One time when she was vomiting, I went to the nurses desk like 20 times and there was no answer, no nurses were there to help us. I had to do everything and even give

> the IV medication. They left me and her alone and I basically did everything for her. (Family Participant 8)

In response to the question: “What is the role of family when you are nursing a child with ASD?” the nurses responded in the following manner:

> Parents know their child best. They know what their child needs. The parents also assist us with caring for their children, one of the mums gave the suppository to the child for me. (Nurse Participant 1)

> The parents were always with the child and did most of the care for the child including giving medications. I allow them to tell us what to do for the child because they have the best knowledge of this child. (Nurse Participant 2)

> These children are very difficult to nurse. Parents can assist in the treatment of their child, the oral medication you can ask the mum to give and comment on the effects of the medication. (Nurse Participant 3)

> The best way is to teach the mum how to fully care for the child including the nursing care, so that she is self-sufficient. (Nurse Participant 6)

From the nurse participants’ responses, it is clear that they agree with the family participants that in hospital the family members do everything for their child with ASD. This could be because nurses believed that the parent knows the child better and therefore it would be easier for the parent to care for the child. Other nurses believed that it made their work easier because nursing children with ASD is very difficult, while other nurses believed that involving parents in the care of their children is a learning experience for the parents and is empowering for them.

From the above analysis, that both the nurse and family participants’ perceptions are that when a child with ASD is admitted to hospital the family members are very involved in the child’s care. The researcher ensured triangulation of this empiric data through the use of literature that agrees with these perceptions. Mimmo *et al.* (2019: 113 and 744) found that nurses depended on parents' continual presence to take on numerous tasks and provide essential care for their intellectually disabled child.

There is unanimous agreement by family and nurse participants with existing literature that families of children with ASD do everything for the child when admitted to hospital

and nurses only do the type of nursing procedures that parents cannot do. After deeper probing, the researcher found that younger parents, who had their children admitted for the first time, were very unhappy doing everything for their child and felt that nurses should have actually done more for them and their children. They perceived this as a bad experience which could be interpreted as a "stressor" according to the NSM. These "newer" parents actually wanted more support from the nurses. Contrary to this, "older" parents who had previous experience in hospital, or who had medical knowledge, were happy to do everything for their children and preferred it when the nurses had minimal contact with their children, thus perceiving doing everything for their child as a positive experience. This finding was corroborated by the findings of Kruszecka-Krówka *et al.* (2019: 7) and Uysal and Cirlak (2014: 437) who found that parents of children under the age of six were much less satisfied with the nursing care their child received in hospital, compared to parents of children over the age of six; the reasons for this were similar to those provide by participants in the current study, which was that the younger parents expected much more support from the nurses as compared to older parents. When questioning the nurses on this point, most of them explained that they knew very little about ASD and recognised the parents as experts on their children and therefore preferred the parent to do everything for the child. Other nurses saw this as empowering the parents to care for the child and still others made parents do everything for child because they knew nursing children with ASD is time consuming and "difficult". Most of the nurse participants therefore perceived parents doing everything for their child as a positive experience and as a method of overcoming the lack of knowledge and time. The researcher therefore interpreted all the above evidence as demonstrating that in eThekwini families were very involved in the in-hospital nursing care of their child in ASD, whether they wanted to or not.

### 5.6.2 Theme 2: The challenges perceived by nurses and families in the involvement of families, in the hospital nursing care of a child with ASD

Theme 2 was formulated in order to address **Objective 2** of this thesis which was: **Identify and describe the challenges perceived by nurses and families in the involvement of families in the hospital nursing care of a child with ASD**

The family participants were asked "What do you think is preventing you from being more involved in your child's care in hospital?" Many parents pointed out challenges

regarding nurses while nurses felt that the challenges they were facing regarding the care of children with ASD were due to inadequate training. From the family participants responses, the following themes and sub-themes emerged:

#### 5.6.2.1 Subtheme 2.1: Lack of knowledge

The number one reason put forward by seven out of the ten family participants was lack of knowledge by nurses regarding ASD. Below are just a few responses from the family participants:

> The nurses don't understand kids with autism, they thought my son was a danger to the other children. They kept on calling him naughty. They did not have any knowledge of autism at all and they treated my child as if he was mad. I also think that they do not know about autism and they have very bad attitudes towards children with autism. (Family Participant 1)

> I don't think the nurses and security guards are clued up at all about autism. They mix up autism with mental health issues. The nurses lack knowledge of autism and they can't differentiate between autism and bipolar disorder. (Family Participant 2)

> The nurses did not know anything about autism and were not trained in autism. They are not trained on how to handle an autistic child. The nurses definitely lack knowledge. (Family Participant 3)

> In my experience nurses also have no knowledge of autism. I think it would be a lack of education on autism. (Family Participant 4)

Lack of knowledge of autism has been found in many studies (Hidiroglu *et al.* 2018; Ellias and Shah 2019; Kostiukow *et al.* 2020; Mukhamedshina *et al.* 2022). Family participants were upset by the misdiagnosis and mistreatment of their children and attributed this to nurses' lack of knowledge on ASD and this caused these family participants to have a poor interpersonal relationship with nurses. This poor interpersonal relationship is therefore a barrier to effective and meaningful family involvement in the hospital nursing care of the child with ASD. HCPs' limited knowledge of ASD has proven to be a barrier to the quality of care and family satisfaction in many other studies (Wilson and Peterson 2018; Morris, Greenblatt and Saini 2019; Walsh *et al.* 2020).

Lack of knowledge is the ‘stressor’ to the environment that NSM mentions, causing stress to the interpersonal relationships of the family-nurse or nurse-patient. Furthermore, some family member participants’ responses indicated negative experiences, contributing to a negative hospital experience for the child with ASD and their families, caused by a lack of knowledge of ASD by the nurses.

When nurse participants were asked: “What do you believe prevents you from involving family members in the nursing care of their child?” three out of the ten agreed with the family participants that lack of knowledge was the main reason they did not involve parents in the care of their children. Their responses were as follows:

> Nurses lack knowledge on ASD and are therefore intimidated and threatened by parents. (Nurse Participant 1)

> It’s just my personal belief. Nurses do not have enough knowledge, so they actually don’t want to be shown up and to receive any question from any parent, because this question might be kind of a challenge to them. (Nurse Participant 10)

From the responses of the seven family participants and three nurse participants, it is apparent that half of participants believed that nurses’ lack of knowledge of ASD is the major challenge in the involvement of families in the hospital nursing care of a child with ASD. This empiric evidence is substantiated by of the large body of evidence in the literature that supports the view that nurses have a lack of knowledge about ASD. Ndubaku (2018: 26) found that nurses unanimously agreed that there are knowledge gaps in the nursing care and treatment of the ASD patient.

When exploring the knowledge of the nursing participants on ASD the researcher asked the question: “Tell me everything that you know about autism spectrum disorder?” All nurse participants unanimously agreed that they had very little knowledge of ASD and had received no training. Some of their responses are presented below.

> I have no formal training on autism, I am not really clued up on autism. I only know what I have seen on TV. (Nurse Participant 1)

> I have no formal training on autism, and I have very minimal knowledge of autism. (Nurse Participant 2)

> It's a condition not a disease, the brain does not work normally … I have never had any training on autism. (Nurse Participant 5)

> It is a mental disorder or chemical imbalance in the brain. I have never been trained on autism. (Nurse Participant 7)

Nurses did not have knowledge of nursing a child with ASD and none of them had ever received training on ASD. Nurse participants therefore relied on parents to assist them with nursing tasks and caring for the child with ASD. Some nurse participants felt intimidated and threatened by parents, because the parent knew more about ASD than they did – they felt that as nurses they should be the experts who are teaching the parents and not the other way around.

While nurses' awareness of ASD classifications and presentations varied, their assessments of their shared experiences revealed a consistent and significant lack of comprehension of the severity and effect of autism in nursing care and management. Family and nurse participants' responses indicated a negative perception of the nurse's knowledge with regard to ASD and therefore contributing to a negative hospital experience for the child with ASD and their families.

The researcher also saw this lack of knowledge as a 'stressor' in the environment as per NSM, which causes stress to the interpersonal relationship of the family-nurse and/or nurse-patient relationship. This lack of knowledge also affects the empowerment and information sharing concepts of the theory of family care during critical illness, thus necessitating the formulation of the framework presented in this study.

#### 5.6.2.2 Subtheme 2.2: Nurses not listening to family

The second challenge identified by the family participants was that of nurses not listening to family. Six out of ten family participants identified this as one of the major challenges in the involvement of families in the hospital nursing care of a child with ASD. Some of the family participants responses are listed below:

> Even though I told them that he does not react well to the tablet, and he takes the syrup, they did not listen and gave him the tablet anyway. I told the nurses when they put a drip for my child to cover the drip because he will pull it out. The nurses would not listen to me and he pulled it out and he had to have another drip put in,

> which was traumatising for him. But the nurses refuse to listen to parents and when parents try to explain to the nurses what to do for the child they are told “Don’t tell me my job!” (Family Participant 1)
>
> When I tried to explain to the nurses what happened and what is wrong with him and about autism they would not listen. (Family Participant 2)
>
> When I spoke to the nurse she said “this is how we do it”. They were not listening to us. (Family Participant 3)
>
> The nurses decided to move us to a general ward, I spoke to the nurses and explained that we needed the private room, but they did not listen. They moved us to a general ward and in the general ward every time the child (next to my son) cried, my son would have a meltdown. (Family Participant 5)

The researcher understood that family participants felt disrespected and annoyed when they were not listened to by nurses. Family participants felt that they were experts on their children and knew what was best for their child but they were being undermined by nurses. Family participants believed that nurses undermined them because nurses felt that they were medical experts and knew better than the family. Family participants therefore interpreted “Nurses not listening to family” as being disrespectful and undermining their knowledge of their child. Benich *et al.* (2018: 40) agreed that parents had the best understanding of how their child responds to stimuli and unfamiliar conditions.

It is clear that the majority of family participants believed that a major barrier to being involved in their child’s care in hospital is that the nurses do not listen to them. The challenge was also pointed out by Nygård and Clancy (2018: 3180) who stated, according to their meta synthesis study of ten articles, that nurses do not always provide care in a courteous manner, appreciating parents’ experience and skills. The nurse participants did not identify this barrier; however, they did mention in their interviews that they believed that nurses should listen to the family. Nurse participants said the following in this regard:

> Parents know their child best. They know what their child needs. Listen to the parents. (Nurse Participant 1)

> Allow them to tell us what to do for the child because they have the best knowledge of this child. … In my opinion the parents know their child the best and they can help to plan the nursing care; we must listen to them. (Nurse Participant 2)

> Firstly, they must listen to the parents, they will tell you the do's and don'ts. Let the parent's guide you. The parents can teach us what works at home with the child. The parents can give us information like the child likes and dislikes so that we can use the likes in the nursing care of the child. The parents can tell us if we can play with the child and some of the child's behaviour like if he/she screams, bites, injures themselves and let the staff know if they do. (Nurse Participant 9)

It is apparent from the above analysis that most family participants and some nurse participants regarded "Nurses do not listen to parents" as a challenge in the involvement of families in the hospital nursing care of a child with ASD. Ndubaku (2018: 36) found that a barrier to quality care of paediatric patients with ASD was "not understanding the ASD patient" which emphasises the necessity of having the information required to individualise treatment for people with ASD, which comes from the parent. This implies that nurses not listening to family is a barrier to providing quality nursing care. Therefore, listening to parents and asking for their help might assist health care practitioners in improving treatment aspects that are likely to be unpleasant for children with ASD.

It is clear from the literature, from the family participants, and from some of the nurse participants, that "Not listening to parents" is a challenge in the involvement of families in the hospital nursing care of a child with ASD.

The researcher's interpretation of this point is that when the nurse listens to the family, it is interpreted by the family as the nurse respecting their expert knowledge of their child, showing a caring interest on how to correctly nurse their child, and acknowledging their lack of knowledge and willingness to learn. Family participants felt that they were the experts on their child and that nurses could learn a lot about their child by listening to them. Family participants interpreted nurses not listening to their concerns as disrespectful. From the family participants' point of view, nurses that did not listen to parents were arrogant in thinking that they knew better than parents, and this forms a barrier to promoting family involvement in the nursing care. On the contrary, if the nurse listened to family participants, this promoted teamwork between

the nurse and family members and thus promoted family involvement in the hospital nursing care of the child with ASD.

Nurses not listening to family members is in direct opposition to the triangle concept of the Bowen's family systems theory discussed in chapter 3. The Bowen's concept of triangle relationship is formed by the child, nurse and family member, because hospitalisation is experienced as a time of anxiety and stress and the parent can help reduce the stress on the nurse and vice versa in the case of hospitalisation. This is facilitated by listening.

#### 5.6.2.3 Subtheme 2.3: Uncaring attitude of nurses

The third challenge identified by family participants was the attitude of nurses. Most of the family participants experienced an uncaring and unhelpful attitude of the nurses towards them as family and their children and therefore cited this as the third major challenge in the involvement of families in the hospital nursing care of a child with ASD. Paediatric nurses must have attitudes that recognise the need of include the child's family as care receivers in addition to the hospitalised child (Oh *et al.* 2018: 275). Some of the family participants are shared below:

> When they used to come, they used to say "Oh we going to that naughty ones room now" and they'd call all the nurses to hold him down because they would say he's naughty. He wasn't naughty he was just afraid of the nurses. They were very disrespectful.
>
> They restrained him to the bed for no reason. They treated him like a danger to other children when he was not. They would say we're going to give medication to that one that fights. And they would be five adults nurses holding my small 9-year-old boy and he would get very anxious with the five nurses holding and injecting him. They would tell me to go outside and wait while they injected. It is not nice at all looking at your child being held by these five nurses and injected.
>
> They treated me and my child very differently from the other parents, they were not nice to me and gave me strange looks. My husband got very angry at the nurses and was shouting at them and then I had to send him away to cool down. He was angry because they kept on saying my child is really naughty.
>
> The nurses are too busy and impatient. They're always in a rush to do their work. They quickly do their work and then go and sit and gossip. I also think that they

don’t know about autism and they have very bad attitudes towards children with autism. (Family Participant 1)

At a private hospital, no one wanted to help me because he was a bit aggressive, they said they couldn’t do anything without his consent, and they refused to even help. They came up to the car and they saw his hand was bleeding and they said they couldn’t help him in any way because he they needed his consent. When I took him to a government hospital, the nurses assessed him, and they diagnosed him with bipolar depression and admitted him. I don’t think the nurses and security guards are clued up at all about autism. they mix up autism with mental health issues. they put my son with other patients with mental health psychiatric issues. He was 16 years old at the time and was treated like a psychiatric patient.
They made the situation worse my son thought that they were fighting with him and so he fought back. Some tried to treat him like a psychiatric patient. They did treat his hand eventually. (Family Participant 2)

Not good at all. The nurses were not helpful, they were not kind. They are not trained on how to handle an autistic child. The handled my child very roughly. When I spoke to the nurse she said “this is how we do it”.
We were not allowed to be with our child in the procedure room when they were sedating him and I could hear him crying. There was like 10 nurses holding him trying to put in a drip, which was not fair. They did not allow us to be with him in the theatre, they did not allow us to be with him in the recovery room. When he came back to the ward, there was no help from the nurses. All the children in that room were with their parents and the parents were doing everything for the children with no help at all from the nurses. We had to try to feed our child by ourselves after theatre. Only when I went and complained to the nurses and screamed at them then they came to help us.
I expected the nurses to be more patient and to help the parents to care for the child. There were no nurses helping us with our child, my husband called the nurses to help us but they did not come. We felt discriminated.
It seems like the nurses are afraid of the child having tantrums and so they don’t help with the child at all. My son also doesn’t like new people. The nurses are also not friendly at all. The nurses also lack gentleness with the children, and they lack knowledge on how to nurse children with autism. (Family Participant 3)

From the above accounts it is noted that most family participants experienced the poor attitudes of the nurses as a challenge in the involvement of families, in

the hospital nursing care of a child with ASD, and believe that this is a contributor to poor nursing care.

Utilising empiric evidence gathered from family participants, it is very evident that "Uncaring attitude of nurses" was identified as a challenge to the involvement of families in the hospital nursing care of a child with ASD. From the interviews it appeared that what led families to perceive nurses to have uncaring attitudes is that nurses did not listen to families. Actively incorporating family members in care was connected with a good attitude toward patients' relatives (Cranley *et al.* 2022: 70). Nurses did not respect family participants as a knowledgeable partner in the care of the child with ASD in hospital, nurses showed a lack of knowledge, understanding and flexibility when nursing the children with ASD, and nurses showed their impatience towards the family and child. Mothers of hospitalised children desired to be respected by nurses, to participate in their children's nursing, and to have adequate information to collaborate with nurses. Instead, many felt insulted by the paediatric nurses or were given little information (Oh *et al.* 2018: 275). It is therefore very evident that the nurse not creating a good nurse-patient or nurse-family relationship led to the family members perceiving this as a bad attitude of the nurse.

The views of nurses on the relevance of family in the care process might influence the quality of the relationship that develops between nurses and family (Alfaro Diaz *et al.* 2019).

Only two of the nurse participants directly identified "Nurses' attitude" as a challenge in the involvement of families, in the hospital nursing care of a child with ASD, but nurse participants suggested that to overcome these challenges nurses must have patience and a caring attitude. This was interpreted by the researcher as all the nurse participants acknowledging that "Nurses' attitude" can be a challenge. The two nurse participants that identified this as a challenge reported the following:

> Nurses attitude is also a problem, I find today that nurses have less compassion for their patients and they don't have patience and time when caring for their patients, I feel nurses today are very task oriented and not caring towards their patients. They don't have a commitment to their patients. (Nurse Participant 2)

> The nurse must have compassion for the child otherwise it will be very difficult. (Nurse Participant 3)

From the quotes above that these nurse participants also agreed with the seven family participants that poor nurse attitude is a barrier in the involvement of families, in the hospital nursing care of a child with ASD. From the nurse participants responses, it is noted that if the nurse has a poor attitude such as feeling intimidated by parents or feeling that involving parents will waste their time, then the nurse will not involve the family in the in-hospital nursing care of the child with ASD. A collaboration between the parents of hospitalised children and nurses has a substantial impact on the quality of paediatric nursing (Oh *et al.* 2018: 275).

Thus, nurses' attitude becomes a barrier to the involvement of families in the in-hospital nursing care of the child with ASD. This poor attitude has been attributed to being intimidated, lacking of compassing and caring, and lack of time. This perception is supported by literature such as a recent multinational comparative study done by Cranley *et al.* (2022: 70) on nurses' attitude towards families, which confirmed that nurses' views toward families might either aid or impede family engagement in treatment. While favourable views about families can lead to improved communication, relationships, and results, negative attitudes toward families can result in bad sentiments among family members, such as feeling alienated and less empowered to engage in caring (Hoplock *et al.* 2019: 392). Understanding nurses' views on the relevance of family in nursing care is crucial since attitudes may influence the behaviour of both nurses and family members (Hoplock *et al.* 2019: 392). These authors confirm the perceptions of the nurse participants and family participants that the nurses' attitude can be a hindrance to involving the family in the care of the child with ASD.

#### 5.6.2.4 Subtheme 2.4: Nurses' lack of time

The next challenge in the involvement of families in the hospital nursing care of a child with ASD that was identified by family participants was "Nurses' lack of time." Nurse participants also identified this challenge, but they perceived it as "Increased time needed to nurse a child with ASD." The researcher will therefore present this as one theme. The family participants had the following to say with regard to this subtheme:

> The nurses are too busy and impatient, they're always in a rush to do their work. They quickly do their work and then go and sit and gossip. (Family Participant 1)
>
> They are short staffed, there are too many patients and too little staff so they lack time with patients. (Family Participant 2)
>
> The nurses don't have enough time and therefore they can't cope. (Family Participant 5)
>
> Nurses need to be more patient and caring towards the child. (Family Participant 6)

Given the empiric evidence provided by family participants, the findings reached by the researcher is that lack of nurses' time is a challenge in the involvement of families in the hospital nursing care of a child with ASD. It was clear to the researcher that family members came to this conclusion because when they needed nurses' help, nurses were not available. Nurses spent as little time as possible with children and interaction with the child was very rushed. Some family participants interpreted this lack of time as an excuse to spend as little time as possible with the child. Other family participants felt that it was because the nurses had too many work responsibilities and therefore did not have much time to spend with their child and them. This lack of time was a barrier to the nurse developing a relationship with the child and family and therefore, posed a challenge to family involvement. This lack of time was perceived as a negative experience by the family participants and made them feel as if their child was less important to the nurse. In a scoping review looking at the medical experience of children with ASD and their parents, Wilson and Peterson (2018: 811) found, that parents of children with ASD reported feeling that they did not have enough time with their health care provider and that the HCPs do not listen and support them due to a lack of time.

From the above family participant accounts, it is noted that half the family participants experienced nurses not having enough time for their child. This sentiment is shared by the nurse participants, however, they phrased it differently saying that nursing a child with ASD requires much more time than nursing a neurotypical child. Presented below are some of the nurse participants responses:

> Personally, when I first started nursing, I used to avoid nursing children with ASD because they were difficult to nurse and treating them takes much longer than a normal child, but as I have grown in nursing I feel more qualified now to nurse autistic children even though I have very minimal knowledge. Time management is a big barrier to involving parents because it takes much longer. Nurses are normally short staffed and therefore don't have that extra time to involve the parents in the care of the child. (Nurse Participant 2)

> These patients are very demanding and takes a lot of the nurse's time, so you have to be patient. Some nurses don't have this patience with the child. Nurses must have understanding and patience with the child because it is easy to get frustrated from my perspective. When you are nursing this child, you will need to be patient and give more time and attention. (Nurse Participant 9)

> The other reason nurses don't involve parents is because with these children it takes time and if the mother is not assertive enough, it will take a lot of your time to give this one child medication, whereas you could have finished a whole room full of children. So, if the mother was not assertive enough it was quicker just to take the child to the treatment room and give the medication there because the children are afraid of the nurses so they take the medication quickly. (Nurse Participant 10)

When probing the nurses, it was apparent that nurses perceived nursing a child with ASD as "difficult and time consuming" and this leads to a negative perception of nursing children with ASD, which leads to the nurse rushing tasks with the child. Nurses felt that nursing the child with ASD took much longer than a neurotypical child and therefore made their work life much more difficult. Wilson and Peterson (2018: 809) corroborated this when they found in their study that children with ASD spent double the time with their doctor during their appointments as did children with other special healthcare needs. One nurse even commented that it was easier to take the child away from the parent and force the child to take their medication. The quotations above suggest that many of the nurses that were interviewed believed that nursing a child with ASD required much more of the nurse's time than a neurotypical child. This led many of nurses to perceive nursing a child with ASD as time consuming and many of the nurses stated that it was difficult to nurse children with ASD. Walsh *et al.* (2020: 421) found that the inability of healthcare professionals to effectively

manage the care of children with autism was another barrier, and they frequently grumbled about the extra time needed for these patients during consultations.

Given the empiric evidence provided by the family and nurse participants and the published evidence provided by Walsh *et al.* (2020: 421) and Wilson and Peterson (2018: 809), the researcher agrees that nurses' lack of time is a challenge in the involvement of families in the hospital nursing care of a child with ASD. On deeper probing of this, it was clear that parents came to this conclusion because when they needed the nurses' help they were not available to help. Nurses spent as little time as possible with their child and when the nurse did interact with their child it was very rushed. When probing the nurses, it was apparent that they perceived nursing a child with ASD as "difficult and time consuming" and therefore this leads to a negative perception of nursing children with ASD, which causes the nurse to rush tasks with the child. In other words, the nurses wanted to get in and get out as soon as possible.

#### 5.6.2.5 Theme 2.5: Shortage of nursing staff

The final challenge identified by some of the family participants was the shortage of nursing staff. This perception was also corroborated by some of the nursing participants and literature as well. Benzies *et al.* (2019: 49) asserts that nursing staff shortage is a barrier to the effective involvement of family in their child's care. The family participants' comments about nursing staff shortage are as follows:

> They are short staffed. There are too many patients and too little staff so they lack time with patients. (Family Participant 2)
>
> I think there should be one nurse per child to help the children. (Family Participant 3)
>
> Allocate one nurse to care for special needs children that are admitted.
> Nurses are short staffed, my son vomited, and I pressed the bell 6 times to call the nurses, but eventually I had to clean it myself. (Family Participant 5)

The researcher acknowledges staff shortages as a challenge in the involvement of families, in the hospital nursing care of a child with ASD, based on the above evidence. Family participants' perception of "short staffed" is perpetuated by the absence of nurses in their child's room when needed and the rushed manner in

which the nurse carry out their duties. Jarrar *et al.* (2018: 469) reported that poor patient care may result from nurses who are overworked and unable to spend time with their families or patients while they are performing procedures. Because of this, having sufficient staffing levels in the department may enable nurses to spend more time with patients, thereby improving the quality of care..

This could just be the perception of the family participants because of the absence of the nurse and not actually a shortage of staff. This absence of the nurse decreases the contact time between the nurse and the parents or the nurse and the child, which in turn decrease the nurse's ability to build a trusting nurse patient/ nurse family relationship, which is necessary to ensure effective family involvement. Thus, a shortage of staff can be considered as a challenge to family involvement.

The nursing participants provided the following comments about being short staffed:

> Time management is a big barrier to involving parents because it takes much longer. Nurses are normally short staffed and therefore don't have that extra time to involve the parents in the care of the child. (Nurse Participant 2)

> The one child would be aggressive with other children and take their toys and so the mothers would complain to us, the nurse, about this child and all we could say is he has a medical condition. This was frustrating for us as nurses because we had to take time to deal with the mothers complaining and we were short staffed and had 22 patients to care for. (Nurse Participant 10)

This perception of shortage of staff as explained in the subtheme above is because of the nurse's perception of nursing a child with ASD as being "difficult and time consuming" and the nurses are therefore of the opinion that nursing this child requires more staff or specialised staff, and therefore more staff are needed. It is apparent that nurses perceived involving the family in their childcare to be even more time consuming for the nurse and thus they mentioned the shortage of staff.

### 5.6.3 Theme 3: Suggestions to promote effective family involvement

Theme 3 was formulated to address **Objective 3** of this thesis which was: **To explore participant perceptions on the range of corrective interventions and actions to overcome challenges and promote effective family involvement, in the hospital nursing care of a child with ASD.**

Many subthemes emerged from the data provided by the family and nurse participants, all of which are presented below.

#### 5.6.3.1 Subtheme 3.1: Nurses must be trained to nurse children with ASD

The first challenge identified by the family participants, the nurse participants, and the literature, was the "lack of knowledge" by nurses regarding ASD, so it is not surprising that this was also the first suggestion put forward by the family participants to promote effective family involvement. The family participants had the following suggestions:

> The nurses must go for workshops to understand autism and how to nurse children with autism. (Family Participant 1)
>
> The nurses must be educated on autism and have some sort of in-service training on autism.
> The nurses need more education on autism. (Family Participant 2)
>
> They need to be comfortable caring for a child with Autism, so they must have training on autism. They need to build a relationship with the child and the parents, this is where the training and knowledge will help. (Family Participant 3)
>
> The nurses are uneducated about autism. Nurses need to be trained about special needs and autism. At least one nurse per shift should be trained on special needs and autism and that person can teach others. (Family Participant 5)

The above accounts suggest that most of the family participants in this study had bad experiences of nursing care in hospital and attributed this bad nursing care to poor education and training on ASD. Even those participants that had a good experience in hospital also noted that the nurses needed education and training on ASD and training on how to nurse a child with ASD. Family participants believed that increased knowledge would lead to better understanding of the nurses when nursing their children, and therefore a better nurse- patient and nurse-family relationship and better family involvement. This suggestion is

substantiated by many authors (Benich *et al.* 2018; Ndubaku 2018; Cranley *et al.* 2022) who found a critical need for further ASD training for nurses and reported that education and training programmes showed increased nursing staff knowledge, reduced anxiety related to caring for ASD children, and a more positive attitude from nurses towards families. This suggestion was also supported by the nursing participants who said the following:

> Nurses need more education and need to share experiences because every child is different. (Nurse Participant 1)
>
> We as nurses must have some knowledge of ASD. (Nurse Participant 5)
>
> Nursing ADHD or autistic kids should be included in the nursing syllabus to have a background knowledge which will aid in their nursing care. (Nurse Participant 7)
>
> Nurses need to have in service training or readable literature informing them of this diagnosis. If we equipped with that knowledge the task become easier to deal with. With knowledgeable nurses, parents will be at ease when we take care of their kids and more well informed. The severity of the cases differs so knowledge is key. (Nurse Participant 8)

It is apparent that the nurse participants also agree that they need education and training on ASD. The chance of successful family involvement will increase with more education to make sure that nurses are sufficiently prepared to meet the needs of parents. Nursing care of children with ASD and the role of their families needs to occupy a more prominent position in nursing education which will create a more supportive environment (Hetland *et al.* 2018; Nygård and Clancy 2018; Wilson and Peterson 2018; Nicholas *et al.* 2020).

Most participants agree that paediatric ward nurses in eThekwini need to undergo education and training on nursing a child with ASD. From the responses of the nurse participants, the nurses perceive their knowledge on ASD to be very minimal and want to be educated on ASD and nursing a child with ASD. This education and training have been included in the framework presented in Chapter 6 as it directly links to improving the concept of empowerment as discussed in the conceptual framework in Chapter 3.

#### 5.6.3.2 Subtheme 3.2: Nurses must have a caring attitude and patience

The next suggestion made by family participants were for nurses to have a more caring and kinder attitude towards their patients and families. The nurse participants also made this suggestion, but they suggested that nurses be more patient with children with ASD and their families. Both these suggestions deal with the attitude of the nurse towards the child with ASD and the family and therefore were grouped together under one theme. It is apparent that the family participants and the nurse participants and literature all agree that this is a very important suggestion to promote effective family involvement. The following are some of the verbatim suggestions of the family participants:

> I expected the nurses to be more patient and to help the parents to care for the child. The nurses need to be calm and friendly with the parents and children. They need to be comfortable caring for a child with autism, so they must have training on autism. They need to build a relationship with the child and the parents. (Family Participant 3)

> I find in general nurses lack compassion and caring for patients. I think to be a nurse you should be caring towards people. Nurses need to be more compassionate to the child and kind to the parents. (Family Participant 4)

> Nurse shouldn't have a "I know it all" attitude. Nurses must be patient, kind and caring. The nurse must bring themselves down to the level of the child. Nurse to be understanding. (Family Participant 7)

It is noticeable that many of the families have experienced bad attitudes from nursing staff. The responses suggest that family participants felt as if their child and family had experienced discrimination from the nurses; they felt that their child and family were treated differently because their child had ASD. Family participants also expressed that nurses were impatient, cold, unfriendly, unhelpful, had a "know it all" attitude and even aggressive behaviour with them and their child. Some family members expressed that having a child with ASD is very stressful and being admitted is very stressful, therefore if the nurse has a kind, patient and understanding attitude it is very reassuring for the family. The family know that nursing their child requires more patience, compassion and time from the nurse and they just want to be reassured by the nurses that they and

their child are not a nuisance. Due to this bad lived experience of the family participants, they are suggesting that if the nurses have a more caring, friendly and understanding attitude, this will create a more conducive environment for them and their child and help build a better nurse-patient/nurse-family relationship, which in turn will promote family involvement in the hospital nursing care of the child with ASD. According to Hetland *et al.* (2018: 68), patients, families, and even nurses benefited from nurses who had positive attitudes toward family caregiver involvement in patient care. Involving families also allowed nurses to concentrate on higher priority or acute work issues, which they believed benefited the process of providing overall patient care. Nurses' attitudes toward family caregiver involvement in patient care can act as both a barrier and a facilitator.

The nurse participants agreed with the above suggestion by saying the following:

> I think the most important thing is for the nurses to have patience with this child. The nurse needs to understand the child, the nurse must have patience with the child.
> The nurse must be patient with the parents and the child.
> Nurses must also understand that these children's behaviour is different and difficult at times. (Nurse Participant 3)

> It is very important to have patience with these children because it takes more time because they are a bit slower than other children, a procedure might take 2 minutes on a normal child but on an autistic child it will take 10 minutes. (Nurse Participant 5)

> Nurses must have understanding and patience with the child because it is easy to get frustrated from my perspective. These patients are very demanding and take a lot of the nurse's time, so you have to be patient. Some nurses don't have this patience with the child. (Nurse Participant 9)

> You need to be patient and take the necessary time that you would need for that specific case.
> I think it has to be more sensitive and more comforting and more sympathetic. (Nurse Participant 10)

It is apparent from the above quotations that the nurse participants believe that patience and empathy, can promote a better nurse-patient/ family relationship and in turn effective family involvement. The nurse participants acknowledge that nursing a child with ASD is different from nursing a neurotypical child because it takes much more time, thus the need for patience. It is already known that involving parents in the care of a child when in hospital is likely to be influenced by the attitudes and actions of health professionals (Heath *et al.* 2016: 12). In order to put family involvement into practice, it is very important for the nurses to recognise the importance of family and to have a supportive attitude towards families; in fact, nurses' negative attitudes towards families are the greatest obstacles to meaningfully involving the family in childcare and, therefore, the attitudes of practicing nurses are vitally important, for promoting effective family involvement in the paediatric nursing field (Oh *et al.* 2018: 275).

The researcher therefore concludes that the nurse and family participant perceptions and literature all indicate that ensuring nurses have a kind, caring, empathetic and patient attitude toward children with ASD and their families will help promote effective family involvement. The above excepts indicate that nurses need to be patient when nursing a child with ASD, and realise that their nursing care is much more time consuming. The family members desired that the nurses display a caring attitude towards their child with ASD, and they expect the nurse to build a good nurse-family relationship by communicating with the family and child, being patient and listening to the family's concerns and suggestions. Nurses need to acknowledge that families are knowledgeable partners in caring for the child with ASD and respect that. This patient and caring attitude of the nurse has been included in the framework presented in Chapter 6 as it directly links to improving the concept of empowerment as discussed in the conceptual framework in Chapter 3.

#### 5.6.3.3 Subtheme 3.3: Nurses must communicate with parents.

"Nurses must communicate with parents" was the third subtheme and suggestion by family and nurse participants to promote effective family involvement. The family participants proposed this subtheme with the following quotations:

> Nurses must communicate with the parent more so they can understand the child. (Family Participant 1)

> They should have asked me about him. they must communicate with the parents. (Family Participant 2)

> I think firstly the nurses should have found out how I take care of my son at home, how I calm him down at home, what triggers aggressive behaviour in him, they should have found out about what he likes to eat. (Family Participant 6)

An analysis of family responses revealed that nurses' communication with the family of the child with ASD when in hospital is vitally important to promote effective family involvement. The researcher interpreted the responses of the family participants as them believing that they were the experts on their children and if the nurses listened to their expert opinion, they could ensure a smooth hospitalisation for the child, family and nurse. Those families that had good hospital experiences were the families that were listened to and valued as experts by the nurses. Family participants equated communication and listening to respect, as interpreted by the researcher. Some of the family participants conveyed negative experiences where the nurses and doctors did not talk to their child at all even though the child could understand the nurses and doctors. Other family participants also had a negative experience where they were not communicated with by the doctors or nurses and therefore suggested that the nurses need to communicate adequately to the family and child all the time in a way that they would understand. Communication is an important component in promoting effective family involvement. When HCPs communicate better with families this facilitates care; when families perceive that the communication as poor, this is a barrier to care (Mahoney *et al.* 2021: 8). Effective continuous communication between nurses and parents helps to build a trust relationship because parents appreciated nurses communicating with them and their child and listening to them (Mimmo *et al.* 2019: 1206). According to Hetland *et al.* (2018: 73) nurses were able to engage in this type of communication particularly well with families who remained at the bedside; by approaching the issue of caregiving early, nurses built trusting relationships with family members that led to successful caregiving involvement. Nurse communication with family members, particularly early in the course of hospitalisation, facilitated family involvement.

In agreement with the family participants suggestions above, Some of the nurse participants echoed the family participant suggestions above:

> I think the most important thing for us as nurses is to communicate with the parents; communicate with the parents and discuss information with the parents. (Nurse Participant 2)
>
> Effective communication plays a major role between the family and the nurse. (Nurse Participant 4)
>
> Communicate with the parents. (Nurse Participant 5)
>
> So I think it's mostly the communication. Even if the doctor is caring for the child the way that the doctor communicates with the mother in terms of giving feedback in the prognosis of the child.
>
> Yeah, I think It is better communication skills among all the members that are involved, including the mother, the child, the doctor, nurses and everybody else. (Nurse Participant 10)

It is apparent that the nurse participants agreed with the family participants that by the nurse communicating with the family of the child with ASD promotes effective family involvement and good quality nursing care. Dahav and Sjöström-Strand (2018: 364) found that the majority of parents value open and honest communication, which fostered their sense of security and trust. Many parents believed that they were well informed and involved in all processes before any examinations or caregiving activities began. Parents were able to feel safe, at ease, and involved in the care and treatment of their children thanks to information and communication. They also commented on how important they felt communication with the family is and said that poor experiences were the result of poor communication (Dahav and Sjöström-Strand 2018: 368).

#### 5.6.3.4 Subtheme 3.4: Nurses must listen to parents

Subtheme four identified by family participants was: “Nurses must listen to parents more”. This is very closely related to communication and could have been included under the subtheme of communication, as some would argue listening is part of communication, however, the researcher chose to present it as a different subtheme because during the analysis and interpretation of data, it became apparent that the family participants viewed these as two different points. In communication, the family participants wanted to be communicated with by the nurse, whereas in this subtheme

the family participants wanted to be listened to by the nurse and be recognised as the expert on their child and valued for their opinion. The following quotes are from the family participants regarding this subtheme:

> The nurses must listen to what the parents are saying and not be offended because the parents know their child better than the nurses. They must not assume that the child is naughty but ask the parent what to do. (Family Participant 1)

> Nurse shouldn't have an "I know it all" attitude. Listen to the parents and work together with the parents. (Family Participant 7)

> And I think that the nurses' perception has to change because parents are really experts on their children and acknowledge, how much anxiety there is for the child and the parent here. (Family Participant 9)

Family members feel that they are the experts on their children and that if the nurses listen to them this will promote effective family involvement and good quality nursing care. When the nurse listens to the family, it is interpreted by the family as the nurse respecting their expert knowledge of their child, showing a caring interest on how to correctly nurse their child, and acknowledging their lack of knowledge and willingness to learn. Family participants felt that they were the experts on their children and that the nurses could learn a lot about their children by listening to them. Family participants interpreted nurses not listening to their concerns as disrespectful. For the family participants, nurses that did not listen to family members were arrogantly thinking they knew better than the family and this formed a barrier to promoting family involvement in the nursing care. On the contrary, if the nurse listened to the family participants this promoted teamwork between the nurse and family members and thus promoted family involvement in the hospital nursing care of the child with ASD. Many authors (Heath *et al.* 2016; Clark, Whitt and Lyons 2019; Mimmo *et al.* 2019: 1207) found that parents conveyed a sense of confidence and security with health care workers who heard them and valued their expertise in order to provide high quality nursing care to the child.

The nurse participants also identified the same subtheme and below are some of their verbatim words:

> I think it is important to involve parents every step of the way. Parents know their child best. They know what their child needs. Involve them in the nursing routine. Try and explain everything you are doing to the family and child. (Nurse Participant 1)
>
> In my opinion the parents know the child the best and they can help to plan the nursing care.
> In my opinion we need to involve the parents from the start, plan your treatments according to the parents and patient. (Nurse Participant 2)
>
> Ask the parents what calms the child down. To work together with the nurses, for example, parents tell us what the child likes and dislikes because the parent knows the child best. Get information from the parent.
> Specific nursing care for this child, develop the problem, figure out your options to help the patient. Check if this option is acceptable to the parent and child. If the child refuses the medications figure out a way to give the medication e.g., in the food. (Nurse Participant 6)
>
> Firstly, they must listen to the parents they will tell you the dos and don'ts. Let the parents' guide you. Listen to the parents.
> The parents can teach us what works at home with the child. The parents can give us information like what the child likes and dislikes, so we can use the likes in the nursing care of the child. The parents can tell us if we can play with the child and some of the child's behaviour like if he/she screams, bites, injures themselves and let the staff know if they do. (Nurse Participant 9)

The nurse participants expressed that listening to the family is a coping mechanism to overcome their lack of ASD knowledge and ensures a better experience for the child, family and the nurse. Listening to the parents also helps them to individualise the nursing care for their child. These nurse participants therefore perceive the family member as a knowledgeable partner in the hospital nursing care of the child with ASD. The nurse participants acknowledged that the parent has expert knowledge of their child and this expert knowledge can assist the nurse in caring for the child with ASD. According to Nygård and Clancy (2018: 3192), while asking pertinent questions that can elicit the parents' values, beliefs, and experiences, the nurse must pay close attention to the parents' responses. This might open-up a conversation. The most effective means of fostering respect and trust between the parents and nurse may be

a sincere conversation between them. Listening attentively to the parents is the most beneficial nursing intervention (Nygård and Clancy 2018: 3193). Nurses should have a high level of empathy and actively listen to the parents' thoughts, opinions, and preferences to improve their involvement and ability to cope with their parental role. Some parents felt as though they weren't being listened to by HCPs, which left them feeling powerless, insecure, and lacking in confidence when they sought health care for their child (Aarthun, Øymar and Akerjordet 2019: 56). Parents' opinions and expertise should be valued and heard, as this leads to the provision of effective, individualised care for children with ASD and their families (Nicholas *et al.* 2020: 95). “Not listening to parents” is a barrier to family involvement in the care of their child (Walsh *et al.* 2020: 422). Parents felt that health care providers sometimes did not listen and support them and the parents believed that this was due to a lack of respect and time; which was perceived very negatively by parents and made them feel helpless (Wilson and Peterson 2018: 812).

The researcher considers “Nurses must listen to parents” to be a sufficiently validated suggestion to promote family involvement for children with ASD in the hospital. This validation was achieved by source triangulation from family and nurse participants and a number of published articles. The researcher’s deeper interpretation of this point is that when the nurse listens to the family, it is interpreted by the family as the nurse respecting their expert knowledge of their child, showing a caring interest on how to correctly nurse their child, and acknowledging their lack of knowledge and willingness to learn. To the nurse, listening to the parent is a coping mechanism to overcome their lack of ASD knowledge and ensures a better experience for the child, family, and nurse. Listening to the family member helps nurses to individualise the nursing care of the child, therefore communication is positive for all concerned.

#### 5.6.3.5 Subtheme 3.5: Nurses need to take a detailed history of the patient

The next suggestion made by family participants and agreed to by nurse participants and literature was: “Nurses need to take a detailed history of the patient.” The family participants had the following to say:

> They should have asked about his history. They should have let me talk to him. Ask the parents for history.”

> He loves KFC he knows pictures of Spiderman and food. They could have got him to do what they wanted, by bribing him. (Family Participant 2)
>
> What I did was I printed copies of an information sheet for the nurses, It said my son's name is A, he is 2 years and 4 months old, he is autistic, it explained his stimming and what makes him aggressive etc. but the nurses don't read. The admission forms should have a section on disability and include all this information. On Admission, the nurses need to take a full history of the child, including the disability or autism traits. (Family Participant 5)
>
> I think firstly the nurses should have found out how I take care of my son at home, how I calm him down at home, what triggers aggressive behaviour in him, they should have found out about what he likes to eat.
> Get a detailed history from the parent. (Family Participant 6)
>
> But it depends. I think the nurses should establish all this in the pre consultation preadmission phase. What is the level of functioning?
> Then I think there should be an additional type of paperwork. So it would be maybe a more detailed history of the child and his likes, dislikes that kind of thing. (Family Participant 9)

The above excerpts illustrate the family participants' assertions that taking a detailed history of the child with ASD will promote effective family involvement and good quality nursing care. Utilising the family participant's assertions, the researcher interprets "Nurse taking a detailed history" as a valid suggestion to promote effective family involvement for the child with ASD. On the detailed interpretation of this point, it is apparent that the family participants feel that if the nurse takes a detailed history, it empowers the nurse to plan care appropriately to meet the special needs of their child and ensure a very pleasant hospital experience for all. The family participants also viewed this detailed history taking as the nurse taking a special interest in their child and equated this as having a caring attitude and willingness to learn. Clark, Whitt and Lyons (2019: 891) acknowledge the critical importance of having pre-anaesthetic nursing staff contact patients' caregivers a few days prior to admission to the hospital or surgery to review and update their history. Austriaco *et al.* (2019) agree that the first step and most important step in nursing an acutely ill child with ASD is detailed history taking.

The family participants assertions were upheld by the nurse participants who said the following:

> Firstly, taking a good history from the parents is very important, especially about who the child responds to etc., ask the parents what triggers the child and what calms him down. (Nurse Participant 1)

> Parents must give a full, detailed history of their child to the nurses. (Nurse Participant 3)

> Interview the parents and get a full detailed history from the parents. (Nurse Participant 6)

> The parents can teach us what works at home with the child. The parents can give us information like the child likes and dislikes, so we can use the likes in the nursing care of the child. The parents can tell us if we can play with the child and some of the child's behaviour like if he/she screams, bites, injures themselves and let the staff know if they do.
> Firstly, they must listen to the parents they will tell you the dos and don'ts. Let the parents guide you. (Nurse Participant 9)

> Get proper data from the parent. Then you would understand the child's habits better and you know. The parent will tell you how to give this medication to this child easily. So, if you take enough data from the parent then you could be successful with nursing this child effectively. (Nurse Participant 10)

The nurse participants also saw the detailed history taking as an empowering exercise in which they could gather as much information as necessary to plan their nursing care in the least disruptive way for the child and gain their trust and co-operation. An interpretation of the nurse participants response can be that the nurse participants acknowledge that children with ASD are different from neurotypical children and each child with ASD is unique and is afflicted in different ways, therefore getting a detailed history from the parents allows the nurse to gain important information about this child. This information is vitally important in planning the nursing care of the child and in involving the parents in the child care. Benich *et al.* (2018: 42) suggest health care workers regardless of how insignificant the intervention may seem, should collaborate with the parent or guardian of the child before any intervention and recognise that they

are the child's expert. Prior to interacting with a specific child, health care professionals should gather data regarding that child's behaviour.

Utilising the family participants and nurse participant assertions and those in the literature, the researcher interprets “Nurse taking a detailed history” as a valid suggestion to promote effective family involvement and has been incorporated into the framework developed in this study and presented in Chapter 6.

#### 5.6.3.6 Subtheme 3.6: Nurses need to use the child’s likes to get co-operation

The family participants next suggested that the nurse utilise the child’s likes to gain the child’s co-operation during nursing care. The family participants had the following suggestions in this regard:

> He loves KFC he knows pictures Spiderman and food they could have got him to do what you they want by bribing him.
> They can even bribe the child with something he likes. (Family Participant 2)

> They need to ask the parent what upsets the child and what keeps him calm. They should find out if the child likes or dislikes physical touch. (Family Participant 4)

> Preferably the child must be admitted in a private room because of the sensory issues of children with ASD, the curtains, room lights etc. are important. The hospital needs to cater for the food preferences of the child. There should be printed handouts on what triggers and calms the child. The paediatric ward should have a playroom with sensory toys to use in the playroom to calm the child down and be a form of distraction. (Family Participant 5)

> Music calms him down, they did not have any music to calm him down. I think firstly the nurses should have found out how I take care of my son at home, how I calm him down at home, what triggers aggressive behaviour in him, they should have found out about what he likes to eat.
> Try and keep to the child routine. (Family Participant 6)

Analysis of the above family participants responses, clearly illustrates that the majority of family participants know exactly what their children’s likes and dislikes are, and suggest that the nurses use these likes to ensure that the nursing care of their children with ASD is more acceptable for the child and easier for the nurse and family member. The family participants felt that if the nurses knew their child’s likes and dislikes the

nurse could create a physical and psychological environment that would be suitable for their child and ensure a good hospital experience for all. The family participants felt that this individualised nursing care showed that the nurses cared about their patients and their families. Oh *et al.* (2018: 275) agreed with this suggestion by stating that in hospital nursing care of children the paediatric patient's family members are advocates for their children who convey the wishes and expectations of the child. In addition to having a general understanding of ASD, the nurse must be familiar with each patient's routines, preferences, and behavioural triggers (Ndubaku 2018: 36). Family members of children with ASD can assist the care process by conveying how the child's likes and dislikes can be incorporated to provide good quality nursing care (Ndubaku 2018: 44). Good nursing care involves putting ASD knowledge into practice and listening to the family members of the child with ASD about the child's preferences (Owen, Gary and Schnetter 2020: 35).

The nurse participants also identified "Nurses should know the child likes and dislikes," as a suggestion to promote family involvement in the hospital nursing care of the child with ASD. Below are some of the nurse participants responses:

> Ask the parents what triggers the child and what calms him down. Try and make the environment more conducive for the child. (Nurse Participant 1)

> Include the child's likes and dislikes in the child's nursing care.
> Specific nursing care for this child, develop the plan, figure out your options to help the patient. Check if this option is acceptable to the parent and child. If the child refuses the medications figure out a way to give the medication e.g. in the food. Interview the parents and get a full detailed history from the parents. (Nurse Participant 6)

> The parents can teach us what works at home with the child. The parents can give us information like the child likes and dislikes, so we can use the likes in the nursing care of the child. The parents can tell us if we can play with the child and some of the child's behaviour like if he/she screams, bites, injures themselves and let the staff know if they do. (Nurse Participant 9)

The majority of the nurse participants in this study agree that using the child's likes and dislikes in their nursing care is very important in ensuring the promotion of effective family involvement in the hospital nursing care, for children with ASD. The nurse

participants also felt that knowing the child's likes and dislikes will help them nurse the child with ASD better and keep the child and family happy during their stay in the hospital and ensure they deliver good nursing care to the child. Similarly to the suggestion above, an interpretation of the nurse participants is that the nurse participants acknowledge that children with ASD are different from neurotypical children and each child with ASD is unique and is afflicted in different ways, therefore getting to know their likes and dislikes from the parents allows the nurse to gain important information about this child. This information is vitally important in planning the nursing care of the child and also in involving the parents in the child care. Magalhães *et al.* (2020: 558) supports this suggestion of using the child's likes and dislikes to develop different strategies in the management of the autistic child with the purpose of promoting successful nursing care, such as: the musical intervention and the use of toy resources, is a very important nursing task. It has been established that families were very pleased to be asked about their children's likes, dislikes and experiences (Clark, Whitt and Lyons 2019: 899). To ensure that health care is provided in accordance with the needs, preferences, and likes of the children and the families, parents in many Western countries have a legal right to participate in decision-making about their children's health care (Aarthun, Øymar and Akerjordet 2019: 50).

Given the above literature that affirms the assertions by the family participants and nurse participants, it is the conclusion of the researcher that "Nurses need to use child's likes to get co-operation." This will ensure the empowerment of the family as discussed in the conceptual framework developed in Chapter 3 and the "Theory of Family Care During Critical Illness."

#### 5.6.3.7 Subtheme 3.7: Nurses need to involve the parents more in the care

The next suggestion made by the family participants was that "Nurses need to involve parents more." Their exact words are below:

> They did not allow us to be with him in the theatre, they did not allow us to be with him in the recovery room. They should allow us in these areas as well. (Family Participant 3)

> I am a nurse and a nursing lecturer at a university, and they did not involve me in the medical care at all. I would have liked to be involved in the medical care of my son since I am a nurse as well.

> They must involve the parents more in the care of the child. (Family Participant 3)
>
> I think it is to get the parents involved in caring for their child. Develop a good relationship with the parents. (Family Participant 7)
>
> The parents know their child the best. Parents are a knowledgeable partner (Family Participant 10)

It is clear that when family participants say they want to be more involved in their child's care, in the researcher's interpretation, they want to be consulted on the medical and nursing care decisions as well. They want to be seen as a knowledgeable partner in the care of their child and would like their concerns and suggestion to be considered and implemented by the nurses. The family participants wanted to be present all the time, even in the operating theatre. The family participants also wanted to be involved in the decision making regarding their child's medical and nursing care. Some family participants wanted their children to be consulted and involved in their own care because their child had the capacity to make some decisions on their own. It is therefore clear that involving the parents in the decision making with regard to medical and nursing care of their child would empower them and thus improve family involvement in the hospital nursing care of the child with ASD. Section 28 (1)(b) of the South African Constitution guarantees all children the right to family or parental care. This right also applies to hospitalised children who need support from parents and family while they are in the hospital (Mahery 2021: 1). Increased parental involvement in children's health care is anticipated to increase the individual customisation of children's health care and thereby increase the quality of care and safety for children. Parents have valuable knowledge about their child and are important helpers in implementing their children's health care (Aarthun, Øymar and Akerjordet 2019: 51). Although parents do not participate as much as they would like to in healthcare decisions for their children, it is important that nurses encourage parents' involvement in their patients' healthcare in order to increase parental influence and control over their patients' healthcare (Aarthun, Øymar and Akerjordet 2019: 55). In order to do this, nurses have to provide parents with better opportunities to understand their child's health condition, needs, and medical treatment through adequate, dependable, and individually tailored information. When this was done, parents feel more secure and in control of the situation because they believe their child is receiving the proper medical treatment. They also become more engaged and active.

The nurse participants agreed with this suggestion and said the following:

> I think it is important to involve parents every step of the way. Involve them in the nursing routine. Involve the parents in the patient's care. Get the parents involved to calm the child down if they are upset. (Nurse Participant 1)

> In my opinion we need to involve the parents from the start, plan your treatments according to the parents and patient. (Nurse Participant 2 )

> Involve the parents in all actions pertaining to their child. If we are putting up an I.V. the mum can be by the head of the child, so he/she see her and is a bit calmer. The parents must help in all nursing care. The nurse must understand this is a special child. Involve the parents, let them do the essential things. (Nurse Participant 9)

Most of the nurses interviewed recognise the family's involvement as vitally important because they feel that the parents are experts on their child and can assist in the nursing care of the child, and this is a suitable coping mechanism for the nurses to overcome their lack of knowledge and training on ASD. Nurses also recognise that the child would trust the parent and be more co-operative if the parent was involved in the nursing care of the child. This can therefore be perceived as beneficial to the nurse, parents and the child. Cranley *et al.* (2022: 69) agree with nurse and family participants by stating that nurses play a key role in advocating and facilitating patient- and family-focused care practices, including social support for high family function and health, in order to provide patient and family-focused care and ensure optimal patient outcomes. Cranley *et al.* (2022: 69) go on to explain that family may play a variety of supportive roles, such as accompanying the patient to medical facilities, and offering emotional support throughout procedures.

Families are co-recipients of care and express the preferences and expectations of the paediatric patient, and play very important roles in caring for their hospitalised child (Oh *et al.* 2018: 275). As a result, it is crucial to take into account the child's family as care recipients in addition to the hospitalised child because the principles of family involvement recognise the value of family, respect the distinctive characteristics and values of the family, and share information with them for better decision-making (Oh *et al.* 2018: 275). The level of paediatric nursing was significantly influenced by the collaboration between the nurses and the parents of the children (Bae and Lee 2017:

528). The provision of professional care based on the interaction between the child and parent constitutes high-quality paediatric nursing. In addition to providing high-quality nursing to hospitalised children, paediatric nurses must also recognise the crucial role that the families of child patients play in the provision of high-quality paediatric nursing (Oh *et al.* 2018: 285).

The published evidence above and the empiric evidence from the family and nurse participants in this study suggest that “Nurse must involve families more” is a valid suggestion and will promote effect family involvement. On deeper interpretation of the data it is apparent that when family participants expressed that they want to be more involved in their child care, they want to be consulted on the medical and nursing care decisions as well. They want to be seen as a knowledgeable partner in the care of their child and would like their concerns and suggestion to be considered and implemented by the nurses. It is also evident that most of the nurses interviewed also recognise that family involvement was vitally important because they felt that the family were experts on their child and could assist in the nursing care of the child, it appears to be a coping mechanism for the nurses to overcome their lack of knowledge and training in ASD.

#### 5.6.3.8 Subtheme 3.8: Building a good relationship between the parent and nurse

Subtheme 8 of theme 3, deals with the building a good relationship between the nurse and the family, this theme emanated from the suggestions of both the family and nurse participants and is linked to all the subthemes explained above. The family participants had this to say:

> The nurses need to build a relationship with the child and the parents. (Family Participant 3)

> I also think that if we speak to the nurse well and develop a good relationship with them, things will go well. Develop a good relationship with the parents. Parents must speak to the nurses and work together with them. (Family Participant 7)

> Not to make the parent feel like they’re being a nuisance. With all this extra help, you got to give them but develop a good relationship. (Family Participant 9)

The above family participants explicitly said, “build a good relationship between the nurse and family”; although even though many other parents did not explicitly say it, this sense was implied in all their interviews. The researcher also notes that this relationship building takes time and is a conscious process and is impacted by all the other subthemes of this theme 3. Deeper interpretation of this point reveals that should the nurse adhere to all the subthemes above, such as listening to parents, communicating with parents, showing a caring attitude to the child and family, this will all help to build a good nurse-family relationship. According to NSM, this interpersonal relationship is part of the stable external environment that is needed for the client system. From the transcripts of the family participants, participants acknowledge that nursing their child is difficult but still want a good relationship with the nurses. Creating respectful and supportive relationships between hospitalised children, their parents, and nurses is a key component of family involvement (O'Connor, Brenner and Coyne 2019: 3364). Families are empowered to get involved in their child’s care when there is a positive nurse-patient relationship and knowledge sharing is in place (O'Connor, Brenner and Coyne 2019: 3364).

Families and nurses can work together to develop a successful relationship by developing their mutual knowledge, their skills, and negotiating their roles (Brødsgaard *et al.* 2019: 3135). The integration of parents' personal knowledge, values, and preferences appears to be essential for the development of a nurse/parent partnership because it gives the nurses a better understanding of the family's unique circumstances and allows them to customise evidence-based information and support to the specific child and family conditions. This, in turn, allows parents to participate in caregiving at their own pace and fosters their empowerment and autonomy (Brødsgaard *et al.* 2019: 3135). First and foremost, parents must feel welcomed and constantly present in the unit for parenting skills and child care competencies to develop, and involving the parent in the child’s care and offering guidance when necessary, this in turn builds a good nurse-parent relationship (Brødsgaard *et al.* 2019: 3135).

The nurse participant quotes presented below are those that explicitly mention building a relationship as a suggestion:

> Parents are there for emotional support and if the mother works with the nurses, for example in terms of convincing the child that he has to take this medication. (Nurse Participant 10)

> To work together with the nurses, for example parents tell us what's the child's likes and dislikes because the parent knows the child best. Get information from the parent. The parents help give the medication, so that before discharge the parents must understand the medication and be totally involved in the care and management of the child. The parents always stay with the child. (Nurse Participant 6)

As seen above nurse participants also agree that building a good nurse-patient relationship is essential to promoting family involvement. Families play a significant role in the planning and delivery of healthcare, and nurses' perspectives on their significance in the care process may have an impact on the quality of the relationships they forge with families (Alfaro Diaz *et al.* 2019: 2310). Making time specifically set aside for nurses to build relationships of trust with patients and family members may also encourage meaningful family involvement in nursing care (Cranley *et al.* 2022: 78). Parents emphasised the value of nurses taking the time to form relationships with the parent and child to understand the parent's support needs, foster parental trust in the nurse, and ensure safe care (Mimmo *et al.* 2019: 1029).

The researcher has interpreted the above empiric evidence and literature as agreeing that the nurse and family must build a good relationship in order to deliver good quality nursing care and promote family involvement. The researcher also notes that this relationship-building takes time and is a conscious process and is impacted by all the other subthemes of theme 3. A deeper interpretation of this point reveals that should the nurse adhere to all the subthemes above, such as listening to parents, communicating with parents, and showing a caring attitude to the child and family, this will help greatly to build a good nurse-family relationship. According to NSM, this interpersonal relationship is part of the stable external environment that is needed for the client system.

#### 5.6.3.9 Subtheme 3.9: The child needs toys or some entertainment in the hospital

The next theme identified by family participants was "The child needs toys and some form of entertainment in the hospital." The family participants reported the following:

> The room was dull no toys, nothing for the children to do but just lie in bed. This is very bad for children who need to have some sort of toys or some sort of way to play in the room should be nice and colourful for the children.
> Lack the tools like toys to entertain the children. There should be some fun activities in the wards for the children. (Family Participant 3)

> They should ask if we need a TV to entertain the child, TV make my son happy. (Family Participant 4)

> The paediatric ward should have a playroom with sensory toys to use in the playroom to calm the child down and be a form of distraction. (Family Participant 5)

> Music calms him down, they did not have any music to calm him down. (Family Participant 6)

> The hospital was not child friendly at all, there were no toys or any distractions to entertain my daughter. They should offer toys or other distraction for the child (Family Participant 8)

The family participants agreed that the suggestion that “Child needs toys or some entertainment in hospital” is a validated suggestion and will promote effective family involvement. It is apparent from the interviews that the family participants have spent years learning about their child and what can stress the child and what can calm the child and the have created a soothing home environment for their children and wish this environment to be replicated as much as possible in hospital so that their child will be calm which will reduce parental stress and ensure a good hospital experience. This good hospital experience can then translate into an effective way to involve the family in the in-hospital nursing care of the child with ASD. Although this is the ideal, in reality, the lived experiences of the family participants were the opposite; there were few to no toys or any form of distraction for their children, which caused stress in the child and in turn stress to the family members, who had to try and keep the child distracted and entertained in hospital. The older family participants who had been admitted to the hospital before brought their own forms of entertainment for their children like Ipad® computers with music and other items loaded to entertain their children. It is suggested from the family participants responses above that having toys or some form of entertainment for the child is very important to distract and occupy the child while

admitted to hospital. According to Litwin and Sellen (2022), although there is substantial individual variance in preferences and aversions, the majority of children and teenagers with ASD exhibit sensory sensitivities, and many healthcare settings are not suited to adequately meet their requirements. Numerous approaches to improving the sensory environment for children with ASD exist, which include providing the child with sensory toys. In an integrative review of recent literature conducted by Magalhães *et al.* (2020: 557), the authors reported that nurses found the following strategies help improve nursing care of the child with ASD: 1) strategies that enable the insertion of playful experiences as a way to promote care, 2) musical intervention as a technique of caring for children with ASD can provide a moment of creative interaction, stimulate the communication, and the change of behaviour of these children, 3) the use of ludic resources (toys), which are used by nursing professionals, to encourage the child's sense of autonomy, communication and behaviour change through creative interaction.

Drake *et al.* (2012: 215) conducted research in which they deployed a coping kit for paediatric inpatients and examined the cost effectiveness and nurse assessment of the kit's usefulness. Visual communication tools such as timetables, paper and pencil, social tales, and sensory objects such as spinning and mouthing toys were included in the coping kit. Coping kits were often used for distraction. The kit improved the child's coping and capacity to engage in operations, according to the majority of nurses in the research. Parents were enthusiastic to put the goods to use and noted that the kit assisted them in working constructively with their children and the healthcare staff.

Nurse participants also agreed with the family participants in this regard by saying:

> I remember that in one case the parents used the music and videos on their cell phone to help calm and entertain the child, with another child the parents brought the child's bunny and then the doctor and nurses examined the bunny first and then examined the child. I remember it was a very long consult but it worked very well. (Nurse Participant 2)

> Dealing with ASD kids, we need to create a playful and safe environment. We need to be at the level of the child. We need to interact with the parents.
> The nurse must get the child to trust you and must not see you as a treat, you can play with the child. (Nurse Participant 6)

> Try and make the environment more conducive for the child. (Nurse Participant 1)

> The parents can tell us if we can play with the child. (Nurse Participant 9)

As seen above, the nurse participants agree that it is vitally important to have toys and some sort of entertainment for the child with ASD when admitted to hospital. The nurses interviewed all work with paediatric patients and therefore know the value of play in the treatment of any child in the hospital. These nurses see the added value that toys and entertainment have with a child diagnosed with ASD, as a positive distraction in the ward for the child. From their response, it is apparent that the nurse participants acknowledge how distractions such as music and toys help the child with ASD cope with their sensory challenges in this new environment. However even though the nurse participants acknowledge the need for these toys and distractions, they do not see it as their responsibility to provide these toys. They see it as the responsibility of the parents and even the hospital to provide distractions for the child.

Taghizadeh *et al.* (2019: 932) discovered in their study that nine caregivers expressly reported bringing their portable tablet computer to the hospital and describing how they utilised it to help the child. According to one caregiver, the youngster brought his portable tablet computer into the operating room and was still clutching it after the procedure. Caregivers were also successful in distracting the children while they waited for surgery on the day of surgery. One caregiver reported how their child utilised an electronic communication gadget to assist him speak with others by pointing to pictures on it and the device proclaiming the related phrases. One anaesthesiologist described utilising a tablet computer with cooperative but apprehensive toddlers. The children were diverted with the computer, which was said to be useful for both inhalational and intravenous inductions. A lot of these children love their iPads® and their games, so if you have a cooperative but anxious child, keep them playing their game rather than taking their iPad away from them. Some of these children would be very happy with IV induction if they were playing a game. If they are playing because the repetitive nature of the game distracts them, find out what game they enjoy playing and that way it may be possible to put them to sleep with a mask or give them an IV (Taghizadeh *et al.* 2019: 932).

From the literature and responses from family participants and nurse participants presented above, the researcher agrees that the suggestion “Child needs toys or some

entertainment in hospital" is a valid suggestion and will promote effective family involvement and good quality nursing care. It is apparent from the interviews that the family participants have spent years learning about their child and what can stress the child and what can calm them and they have created a soothing home environment for their children and wish this environment to be replicated as much as possible in hospital so that their child will be calm which will reduce parental stress and ensure a good hospital experience. Some of the nurses also see the same value in toys and entertainment as a positive distraction in the ward for the child.

#### 5.6.3.10 Subtheme 3.10: Safety of child and other children

Subtheme 3.10: Safety of child and other children, was a subtheme that was suggested by the nurse participants only. The family participants did not mention this theme at all; therefore, the researcher will only present the quotations from the nurse participants and the associated literature. The nurse participants had the following to say in this regard:

> It's also important to make sure the child feels safe with you. You need to build a relationship with the child. The child needs to trust you and you must have empathy. Hospitals are really not a conducive environment for children with ASD. (Nurse Participant 1)

> Safety of the child must be prioritised due to their ability to wander. (Nurse Participant 4)

> Dealing with ASD kids, we need to create a playful and safe environment. (Nurse Participant 6)

> The parents have to watch the child when the nurse is not there, so they do not injure themselves. The nurse has to be patient with the child, the parent must tell the nurse that they child is autistic. If the child has mild ASD then they are easier to nurse but if the child is very aggressive the nurse rather stay away from the child and chat with the mum. (Nurse Participant 9)

> I would say the safety of the child and safety of other children in the ward, is the most important thing when nursing a child with ASD. (Nurse Participant 10)

At least half of the nurse participants felt that creating a safe environment for the child with ASD is vitally important. Some nurses feared for the

safety of the child with ASD and of other children. The nurses felt that ensuring the child with ASD was safe and did not hurt other children was a huge concern of theirs – they feared being held responsible for injuries that the child with ASD or other children, and this increased the stress of the nurses and made nursing the child with ASD difficult. The nurses, therefore, appreciated the parents being with the child at all times as this lessened the chance of the child with ASD being hurt or hurting other children. Children with ASD have a higher rate of injury and a higher death due to injuries, therefore, nurses who care for ASD children must be ready to discuss safety with the family of the child with ASD and provide a safe environment for the child (Celia *et al.* 2020: 222). The primary caregiver parent is an expert on their child and a vital source of knowledge, and all medical personnel should recognise this, especially when it comes to safety (Celia *et al.* 2020: 228).

McIntosh and Thomas (2020: 2) explain that children with ASD can be exposed to unintentional injuries, for example: needles, tablets, bodily injury, food and too much stimulation during hospitalisation. McIntosh and Thomas (2020: 2) warn that it is important to take safety precautions while changing the surroundings, which should include securing sharps containers to prevent children from sticking their hands inside them. Scissors and other pointed objects must be put away or secured in a cabinet. To prevent injuries, any extra furniture and equipment should be taken out of the child's room. Some ASD children may get fixated on and desire to touch shiny things like scissors and medical equipment, placing them in danger of cuts and accidents. To prevent unintentional drug intake, all cabinets must be secured as people with ASD may try to open drawers and cabinets to start sorting the contents (McIntosh and Thomas 2020: 2).

With the above empiric evidence from the nurse participants and the published evidence, the researcher has decided that "Safety of child and other children" is indeed a valid suggestion to promote family involvement and good quality nursing care of a child with ASD in the hospital.

### 5.6.4 Theme 4: Family participants' perceptions of their children's experience in hospital

This theme does not directly link with any of the objectives of this study but is a theme that emerged from the data, during the data analysis process. During the interviews

the family participants described the hospital experience for their children and these interviews were coded. These codes were then grouped into subthemes and then the subthemes were grouped into themes. Theme 4: family participants' perception of their child's experience in hospital, has two subthemes which will be presented below:

#### 5.6.4.1 Subtheme 4.1: Bad hospital experience

Seven out of the ten family participants that were interviewed shared bad hospital experiences, and discussed how terrible the experience being in hospital was for them and their children. The researcher will present these experiences in the form of the most common codes that were derived from this subtheme.

##### 5.6.4.1.1 Subtheme 4.1.1: Forced treatment

Several family and nurse participants related stories of how children with ASD were forcefully treated by nursing staff in a physically. This forceful treatment can be very traumatising for the child with ASD and any child. These are some quotes confirming this:

> They forced him to drink glucose and take the Risperdal tablet, even though I told them that he does not react well to the tablet.
> They restrained him to the bed.
> They would say we're going to give medication to that one that fights. And they would be five adults nurses holding a small 9-year-old boy and he would get very anxious with the people. Five nurses holding and injecting him. They would tell me to go outside and wait while they injected. It is not nice at all looking at your child being held by these five nurses and injected. (Family Participant 1)

> There were two or three guards that held him and they took him by force to the psychiatric ward.
> They sedated him and locked him in a psychiatric ward. I was not allowed to look after him at all. I was not allowed to visit him for two days. I did not see him. I could not speak to him at all. I can imagine how afraid he was to be locked in this dark room without anyone that he knows with people he doesn't know and without me his mother. (Family Participant 2)

> There was like 10 nurses holding him trying to put in a drip, which was not fair. (Family Participant 3)

> When they wanted to put up an IV (drip) on my child the Dr ordered 2mgs of Dormicum which I told him would not be enough for my son. Two nurses and a doctor took my son to the treatment room to put up the IV which was a bad experience for my son. (Family Participant 5)

The researcher was not expecting any of the nurse participants to admit to physically forcing the child to accept treatment but was surprised when in addition to the statements above from the family participants, one of the nurse participants said the following:

> I don't know if it was acceptable or legal or illegal but we had our own way of doing the drips for the children – we would wrap them in sheet and hold them, our main aim was to make sure that the child is still. (Nurse Participant 10)

Children with ASD who have been physically held by many nurses when being given an injection or putting up an IV drip will have had psychologically traumatising experiences. This is very concerning to the researcher especially because, according to Bourke *et al.* (2021: 1572), numerous fatalities as well as psychological and physical illnesses have been directly linked to the use of physical restraints. Bourke *et al.* (2021: 1572) discovered that on average 3 out of every 100 children without an ASD diagnosis and 9 out of 100 children with an ASD diagnosis were physically restrained. On deeper interpretation of this point, it was apparent that family participants and the children were traumatised and angered by the forced treatment they received in the hospital at times and this influenced their perceptions of hospitalisation in general. It also demonstrates how the lack of knowledge by the nurses, and lack of knowledge on how to nurse a child with ASD, leads nurses to use physical force and which then traumatises the child with ASD. This has been so traumatising for some family participants in the current study that they mentioned that they would never again have their child admitted to the hospital because of this very poor nurse-patient and nurse-family relationship resulting from the family not being adequately involved in the in-hospital nursing care of their child with ASD.

#### 5.6.4.1.2 Subtheme 4.1.2: Problems with hospitalisation of child with ASD

Ndubaku (2018: 10) discovered that patients with ASD and their families encountered a variety of issues in the hospital setting, including, but not limited to, communication difficulties, increased sensory emotions, environmental variables, and problems

navigating the hospital organisations. In this study the researcher found that the family participants highlighted the following specific problems experienced by their child while in hospital.

> Nurses put us in a room with six other children there was not enough space in the room for all six children and parents.
> We also had to wait in long queues.
> My son also doesn't like new people. (Family Participant 3)

> They moved us to a general ward and in the general ward every time the child next to my son, cried, my son would have a meltdown. Every time the monitors and machines alarms went off he would get up from his sleep and have a meltdown. The nurse battled to give my son the medication because he would spit it out or vomit the medication. (Family Participant 5)

> I went home and then the nurses call me back to the hospital because he became very aggressive with them and broke the bed.
> My son does not like change in the environment, he becomes aggressive. (Family Participant 6)

> When the theatre trolley came to take her to theatre, she became hysterical and did not want to be touched, so I had to walk with her to theatre. In theatre she refused to lie on the theatre bed, I went with her into theatre, after 15 to 20 minutes of me negotiating with her. And she was getting aggressive. The anaesthetist threatened to poke her with a needle then she lay on the bed. We had to hold her down and the anaesthetist put her off to sleep with gas and then I left. (Family Participant 7)

The responses above suggest that being hospitalised is a very stressful and traumatising experience for the child with ASD and the family and that families feel that hospitals are not suitable places for children with ASD. The family members and children have a bad perception of hospitalisation due to the harsh physical environment and inflexible policies and procedures of the hospital and nurses, which they perceive as uncaring and not a conducive environment for their children.

The above quotes can be summed up by the one quote by nurse participant 1 who said: "*Hospitals are really not a conducive environment for children with ASD".*

Winslow (2017: 13) states that the noises heard in a hospital setting can be very overwhelming for people with autism, and a large number of people inside a building

and all taking at once and noises coming from various hospital equipment can cause sensory overload for people with autism. Winslow (2017: 13) further explains that people with autism have heightened sensory abilities that are hard to ignore; they may experience increased sensitivity to auditory, tactile and visual stimuli, especially in a crisis situation like admission to hospital. Overwhelmed people with autism may flap, scream, rock or use other calming methods to cope with the sensory overload. Hospitalisation for children with ASD can be very stressful which Winslow (2017: 13) can provoke difficult behaviour in these children and increased stress for the family and care givers (Winslow (2017: 1).

The above responses suggest that being hospitalised is a very stressful and traumatising experience for the child with ASD and the family and that the families feel that hospitals are not suitable places for children with ASD. The families and children have a bad perception of hospitalisation due to the harsh physical environment and inflexible policies and procedures of the hospital and nurses, which they perceive as uncaring and not conducive.

#### 5.6.4.1.3 Subtheme 4.1.3: Food requirements for ASD child not met

To any parent making sure their child is fed is an important parenting duty, likewise it is a basic nursing need that a nurse is required to meet for any patient. The following excerpts shows that this need was frequently not met:

> He did not eat at all in the hospital and did not like any of the food they offered so he did not eat all day.
> They need to ask what food the child eats, so they can make that food for the child. (Family Participant 3)

> The menu did not cater for my son and the food he likes to eat, so we bought our own food for him.
> They should ask what does the child like to eat.
> They should accommodate the food preference of the child. (Family Participant 4)

> Food offered does not accommodate the child. We were given the same bland food for 6 days a week, I called the catering manager to complain, but he replied that is just his job. The hospital needs to cater for the food preference of the child. (Family Participant 6)

The above point was interpreted by the researcher as being deeper than just not providing food preferences for the child with ASD: the family participants perceived this as the hospital and nurses being uncaring towards their child and not even meeting their child's basic physiological need for nutrition. This was perceived as a grave oversight by the family participants concerned. It also demonstrated the nurses lack of knowledge regarding the eating habits of autistic children and the hospitals inflexibility to the special needs of the child with ASD.

According to Mendive Dubourdieu and Guerendiain (2022: 1) it is a well-known and researched fact that many children with ASD follow a gluten- and casein-free (GCF) diet or have a limited diet because of sensory issues. It is therefore very important for nurses in hospitals to interview the parents and enquire about their diet in order to meet the child's basic nurses needs of nutrition. From the extracts above it is very apparent that this was not done and affected the family participants perception of the hospital experience of their child.

#### 5.6.4.2 Subtheme 4.2: Good hospital experience

Three out of the ten family participants described the hospital experience in a positive manner. The researcher will present these experiences in the form of the most common codes that were derived from this subtheme.

##### 5.6.4.2.1 Subtheme 4.2.1: Quiet environment and private room helps

Winslow (2017: 13) explains that children with autism have heightened sensory abilities that are hard to ignore, and may experience increased sensitivity to auditory, tactile and visual stimuli in a crisis situation like admission to hospital. Overwhelmed people with autism may flap, scream, rock or use other calming methods to cope with the sensory overload (Winslow 2017: 13). Hospitalisation for children with ASD can be very stressfully because of this. Parents of children with ASD know this too well and therefore limit sensory stimuli of their child and request a private room if possible. A private room is a room which accommodates only one child and thus limits sensory stimuli from other children and parents. From the quotes below it is very evident that providing a child with ASD with a private room has a very positive impact on their hospital experience and the opposite is true as well.

> The nurses were very good listeners, we had a private room and I did everything for my son, they did some of the nursing care when necessary. (Family Participant 4)
>
> We were put in a private room, which was very good because I kept the curtains closed and lights off because the light affects my son, who is sensitive to bright lights.
> The child must be admitted in a private room because of the sensory issues of children with ASD, the curtains, room lights etc. are important. (Family Participant 5)
>
> You know all those things that we need. For example, trying to organise a room that is more quiet, if possible a private room. So that the parents can stay over.
> We would also not being put next to a child that is continuously crying because that would have upset my son. (Family Participant 9)

From the above quotations it is very clear that if the child is provided with a private room so as to accommodate the child's sensory issues, this leads to a very positive experience for the child and family. On deeper analysis and interpretation of the above it is apparent that the family participants that had good hospital experiences, were listened to by the nurses and their requests were granted. This means that in these instances the parent was recognised as the expert on their child and their opinions and suggestions were valued and implemented. This ensured a positive internal and external environment for the child with ASD and the family. If the child was given a private room the parents also interpreted this as the hospital and nurses understanding that their child has special needs and were prepare dot accommodate that need, thus creating a positive hospital experience for the parent and child. From the above quotation it is very clear that if the child is provided with a private room so as to accommodate the child's sensory issues this leads to a very positive experience for the child and family.

#### 5.6.4.2.2 Subtheme 4.2.2: If parent is a doctor or nurse child gets better care

Coincidentally, four of the family participants that were interviewed were medically trained: two family participants were nurses, one participant was a psychologist and her husband a doctor, and one participant was a doctor and her husband a doctor as well. Of the four family participants that are medically trained, three had good hospital

experiences. Although it cannot be proved that they had better hospital experiences because they were medically trained, it seemed to have been an influencing factor. These three family participants had this to say:

> Because we are both doctors and my husband works at the same hospital, we informed the nurses who we were, and my son got a private room. (Family Participant 4)

> Well, it was good, because I am a nurse and I work in that hospital, all the staff listened to me. I was in theatre, recovery room and ward and did all the nursing care for her. It was a good experience; the nurses were open and allowed me to do what I needed to do.
> I also explained to him that she is autistic. So, he arranged a direct admission to the surgical ward S3. (Family Participant 7)

> The doctors are my husband's colleagues so I mean just the easiness of getting a room, you know, like a private room. It's always so easy for us to organise our own room and a sleepover chair for me and all of that. (Family Participant 9)

In this study the above extracts show that if the child with ASD is the child of a doctor or nurse they seem to have a better experience. The researcher's interpretation of this point is that the nurses would more readily listen to the parent if they were a doctor or a nurse because the nurses believed that these parents are more knowledgeable than a normal parent. It can also be interpreted that a parent that is a nurse or doctor has more knowledge of their rights as parents and more knowledge of the health system and therefore could forcefully advocate for the correct level of care for their child.

#### 5.6.4.2.3 Subtheme 4.2.3: Nurses listen to us

According to Nygård and Clancy (2018: 3192), the nurse must listen attentively to the parents and ask relevant questions that can reveal their values, beliefs and experiences. This can pave the way for dialogue. A true dialogue between the parents and nurse may be the most important way of promoting mutual trust and respect. Nygård and Clancy (2018: 3193) explains that listening attentively to the parents is the most beneficial nursing intervention; listening with an open and attentive attitude is required to preserve their integrity, boost their confidence, and provide opportunities for reflection.

The three family participants below all regarded their hospital experiences for themselves and their children as being very positive and this can be attributed in part, to the nurses listening to the parents and taking instructions from them. The family participants had this to say:

> Very involved. The nurses were very good listeners, we had a private room and I did everything for my son, they did some of the nursing care when necessary. They supported us when we needed help. Everything went absolutely fine (Family Participant 4)

> Well, it was good, because I am a nurse and I work in that hospital, all the staff listened to me. I was in theatre, recovery room and ward and did all the nursing care for her. It was a good experience; the nurses were open and allowed me to do what I needed to do. I also think that if we speak to the nurse well and develop a good relationship with them, things will go well. (Family Participant 7)

> Because they are a paediatric psychiatric hospital the nursing care was excellent. The paediatric psychiatrist explained to the nurses the do's and don'ts and they listened to us as well. So, the care was very good. (Family Participant 10)

From the three quotes above it is apparent that parents and children that had a positive hospital experience, were all given a private room, had some medical knowledge, and were listened to by the nurses. The combination of these codes lead to a good hospital experience. Conversely it was found that a bad hospital experience was due to forced treatment of the child, an environment that is not conducive to a child with ASD, and not meeting the child's dietary requirements. The parents also interpreted the nurses listening to them as a sign of respect for their expert knowledge on their child and this created a friendly and conducive environment for the parent and the child.

## 5.7 Chapter Summary

Chapter five was dedicated to data presentation, analysis and interpretation. The chapter started by reminding the reader of the objectives of this study in the introduction and then went on to unfold the data analysis process that was followed, which was IPA analysis. The body of this chapter revealed the themes, subthemes and codes that were discovered by the researcher during the analysis. Table 5.1 is a graphical summary of the themes, subthemes and codes discussed in this chapter.

# CHAPTER 6: THE FRAMEWORK FOR THE IMPROVEMENT OF FAMILY INVOLVEMENT IN THE HOSPITAL NURSING CARE OF A CHILD WITH ASD

## 6.1 Introduction

In chapter 5 the findings of the data analysis and interpretation was presented. Themes subthemes and codes were presented. Three of the four research objectives were met. In the current chapter, the fourth research objective was met, namely: to develop and validate a framework for the improvement of family involvement in the hospital nursing care of a child with ASD.

The purpose of this penultimate chapter is to amalgamate the empirical findings from the previous chapter and the conceptual framework developed in Chapter 3 into a framework for later implementation by nurses. This chapter provides a description of the Neil Williams framework for the improvement of family involvement in the hospital nursing care of a child with ASD.

The Chapter starts with the framework developing process to be followed, according to Gray and Grove (2021: 182), in this chapter the Neil Williams framework for the improvement of family involvement in the hospital nursing care of a child with ASD is developed using that process.

## 6.2 Concluding statements forming the basis of the framework formulation

In Table 6.1 below the researcher will present the research questions in column 1, The conclusive statements addressing these research questions in column 2 and the motivation for the formulation of the research framework in column three. This table will comprehensively motivate for the need to formulate a framework to address the main conclusions of this study.

**Table 6.1: Conclusive statements and motivation for framework development.**

| Research Question | Conclusive Statement | Motivation for the development of a framework |
|---|---|---|
| 1 What are the perceptions of professional nurses and families regarding the involvement of families in the hospital nursing care of a child with ASD? | The researcher concluded that families were very involved in the in-hospital nursing care of their child in ASD, whether they wanted to or not. Some families had negative experiences and other families had positive experiences. | The fact that some families had a negative experience and others had positive experience, demonstrates a lack of consistency in this involvement and therefore the need for standardisation, which can be achieve through the formulation and implementation of a framework. |
| 2 What do professional nurses and families perceive as challenges to the involvement of families in the hospital nursing care of a child with ASD? | The researcher concluded that the following were perceived challenges to the involvement of families in the hospital nursing care of a child with ASD:1. Nurses lack knowledge of ASD and how to nurse children with ASD. 2. Nurses were perceived as not listening to families or respecting their specialised knowledge of their child. 3 Nurses were perceived as have an uncaring attitude towards families of children with ASD. 4 Nurses and families perceived that there was a lack of time for nurses to adequately involve families in the in-hospital care of their child with ASD.5. The participants all perceived that this lack of time was caused by a shortage of nursing staff in the paediatric wards. | Identifying the perceived challenges to the involvement of families in the hospital nursing care of a child with ASD, was the first step in effectively overcoming these barriers, the next step would be the development of a framework to overcome these challenges and the final step would be implementing and evaluating this framework for effectiveness. |
| 3 What corrective interventions and actions can be developed to overcome these challenges and promote effective | The participants proposed the following actions in order to promote effective family involvement in the hospital nursing | The suggestions made by the participants is very important in promote effective family involvement in the hospital nursing |

| | | |
|---|---|---|
| family involvement in the hospital nursing care of a child with ASD? | care of a child with ASD: 1 Nurses must be trained to nurse children with ASD, 2 Nurses must have a caring attitude and patience towards the child with ASD and their families. 3 Nurses must communicate with family, 4Nurses must listen to family, 5 Nurses need to take a detailed history of child with ASD, 6 Nurses need to use child's likes to get his/her co-operation, 7 Nurses need to involve the family more in the nursing care of their child, 8 Building a good relationship between the family and nurse is very important, 9 Child needs toys or some entertainment in hospital and 10 Safety of child and other children is very important. | care of a child with ASD, however it needs to also be grounded in recognised and tested theories and therefore the formulation of a framework, is a way of incorporating these suggestion with recognised theory to produce a new framework which could promote effective family involvement in the hospital nursing care of a child with ASD. |

### 6.3 Theory

In order to give a systematic understanding of a reality, a theory must be a creative and rigorous structuring of ideas that contains integrated concepts, existence assertions, and relationship statements (Gray and Grove 2021: 170). A theory is made up of a number of specified and connected concepts that offer a perspective on a certain phenomenon (Gray and Grove 2021: 170). It is created through a confluence of individual experiences, academic discoveries, and speculative thought processes. Theorists may organise research findings to better describe the empirical reality after using the findings as a starting point. As an alternative, the theorist may create a theory of a phenomenon using abstract reasoning, firsthand experience, and intuition. The validity of this hypothesis must then be tested through study to see if it accurately captures reality. Therefore, research plays a crucial part in the creation, testing, and improvement of theories. Some qualitative research methods concentrate on creating new ideas or enhancing current theories (Polit and Beck 2021: 113).

## 6.4 Theory development strategies used in nursing

According to Im (2018: 2), the creation of nursing theories in general today uses a variety of theory development methodologies. Depending on the theorist's viewpoint, there are several distinct kinds of theory development techniques. Three main categories, according to (Walker and Avant 2018: 50), are: theory analysis, theory synthesis, and theory derivation. A theory's strengths and faults are assessed through theory analysis. Theory synthesis is where concepts and claims are used to explain a nursing phenomena. Theory synthesis uses analogies from explanations or forecasts in one field to explain or forecast an event in a different field (Im 2018: 2).

Meleis (2011: 1) presents five strategies for theory formation in nursing, namely: (1) theory-practice-theory, (2) practice-theory, (3) research-theory, (4) theory-research-theory, and (5) practice-theory-research-theory. The first strategy of theory-practice-theory is where a theorist starts his or her theorising with an existing theory as a mother theory (deduction), applies the theory in nursing practice, and adjusts the theory based on the evidence from the practice (induction). The second strategy of practice-theory is where a theorist theorises from practice and constructs a theory utilising induction from his or her practice experience. The third strategy of research-theory starts with research findings and develops a theory through inference from these finding. The fourth strategy of theory-research-theory begins by theorising from an existing theory, conducts research using the theory as the theoretical foundation, and then develops the theory further using induction from the research findings. The fifth strategy of practice-theory-research-theory is where a theorist begins by theorising from practice, develops a theory based on his or her practice experience, conducts research using the theory as the foundation, and further develops the theory in light of the research findings (Im 2018: 3).

## 6.5 Types of theories

According to Im (2018: 1) various theories have been created throughout the history of nursing. Grand nursing theories were initially developed by nursing scholars in an effort to define nursing and establish the theoretical underpinnings of nursing. The grand theories were then criticised by nursing academics for lacking specificity, plans, and empirical testing. Additionally, it was difficult to apply these grand nursing theories to both nursing practice and research (Im 2018: 1). The development of situation-

specific and mid-range theories that could directly influence nursing research and practice began in the middle of the 1980s. In response to the growing demand for theories that could directly be used to guide nursing research and practice while incorporating both the quantitative and qualitative paradigms, a number of mid-range theories that aimed at hypothesis generation and testing as well as several situation-specific theories were developed (Im 2018). Mid-range theories and situation-specific theories have recently emerged as major theoretical pillars for nursing practice and research all over the world.

A grand nursing theory explains the nature of nursing, situation-specific theories reflect both the quantitative and qualitative paradigms in nursing, while mid-range theories generate and test hypotheses based on the quantitative paradigm (Im 2018: 13). Developing a grand nursing theory, mid-range theory or situation specific theory would not be appropriate for this current study, due to the design and mainly because it was not feasible given the time frame and finances of the Doctor of nursing degree.

The researcher therefore chose to develop a framework for this study because it was more feasible to develop and can be implemented by professional nurses working in paediatric wards.

### 6.6 Framework development process

Gray and Grove (2021: 182) explain that the most widely used method of theory development, known as the research-to-theory strategy, is an inductive approach that involves creating a theory or framework from research findings. The researcher followed the process of framework development as described by Gray and Grove (2021: 182), which is: 1) Defining relevant concepts, 2) Developing relational statements, and 3) Constructing a conceptual map.

The researcher used both the inductive and deductive approaches, incorporated in the above process. The inductive phase utilised empiric findings from this research study and the deductive phase utilised published findings from the three theories described in Chapter 3. The researcher incorporated findings of this study into the conceptual framework presented in Chapter 3 to create a new framework for this study.

### 6.6.1 Defining relevant concepts

According to Gray and Grove (2021: 182), the first step in framework development is defining the relevant concepts. These authors go on to say that concepts are chosen for the framework based on their relevance to the phenomenon of interest, problem statement and literature. Each concept included in a framework must be defined conceptually, and should findable in existing theoretical works (Gray and Grove 2021: 182)

### 6.6.2 Developing relational statements

Gray and Grove (2021: 183) outlined how linking all of the study concepts together using relational statements is the next step in the framework development process. The researcher must find proof that relationships exist between some or all of the concepts in order to synthesise research findings (Gray and Grove 2021: 183)

### 6.6.3 Constructing a conceptual map

Gray and Grove (2021: 184) describes a conceptual map as the visual representation of a research framework. This conceptual map is a visual presentation of all the relevant concepts of the study and demonstrated the relationship between these variable, also known as the relational statements.

## 6.7. Step 1: Defining relevant concepts

Concepts utilised in the Neil Williams framework for the improvement of family involvement in the hospital nursing care of a child with ASD are presented below.

### 6.7.1 Child with ASD

Lansdown and Vaghri (2022: 407) defines the child as a human being who is below the age of 18 years, however in the NSM the definition of ‘human being’ (also known as client system) could represent a patient, family, group, community, or social issue. This client system is made up of physiological, psychological, sociocultural, developmental, and spiritual factors. In this study the child with ASD and their family is the client system, which is the centre of the NSM and the centre of this research, and more specifically, the client system refers to the child with ASD admitted to a paediatric ward.

### 6.7.2 Nurse

The NSM views nursing as a unique profession that is concerned about the patient as a whole and all variables in the client's environment that may affect them, including the nurses' perception (Lawson 2021: 234). This model is applicable to this study as this study looked at the perceptions of nurses regarding the involvement of families in the hospital nursing care of a child with ASD, as this perception affects the nurse's willingness to involve the family in the child's care. The concept of 'nurse' has been incorporated into the conceptual framework by linking the nurse to the patient/child with ASD/human being, because the nurse has a direct influence on the health and wellbeing of a patient admitted to hospital. The nurse is there to control he environment in such a way as to move the child to a state of wellness on the health continuum.

### 6.7.3 Family member

The family systems theory put forth by Dr Murray Bowen in the 1950s, contends that because families are emotional units it is not possible to understand people as separate entities. Instead, people must be seen as parts of their families. Families are networks of connected, dependent individuals, and none of them can be understood in isolation from the system (Jakimowicz, Perry and Lewis 2021: 1)

In this study, the family member is the mother, father or other family member that will be present with the ASD child in hospital.

### 6.7.4 Suggestions to promote effective family involvement

The following suggestions emerged from the empiric data collected during this study, as suggestions to promote effective family involvement.

1: Nurses must be trained to nurse children with ASD, 2: Nurses must have a caring attitude and patience, 3: Nurses must communicate with parents, 4: Nurses must listen to parents, 5: Nurses need to take a detailed history of patient, 6: Nurses need to use a child's likes to get co-operation, 7: Nurses need to involve the parents more in the care of their child, 8: Build a good relationship between the parent and nurse, 9: Child needs toys or some entertainment in hospital, 10: Safety of child and other children.

### 6.7.5The core concept: Empowerment

Empowerment (de Beer and Brysiewicz 2019: 21) in this study refers to the

empowerment of family members and nurses and is facilitated by suggestions as put forward in 6.5.1.4 above. These have been incorporated into the sub-concepts of empowerment listed below, namely: information exchange, closeness, resource gathering, and cultural and religious collaboration.

#### 6.7.4.1 Sub-concept 1: Information sharing

De Beer and Brysiewicz's (2019: 22) definition of information sharing will not be repeated here, as it can be found in Chapter 3. In the current study the theme "information sharing" incorporates: **Theme 3:** suggestions to promote effective family involvement, and the following **subthemes** of this study: 1. Nurses must be trained to nurse children with ASD, 2. Nurses must communicate with parents, 3. Nurses must listen to parents, 4. Nurses need to take a detailed history of the patient, 5. Nurses need to use child's likes to get co-operation.

Information sharing also helps overcome **Theme 2:** the challenges perceived by nurses and families in the involvement of families in the hospital nursing care of a child with ASD, and **subthemes:** 1. Lack of knowledge, and 2. Nurses not listening to the family.

#### 6.7.4.2 Sub-concept 2: Proximity

Proximity according to de Beer and Brysiewicz (2019: 22) is explained in Chapter 3 and therefore will not be repeated here, the same definition applies.

This sub-concept of proximity incorporates **Theme 3:** suggestions to promote effective family involvement, and the following subthemes of this study: 7. Nurses need to involve the parents more in the care, 8. Build a good relationship between the parent and nurse.

Proximity also incorporates **Theme 2**: The challenges perceived by nurses and families in the involvement of families in the hospital nursing care of a child with ASD, and subthemes: 3. Uncaring attitude of nurses, 4. Nurse's lack of time, and 5. Shortage of nursing staff.

#### 6.7.4.3 Sub-concept 3: Garnering resources

Please refer to Chapter 3 for the full definition of garnering resources.

This sub-concept incorporates the following themes and subthemes: **Theme 3:** suggestions to promote effective family involvement, and the following subthemes: 9. Child needs toys or some entertainment in hospital, 10. Safety of child and other children, as well as **Theme 4:** family's perception of child's experience in hospital, **Subtheme 1**: Bad hospital experience, Code 2. Problems with hospitalisation of child with ASD, Code 3. Food requirements for ASD child not met, and **subtheme 2**: Good hospital experience, Code 1. Quiet environment and private room helps.

#### 6.7.4.4 Sub-concept 4: Cultural and religious cooperation replaced by nurses must have caring attitude and patience

The concept of cultural and religious cooperation according to de Beer and Brysiewicz (2019: 23) is provided in Chapter 3.

In this empiric study this sub-concept was not found to be relevant and was therefore replaced by one sub-theme that was not incorporated in the above sub concepts, namely, **Theme 3:** Suggestions to promote effective family involvement, and **subtheme: 2:** Nurses must have a caring attitude and patience.

## 6.8 Step 2: Developing relational statements

Links between the concepts, in the form of relational statements. In the subheadings below the relational statements for this study have been described.

### 6.8.1 Relationship between the nurse and the child with ASD

The conceptual framework developed in this study incorporates the human being, but in this case, it is a child with ASD. Neuman's System Model (NSM) demonstrates that the nurse has a direct effect on the child with ASD, because as described above, the child depends on the nurse to control stressors in the hospital environment and so help the child move to a state of wellness. The conceptual framework for this study shows a direct link or relationship between the nurse and the child with ASD (Figure 6.1).

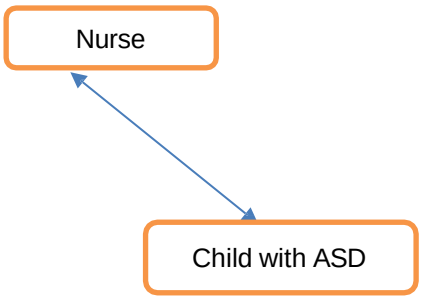


**Figure 6.1: Relationship of the nurse and child with ASD according to the NSM**

### 6.8.2The relationship between the family member and child with ASD

As explained under the definition of family member above, according to Bowens Family Systems Theory (BFST), the family member has a direct influence on the child with ASD and the child's health and can be depicted as follows:

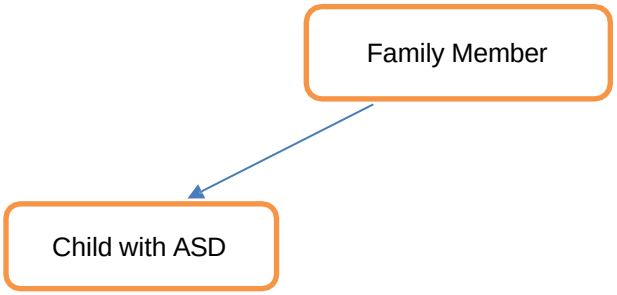


**Figure 6.2: Relationship between the family member and child with ASD**

### 6.8.3The relationship between the nurse, family member and child with ASD

One main concept that was incorporated from the BFST was the concept of 'triangles'. A detailed explanation of a triangle as per Pfeiffer and In-Albon (2022: 186) can be found in Chapter 3.

In the current study, Bowen's concept of triangle relationship would be formed by the child, nurse and family member because hospitalisation is experienced as a time of anxiety and stress by all parties; the family member can help reduce the stress on the nurse and vice versa in the case of hospitalisation. This relationship is illustrated in Figure 6.3.

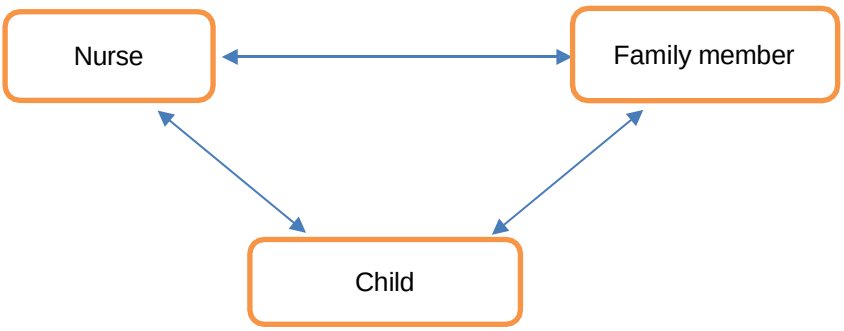


**Figure 6.3: The relationship between the nurse, family member and child with ASD**

### 6.8.4The relationship between the nurses and family member

The theory of family care during critical illness has a single central concept of empowerment and four sub-concepts that contribute to empowerment, namely: garnering resources, cultural and religious cooperation, information sharing and proximity. These are all applicable to the current study because they can promote the involvement of family in the hospital nursing care of the child with ASD. These five concepts can promote or hinder the family involvement in the hospital nursing care of the child with ASD. These concepts have been incorporated into the conceptual framework that was developed for this study by the researcher.

These concepts were described in detail earlier in this chapter and will therefore not be described again. The researcher will, however, explain that these concepts affect the relationship between the nurse and the family members and will therefore be illustrated directly above the line connecting the nurse to the family member as illustrated in Figure 6.4 below, which is the empiric framework for this study

## 6.9 Step 3: Constructing a conceptual map

As described in chapter 6 the third and last step of developing a framework is constructing a conceptual map.

Figure 6.4 is the conceptual map or framework for this study, and is entitled: the “Neil Williams framework for the improvement of family involvement in the hospital nursing care of a child with ASD”. This conceptual map of framework contains all the concept discussed above.

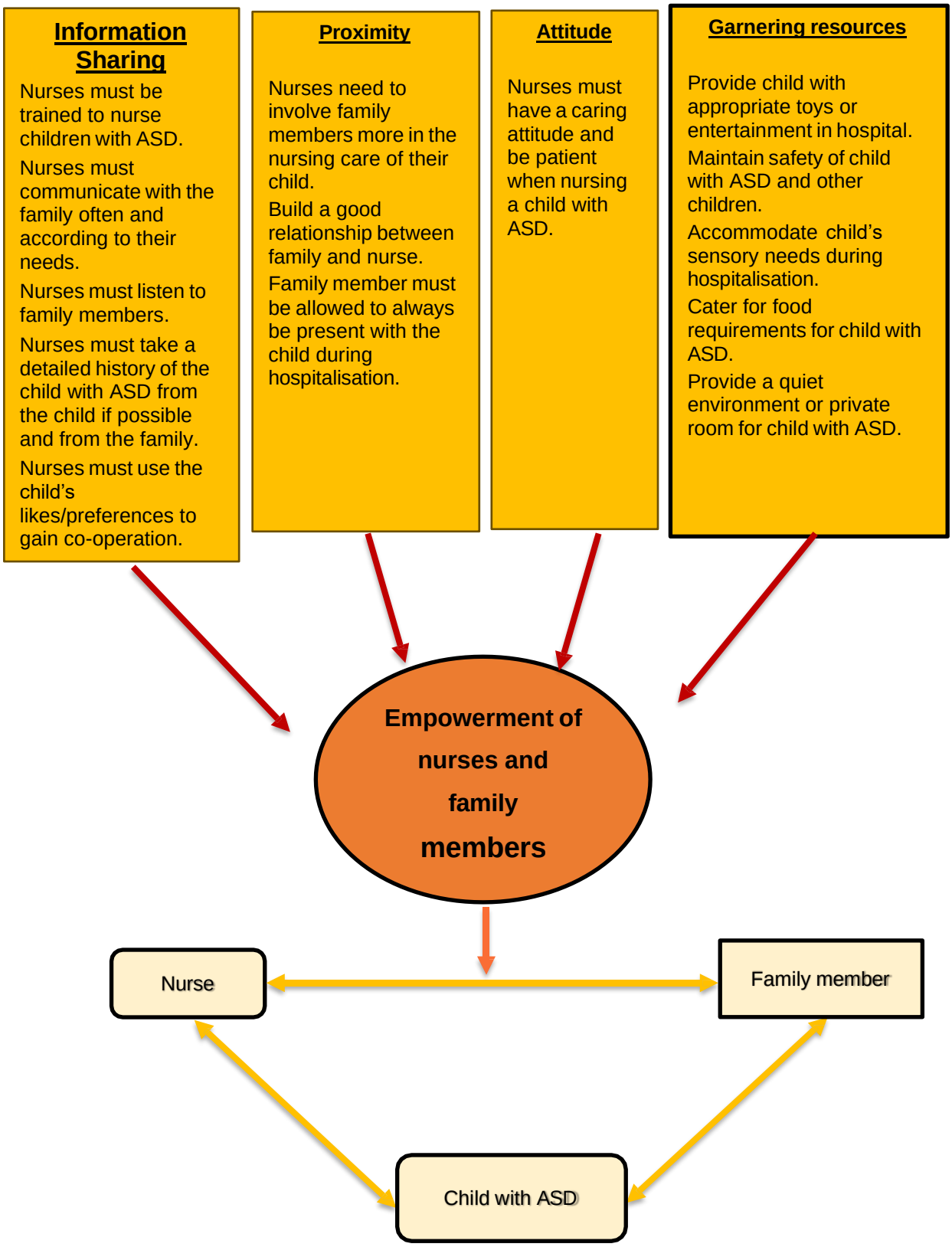


**Figure 6.4: The Neil Williams framework for the improvement of family involvement in the hospital nursing care of a child with ASD**

## 6.10 Description of Neil Williams's framework for the improvement of family involvement in the hospital nursing care of a child with ASD

The Neil Williams framework for the improvement of family involvement in the hospital nursing care of a child with ASD was developed during this study because no such framework currently exists. It was developed in order to promote family involvement in the hospital nursing care of a child with ASD, and was developed as a framework to guide the nurses working in paediatric wards. If implemented correctly this framework will improve family involvement in the hospital nursing care of their child with ASD and thus improve the quality of nursing received by this child and their family.

The paediatric nurse is expected to implement the subthemes, namely: information sharing, proximity, garnering resources, and attitude.

Under the heading "Information sharing", the nurse must be trained to look after a child with ASD, so that she/he can share the information she/he received from the training with the family and nurse the child effectively. In addition, the nurse must communicate effectively with the family, keeping the family informed of all medical and nursing procedures and ward routines. This will help build a relationship between the family and the nurse and thus promote the improvement of family involvement in the hospital nursing care of a child with ASD. The nurse must listen to the family; by listening to the family the nurse acknowledges the family member as the specialist on their child and will therefore promote a good nurse-family relationship and family involvement. Furthermore, the nurse needs to take a detailed history of the patient which will demonstrate to the family that the nurse has a caring attitude and will empower the nurse to adequately care for the child with ASD. Lastly, nurses need to use the child's likes and dislikes to gain co-operation from the child. This will make it easier for the nurse to effectively care for the child and show the family that the nurse can personalise care according to the child's needs which will build a good nurse-family relationship and promote family involvement in the hospital nursing care of a child with ASD.

The concept of 'proximity' incorporated just two points. The first point was that nurses need to involve family more in nursing care. This increased involvement in the nursing care promotes a good nurse-family relationship and empowers both parties. The second point under this topic was to build a good relationship between the family and

the nurse, which in turn would promote family involvement in the hospital nursing care of a child with ASD.

‘Attitude’ as a concept only contained one point which reads: nurses must have a caring attitude and be patient when nursing a child with ASD. This will build a good nurse-family relationship and promote family involvement in the hospital nursing care of a child with ASD.

Encompassed in the concept of ’Garnering resources’ are the following suggestions: firstly, provide the child with ASD with toys or some entertainment in the hospital because this will calm the child and gain their co-operation, which in turn will calm the family and promote a good nurse-family relationship. Secondly, maintaining the safety of children with ASD and other children, is an important way of building a good interpersonal relationship between the family and nurses. Resolving the child’s sensory problems related to hospitalisation was also suggested because this is a very important point for nurses to acknowledge, that children with ASD experience many sensory problems when hospitalised and every effort must be made to accommodate their sensory needs, which will make the children’s and families’ hospital experience much better. Furthermore, in catering for the food requirements of the child with ASD; nurses need to understand that due to sensory issues and other health problems, children with ASD have very restricted diets which need to be catered for during hospitalisation. If this is done, the child and family will be happy and this will strengthen the nurse-family relationship and improve family involvement. Lastly, providing a quiet environment or private room for a child with ASD, will limit the sensory stimuli for the child with ASD and ensure the child and family have a much better hospital stay which in turn will promote family involvement in the hospital nursing care of a child with ASD.

If the nurse implements the above suggestions, then the nurse will empower the family member and this will, in turn, improve the relationship between the nurse and family member, which will help both the nurse and family member to help the child with ASD to improve his/her health. Once the child with ASD has improved their health, they will no longer need to be hospitalised and will be able to return to the care of the family.

This framework should be implemented whenever a child with ASD is admitted to the paediatric ward.

## 6.11 The unique contribution of the study and framework

### 6.11.1 Contribution regarding the identified gap in knowledge

The knowledge gap identified by this study was the lack of research on: 1) the perceptions of nurses and families regarding the involvement of families in the hospital nursing care of a child with ASD in KZN and South Africa; 2) the challenges perceived by nurses and families in the involvement of families in the hospital nursing care of a child with ASD in KZN and South Africa; 3) the corrective interventions and actions to overcome challenges and promote effective family involvement in the hospital nursing care of a child with ASD in KZN and South Africa; and 4) a framework for the improvement of family involvement in the hospital nursing care of a child with ASD in KZN and South Africa. This study has contributed to the body of knowledge by closing the gap in knowledge on these areas in the eThekwini region of KZN.

The Neil Williams framework is the first framework for the improvement of family involvement in the hospital nursing care of a child with ASD.

### 6.11.2 Contribution to nursing practice

The framework developed in this study can contribute to improving nursing practice for paediatric ward nurses in the eThekwini region of KZN, and may improve the in-patient experience of children with ASD and their families. It can ensure that families are meaningfully involved in the treatment of their children which may lead to improved health outcomes for children with ASD and increase positive work experience for nurses in this region if implemented correctly.

### 6.11.3 Contribution to legislation/policy

Similar to other frameworks, this one is meant to serve as a roadmap for policymakers, HCPs, and families in order to increase family involvement in the hospital nursing care of children with ASD. This thesis and framework will be presented to the KZN Department of Health, private hospital groups and autism support groups that assisted during data collection. The framework will hopefully be adopted by all these groups and included in their policies.

### 6.11.4 Contribution in the context of social issues

This study has value for more than just academic literature, policymakers, and health services. Ultimately, the aim is to have a positive impact on individuals with autism and their families in terms of hospital experience. If the framework is successfully implemented, it will lead to a more pleasant in-hospital experience for the child with ASD and his/her family members and potentially better health outcomes for the child.

## 6.12 The Delphi Process

Even though this is a newly developed framework, it has been validated using the Delphi method of validation. The framework was validated by two child nursing science specialists, two professional nurses working with children with ASD, two members of ASD support group and one medical doctor with knowledge of children with ASD.

### 6.12.1 The Delphi technique

In order to make decisions, determine priorities, or create forecasts, the Delphi technique solicits the opinions of a group of experts (Polit and Beck 2021: 236). This method enables a wide range of viewpoints and comments from subject-matter specialists. Classic or consensus Delphi, decision Delphi, and dialectic Delphi are the three categories of Delphi techniques that have been identified. The goal of classic Delphi is to reach consensus. The goal of dialectic Delphi, also known as policy Delphi, is to identify, comprehend, and settle disagreements rather than to reach consensus. Decision Delphi is a process where a group of people in decision- making roles collaborate to reach a decision or solution (Gray and Grove 2021: 511). . Classic or consensus Delphi technique was used for this study to validate the newly formulated framework, in which all the experts needed to reach consensus on the framework

### 6.12.2 Design of the Delphi study

This study employed a two-round Classic/ Consensus Delphi technique, which mean that the researcher asked the experts to evaluate the framework until consensus was reached by all the experts. In this case consensus was reached in two rounds of consultation.

### 6.12.3 The Delphi procedure followed

The researcher sent **a letter of** invitation **(Annexure 19)** to participate in the study via email to all identified **experts**, **along with the expert feedback form (Annexure 20) and the draft framework.** Informed consent was requested **on e**mail from **twelve** (1**2**) experts that **met** the inclusion criteria to participate in the Delphi study. **seven** (**7**) of the invited experts **participate in the Delphi** study**, which is a** response rate of **58**%. The **method** employed the use of a self-administered questionnaire**/feedback form, utilised to evaluate the newly formulated framework for this study.**

### 6.12.4 Sampling and study population for Delphi technique

The purposive sampling technique was used in this **Delphi technique** to achieve the **sample**. The sampling technique used**,** assisted the researcher in selecting participants who **were** knowledge**able or** experience**d** in the field of the **Child Nursing and/or ASD.**

### 6.12.5 Inclusion criteria for the Delphi technique

As the Delphi technique requires the identification of experts and their participation, the first step is to operationalise the concept of 'expert'; hence, the researcher used the following inclusion criteria:

- Should be knowledgeable about ASD either as a result of studying or personal experience.
- Should be knowledgeable about nursing or parenting a child with ASD.
- Should have more than 5 years' experience of Nursing / interacting with children with ASD or their families.

The group of experts recruited for the validation of the newly developed framework were: two child nursing science specialists, two professional nurses working with children with ASD, two members of ASD support group and one medical doctor with knowledge of children with ASD. The two-child nursing specialist were identified because of possessing a post basic Diploma in Child Nursing Science, Degrees in Nursing Education and a Master's Degree in Nursing, both of which are nursing lecturers teaching the Diploma in Child Nursing at a nursing college in KZN. These child nursing specialist are both experts in child nursing but also academics familiar with the theories used to develop the framework, it is for these reasons that the two child nursing specialist were Identified as experts by the researcher. The researcher

also included two professional nurses who are currently working in paediatric wards in the eThekwini region and that regularly nurse children with ASD. The two professional nurses were considered experts due to many years of experience nursing children with ASD. These professional nurses would be the end users of the newly developed framework and thus were identified as experts. The two members of the ASD support group have been active members of the ASD support group for many years and interact with families of children with ASD regularly, as part of their duties in the support group. The two members are also parents of children with ASD and would thus benefit from the framework and therefore their opinion on the framework was important as a possible beneficiary of the framework.

### 6.12.6 Delphi data collection tool

The Delphi data collection/ feedback form (Annexure 20), was developed by the researcher in consultation with two academics one with a Doctor of Nursing Degree and the other a Professor of Nursing both with many years of research experience. The Delphi data collection/ feedback form (Annexure 20), was approved by the research supervisors prior to administration.

### 6.12.7 Delphi data collection and analysis process

When the draft Neil Williams framework for improvement of family involvement in the hospital nursing care of a child with ASD, was developed and ready to be validated. The researcher developed a Delphi feed back form (Annexure 20) as described above. The experts that met the inclusion criteria were emailed, the information letter (Annexure 19), the Delphi feedback form (Annexure 20) and the first draft of the Neil Williams framework for improvement of family involvement in the hospital nursing care of a child with ASD. The researcher asked the experts to evaluate the framework using the Delphi feedback form (Annexure 20) and return only the feed back form. The researcher gave the experts 7 days to do this. Once all the feedback forms were returned to the researcher the researcher made the changes as described in round 1 below and amended the framework accordingly. The second draft of the framework was emailed again to the experts with the Delphi feedback form (Annexure 20). One the second round all the experts were completely happy with the framework and had no further suggestions. The data collection round 1 and round 2 will now be discussed.

### 6.12.8 Expert review process: Round 1

Table 6.1 is a summary of the first round of feedback received from the experts on the Neil Williams framework for the improvement of family involvement in the hospital nursing care of a child with ASD.

**Table 6.1: Expert review process: Round 1**

| Information | Appropriate | Amendments required | Comments/Suggestions |
|---|---|---|---|
| Name of the Framework | 7 experts | None | None |
| Colours of the framework | 5 | 2 | Colours do not copy well.<br>Lighter colours needed. |
| Structure of the framework | 7 | | |
| Language clarity | 6 | 1 | Change parent to caregiver or family member |
| Relevance of content | 4 | 3 | • Add a point on parents being allowed to stay with the child all the time during hospitalisation to prevent meltdowns.<br>• Provide play therapy with appropriate toys.<br>• Garnering resources: Suggest: "Provide appropriate toys and play therapy."<br>• Information sharing: Nurse must communicate with parents according to their needs. |

**Additional comments**: Family members must be allowed to always stay with the child in the hospital, nurses specialising in ASD, nurses must guide doctors when treating a child with ASD.

The above feedback was incorporated into the framework, except the suggestion on play therapy as these suggestions were not forthcoming from the participants. Once the changes were made to the framework it was re-circulated to all the experts.

### 6.12.9 Expert review process: Round 2

Table 6.2 is a summary of the second round of feedback received from the experts on the Neil Williams framework.

**Table 6.2: Expert review process: Round 2**

| Information | Appropriate | Amendments required | Comments/ Suggestions |
|---|---|---|---|
| Name of the framework | 7 experts | None | None |
| Colours of the framework | 7 experts | None | None |
| Structure of the framework | 7 experts | None | None |
| Language clarity | 7 experts | None | None |
| Relevance of content | 7 experts | None | None |

All seven experts reached consensus with the amended framework (Figure 6.4). Thus, the framework was validated using the classic Delphi technique where all the experts reached consensus.

### 6.12.10 Ethic in Delphi technique

In the Delphi process, the expert's anonymity was assured by avoiding any face-to-face meetings, as the experts were requested and expected to respond to the emails individually, thus their responses could be unbiased and trustworthy and consensus achieved. Consensual agreement among expert panellists of anonymous opinions were achieved

through repeated iterations by email. The panellists were provided with information of the study via email and consent was implied by replying to the email and giving feedback on the framework. All the panellists agreed to participate in the Delphi voluntarily and received no remuneration for their participation.

## 6.13 Strengths and weaknesses of the developed framework

In this chapter, a new framework (Figure 6.4) named: the “Neil Williams framework for improvement of family involvement in the hospital nursing care of a child with ASD” was developed utilising the empiric data from this study and the theoretical frameworks of the NSM, BFST and the theory of family care during critical illness. The framework as with all newly developed frameworks has its strengths and its weaknesses, which are discussed below.

### 6.13.1 The framework is a newly developed framework and not been implemented

**Weakness**

One criticism of this newly developed framework is that it is new and has not yet been implemented. Although this is true, the framework itself is based on the NSM and BFST which have been empirically tested many times and have been validated. The newly developed framework derived its concepts and relational statements from the NSM, BFST and the theory of family care during critical illness, which are regarded as grand and mid-range theories. All data that have been added to this framework were empirical data. Therefore, this newly developed framework is rooted in empirical, published and theoretical data. The development of this framework has a thick description to ensure transparency in its development and to allow other researchers to test its validity.

**Strength**

The strength of being a new framework is that it adds to the body of knowledge a framework that has not previously existed. The new framework has been validated by experts in the field.

### 6.13.2 Limitations of the framework

**Weakness**

The main limitation of the framework is that the newly developed framework is grounded on data solicited from a sample in the eThekwini region of KZN in South Africa and as such, application may be limited in describing family involvement in hospital nursing care of a child with ASD in other provinces of South Africa, nationally and internationally.

**Strength**

However, considering that all data is empirical and was corroborated by international and national studies, and showed very similar findings to these studies, this framework may have a wider application nationally and internationally. The framework itself is derived from the NSM and BFST, which are internationally recognised models and theories. The strength of this study being developed in the eThekwini region of KZN in South Africa means that it can be readily used and tested by nurses in this region.

### 6.13.3 Lack of generalisation due to limited sample and methodology

**Weakness**

Another criticism of the framework may be that it was developed from a small sample and therefore cannot simply be generalised to the wider population. Even though the sample size for this study was 20 participants, as has been noted in Chapters 1 and 4, in an IPA study the sample sizes are small to ensure in-depth data collection and analysis of the lived experience of the participants. Furthermore, sampling ceased when data saturation had been reached meaning that no new data was emerging. When data saturation is reached there is no point in carrying on just to have a big sample because a big sample will yield the same data as a small sample. In this study maximum variation sampling was used to ensure that a wider range of perceptions were obtained, thus making the findings more generalisable.

**Strength**

The findings were corroborated by similar findings in many national and international peer-reviewed and published studies, ensuring that these findings can be generalised. The strength of this study is that it offers an in-depth explanation of the lived experience of the participants and sheds light on a topic that has not been researched in these areas before and adds a framework that has never been developed before. The developed framework can be implemented post-doctoral and evaluated through implementation over a larger environment

## 6.14 Conclusion

In this chapter the researcher followed the steps in developing a framework and utilising the empiric data of chapter 5 and the conceptual framework of chapter 3, developed a new framework (Figure 6.4), entitled: the Neil Williams framework for the improvement of family involvement in the hospital nursing care of a child with ASD. After the presentation of the framework, the unique contributions of this study and the framework was discussed. The chapter ended with the strengths and weaknesses of this framework. In the final chapter that follows, the thesis will be summarised and the research findings will be present, along with recommendations and limitations.

# CHAPTER 7: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

## 7.1 Introduction

This chapter concludes the research by summarising the key findings of the study in relation to the research aims, as well as presenting the unique contribution of this study to nursing. It also reviews the limitations of the study and proposes opportunities for further studies.

## 7.2 Overview of the study

Studies such as those conducted by Taghizadeh et al. (2019: 927), Russell and McCloskey (2016: 21) and Muskat et al. (2015: 482) corroborate the perceived poor nursing care received by children with ASD during hospitalisation in South Africa and worldwide. The literature has further revealed that this poor nursing care can be resolved by effectively involving parents in the care of their children, however this is not being done by many nurses in countries. In South Africa and in KwaZulu-Natal in particular there have been no studies undertaken to corroborate the literature findings and therefore a gap exists in the literature. If this gap in the literature is resolved it may help improve the nursing care of children with ASD in hospitals in KZN.

After identifying this gap in literature, the researcher proposed this study with the aim of developing in-depth insights into the influences that contribute to promoting family involvement in the provision of in-hospital nursing care for children with ASD in the eThekwini region of KZN. With this aim in mind, the researcher developed the following objectives:

1. Critically assess the perceptions of nurses and families regarding the involvement of families in the hospital nursing care of a child with ASD.
2. From the in-depth interviews an analysis, challenges perceived were identified and described by nurses and families regarding the involvement of families in the hospital nursing care of a child with ASD.
3. Explore participant perceptions on the range of corrective interventions and actions to overcome challenges and promote effective family involvement in the hospital nursing care of a child with ASD.
4. Develop and validate a framework for the improvement of family involvement in the hospital nursing care of a child with ASD.

In pursuit of these objectives, the researcher conducted this study based on relative ontology, social constructivism epistemology, and an interpretivist research philosophy, with an inductive research approach utilising a cross-sectional time horizon. The methodology that was followed was the qualitative, interpretative phenomenological analysis (IPA) strategy, utilising the maximum variation purposive sampling method to determine the sample that used semi-structured one-on-one interviews to collect data.

On 23 November 2021 the researcher received full approval from Durban University of Technology (DUT) Institutional Research Ethics Committee (Annexure 14), Clearance Number 221/21. The researcher then immediately embarked on a process to recruit participants for this study. Family participants were recruited for this study by means of an advert (Annexure 5). This advert was posted on the researcher's Facebook page and WhatsApp status. The advert was also posted by a non-profit autism support organisation (Annexure 6) on their Facebook page, on their WhatsApp support group, and their website. The advert (Annexure 5) was also emailed by a special needs school (Annexure 7) to all their parents of children with ASD. Registered nurses were recruited via their employers and via social media. The researcher recruited some nurses via social media by posting an advert (Annexure 8) on the researcher's Facebook page and WhatsApp status.

Data was collected from the 30 November 2021 until 21 January 2022. The data was collected by means of individual or one-on-one, semi-structured interviews with the participants, utilising interview guides (Annexures 1 and Annexure 2). A total of 20 participants were interviewed, ten being parents or family participants' and ten being registered/professional nurse participants. The average time taken to interview each participant ranged from 30 to 60 minutes per interview.

The data was analysed as described in chapter 4. This data analysis resulted in four major themes and 17 subthemes, which will be discussed in the following section of this chapter.

These four themes and 17 subthemes where then developed into a framework for the improvement of family involvement in the hospital nursing care of a child with ASD (Figure 6.4). In the section that follows the findings of the study will be discussed.

## 7.3 Findings of the study

This study aimed to develop in-depth insights into the influences that contribute to promoting family involvement in the provision of in-hospital nursing care for children with ASD in the eThekwini region of KZN. The results indicate that the professional nurse and the paediatric ward (environment) both have an influence on this phenomenon. Results are discussed below according to the objectives of the study.

### 7.3.1 Critically assess the perceptions of nurses and families regarding the involvement of families in the hospital nursing care of a child with ASD

This objective was accomplished by conducting interviews with family participants and nurse participants the results of which are presented in Chapter 5. The family participants and nurse participants as well as the literature agreed that parents are very involved in the care of their child with ASD when admitted to hospital. The researcher's interpretation is that parents are very involved in the care of their child with ASD when admitted to hospital and that the parent in fact does everything for the child except certain nursing duties which they cannot do.

### 7.3.2 Identify and describe the challenges perceived by nurses and families in the involvement of families in the hospital nursing care of a child with ASD

The following challenges in the involvement of families in the hospital nursing care of a child with ASD were identified by the family and nurse participants:

#### 7.3.2.1 Lack of knowledge

The nurse participants' and family participants' perceptions and the literature all agree that the lack of knowledge of ASD by nurses is a challenge in the involvement of families in the hospital nursing care of a child with ASD.

#### 7.3.2.2 Nurses not listening to parents

The nurse participants' and family participants' perceptions and the literature all agree that nurses not listening to family opinion on nursing care and not recognising parents as experts on the children is another challenge in the involvement of families in the hospital nursing care of a child with ASD.

#### 7.3.2.3 Nurses' attitudes

The nurse participants and family participants' perceptions and the literature all agree that uncaring, unhelpful and impatient attitudes of nurses towards the child and family is also a challenge in the involvement of families in the hospital nursing care of a child with ASD.

#### 7.3.2.4 Time

All participants' and the literature agree that nurses generally have a lack of time to effectively nurse the child with ASD and also a lack time to involve family in the nursing care of their child, therefore this is another challenge in the involvement of families in the hospital nursing care of a child with ASD.

#### 7.3.2.5 Shortage of nursing staff

The participants and literature all agree that a shortage of nursing staff is a challenge in the involvement of families in the hospital nursing care of a child with ASD.

### 7.3.3 Explore participant perceptions on the range of corrective interventions and actions to overcome challenges and promote effective family involvement in the hospital nursing care of a child with ASD

The participants perceived and suggested the following as corrective interventions and actions:

Nurses must be trained to nurse children with ASD.
Nurses must have a caring attitude and patience.
Nurses must communicate with parents.
Nurses must listen to parents.
Nurses need to take a detailed history of patient.
Nurses need to use the child's likes to get co-operation.
Nurses need to involve the parents more in the care of their child.
Building a good relationship between the parent and nurse.
The child needs toys or some entertainment in hospital.
Safety of the child and other children.

### 7.3.4 Develop and validate a framework for the improvement of family involvement in the hospital nursing care of a child with ASD

This framework (Figure 6.4) was developed, validated and presented in Chapter 6.

## 7.4 The unique contribution of the study and framework

### 7.4.1 Contribution to addressing the gap in knowledge

The gap in knowledge identified by this study was a lack of research on: 1) the perceptions of nurses and families regarding the involvement of families in the hospital nursing care of a child with ASD in KZN and South Africa; 2) the challenges perceived by nurses and families in the involvement of families in the hospital nursing care of a child with ASD in KZN and South Africa; 3) the corrective interventions and actions to overcome challenges and promote effective family involvement in the hospital nursing care of a child with ASD in KZN and South Africa and 4) a framework for the improvement of family involvement in the hospital nursing care of a child with ASD in KZN and South Africa. This study has contributed to the body of knowledge by closing the gap in knowledge on these areas in the eThekwini region of KZN.

The framework developed is the first framework for the improvement of family involvement in the hospital nursing care of a child with ASD.

### 7.4.2 Contribution to nursing practice

The framework developed in this study can contribute to improving nursing practice for paediatric ward nurses in the eThekwini region of KZN and may improve the in-patient experience of children with ASD and their families. It can ensure that families are meaningfully involved in the treatment of their children which may lead to improved health outcomes for children with ASD and increased positive work experience for nurses in this region, if implemented correctly.

### 7.4.3 Contribution to legislation/policy

This framework, like others, aims to assist decision-makers, HCPs, and parents in enhancing family involvement in the hospital nursing care of children with ASD. This thesis and framework will be presented to the KZN Department of Health, private

hospital groups and autism support groups that assisted during data collection. The framework will hopefully be adopted by all these groups and included in their policies.

### 7.4.4 Contribution in the context of social issues

This study offers something more than just useful information for health care providers, policymakers, and academic literature. Ultimately, the aim is to have a positive impact on individuals with autism and their families in terms of hospital experience. If the framework is successfully implemented, it will lead to a more pleasant in-hospital experience for the child with ASD and his/her parents and potentially better health outcomes for the child.

## 7.5 Recommendations

The researcher has developed a framework for the improvement of family involvement in the hospital nursing care of a child with ASD, which could be utilised in the recommendations below.

### 7.5.1 Recommendations for policy and guidelines formation

According to Mahery (2021: 86), the successful application of current and potential future healthcare policy requirements can help hospitals ensure that all hospitalised children get consistent and equal parental and family care.

Similar to previous frameworks, this one is meant to help policymakers, health professionals, and parents improve family engagement in the hospital nursing care of children with ASD. This thesis and framework will be presented to the KZN Department of Health, private hospital groups and autism support groups that assisted during data collection. The framework will hopefully be adopted by all these groups and included in their policies and guidelines for professional nurses.

### 7.5.2 Implementation of the framework by professional nurses

The framework produced from this research may contribute to improving nursing practice for paediatric ward nurses in the eThekwini Region of KZN if adopted and implemented. It also may improve the in-patient experience of children with ASD, and their families. It can ensure that families are meaningfully involved in the treatment of their children which will lead to increased health outcomes for children with ASD and

increase positive work experience for nurses in the paediatric ward, in the eThekwini region.

### 7.5.3 Recommendations for future research

Based on the findings of this study, the researcher recommends the following avenues for future research:

- This research be repeated in other provinces of South Africa to see if it yields similar findings.
- The same research be conducted with a larger sample of participants.
- A similar study be conducted using a quantitative research design with a questionnaire to test generalisation.
- A study is be conducted to establish if having parents who are nurses or doctors improves the child with ASD's chances of having a good hospital experience.
- Testing of the framework developed in this study
- An implementation study of the framework developed in this study.

## 7.6 Limitations of the study

The researcher concedes the undermentioned limitations of the research:

- **Profile of the sample:** Unfortunately, due to the lack of access to government hospitals, all the nurse participants are currently working in private hospitals. Even though some of these nurses have worked in government hospitals previously, this can still be considered to be a limitation of this study.

- **Method:** Since the study was an IPA study with a small sample size of 20 participants, the findings cannot be generalised.

- **Age of Children**: The parents could have forgotten some of their experiences if their child with ASD were admitted in hospital a couple of years ago

## 7.7 Conclusion

This study aimed to develop in-depth insights into the influences that contribute to promoting family involvement in the provision of in-hospital nursing care for children with ASD in the eThekwini region of KZN. The results indicate that the professional nurse and the paediatric ward (environment) both have an influence on this

phenomenon, and further results found that 1) Families were very involved in the care of their child with ASD in hospital and in fact did everything for their children with the exception of a few nursing procedures; 2) The following challenges in the involvement of families in the hospital nursing care of a child with ASD were identified: lack of knowledge, nurses not listening to families, nurse's attitude, time and shortage of nursing staff; 3) In order to improve family involvement the researcher found the following could be done implemented with and by nurses: be trained to nurse children with ASD, have a caring attitude and patience, communicate with families, listen to family members, take a detailed history of patient, use the child's likes to get co-operation, involve the parents more in the care of their child, build a good relationship between the family and nurse, provide toys or some entertainment in hospital, ensure the safety of child and other children; 4) A framework was developed for the improvement of family involvement in the hospital nursing care of a child with ASD. The researcher developed the framework based on the empirical data presented and analysed in Chapter 5 and the theoretical frameworks and conceptual framework described in Chapter 3. The framework seeks to strengthen family involvement through the empowerment of nurses and family members. This empowerment can be achieved by implementing the four components of empowerment, namely: information sharing, proximity, attitude and garnering resources.

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## ANNEXURES

### Annexure 1: Interview guide for nurse participants

**Date:** _____ Time:_____

Institution: _____ Participant Code:_____

**Private or Public institution:** _____

**Demographic Information**

Age:_____ Gender:_____Marital Status**:**_____

Do you have children**:**_____ Level of Education:_____

Years of Service:_____

**Interview Questions:**

1. Tell me everything you know about Autism spectrum disorder:
2. Have you nursed a child with autism Spectrum disorder, if yes describe that experience?
3. What is the most important thing when nursing a child with Autism or any child?
4. what is their role of the family when nursing a child?
5. What do you believe prevents you from involving family in the nursing care of their child?
6. What is the best way to involve Family in the care of their child in hospital and post discharge ?

**Annexure 2: Interview guide for family participants**

**Date:** _____ Time:_____

Participant Code:_____

**Demographic Information**

Age:_____ Gender:_____ Marital Status**:**_____

Age of Autistic child**:**_____ Relationship to Child:_____

**Interview Questions:**

1. Tell me about your child:_____
   _____
   _____
   _____
   _____
   _____
2. Has your child been admitted to hospital? when and why? government or private hospital?_____
   _____
   _____
   _____
   _____
   _____
3. What was your perception of the nursing your child and you received from the nurses?_____
   _____
   _____

4. Explain how you were involved in your childs care in hospital and post discharge and was there collaboration with you in your child's care?_____

5. How did you expect the nurse to involve you in the care of your child in hospital?

6. What do you think is preventing you from being involved more in the nursing care of your child in hospital and care of your child post discharge?_____

7. What is the best way to involve you and your spouse in the in hospital and post discharge care of your child?_____

**Annexure 3: Information letter and consent to nurse participants**


**LETTER OF INFORMATION FOR NURSE PARTICPANTS**

Dear Sir/Madam,

Thank you for taking part in this study.

**Title of the Research Study:** An Interpretative Phenomenological Analysis of family involvement in, the hospital nursing care of children with Autism Spectrum Disorder, within eThekwini District.

**Principle researcher:** Mr. N. A. Williams (Masters of Health sciences in Nursing)

**Supervisors:** Professor. T. Mgutshini (PhD) and Dr. D. Sokhela (D Nursing)

**Brief Introduction:** I will be conducting the study determine your involvement of Family in the care of their child with Autism spectrum disorder.

**Purpose of the Study:** The aim of this research will be to develop in-depth insights into the influences that contribute to promoting family involvement in the provision of in-hospital nursing care, for children with ASD.

**Outline of the Procedures**: Firstly, I will ask you to read this information letter, ask questions where you do not understand and I will then ask you to sign the consent agreeing to take part in the study. Secondly, I will interview you, the online interview will take approximately 30 to 60 minutes.

**Risk or Discomforts to the Subject:** You will not experience any risk or discomfort because you will be interviewed by me and you can stop the interview at any time.

**Benefits:** The is no real benefit to you, except that you will be assisting in developing a framework for the improvement of family involvement in the hospital nursing care of a child with ASD.

**Reason/s why the Subject May Be Withdrawn from the Study:** You may decide not to attend the interview if you wish. There will be no adverse consequence to you.

**Remuneration:** You will not be given any money or any reward for participating in the study. You will be doing this on your free will.

**Costs of the Study:** All costs, that is transport, stationery, data etc, will be borne by myself as the researcher

**Confidentiality:** The interview is completely anonymous and cannot be traced back to you or your institution. All information gathered will be kept confidential and used only for the purpose of this research.

**Research-related Injury**: No compensation, however you will not suffer any injuries because you are only attending an interview.

**Persons to Contact in the Event of Any Problems or Queries:** For any queries please contact me on 0764809130 or the study supervisors: Professor T Mgutshini on 012 429 3377 or Dr. D. Sokhela on 0313732992 or the Institutional Research Ethics administrator on 031 373 2375. **Complaints can be reported to:** the Director: Research and Postgraduate Support Dr L Linganiso on 031 373 2577 or researchdirector@dut.ac.za.

**Annexure 4: Information letter and consent to family participants**

**LETTER OF INFORMATION FOR FAMILY PARTICPANT**

Dear Sir/Madam,

Thank you for taking part in this study.

**Title of the Research Study:** An Interpretative Phenomenological Analysis of family involvement in, the hospital nursing care of children with Autism Spectrum Disorder, within eThekwini District.

**Principle researcher:** Mr. N. A. Williams (Masters of Health sciences in Nursing)

**Supervisors:** Professor. T. Mgutshini (PhD) and Dr. D. Sokhela (D Nursing)

**Brief Introduction:** I will be conducting the study to determine your perception of the nursing care you and your child with Autism received in the paediatric ward when he/she was admitted there..

**Purpose of the Study:** The aim of this research will be to develop in-depth insights into the influences that contribute to promoting family involvement in the provision of in-hospital nursing care, for children with ASD.

**Outline of the Procedures**: Firstly, I will ask you to read this information letter, ask questions where you do not understand and I will then ask you to sign the consent agreeing to take part in the study. Secondly, I will interview you, the online interview will take approximately 30 to 60 minutes.

**Risk or Discomforts to the Subject:** You will not experience any risk or discomfort because you will be interviewed by me and you can stop the interview at any time.

**Benefits:** The is no real benefit to you, except that you will be assisting in developing a framework for the improvement of family involvement in the hospital nursing care of a child with ASD

**Reason/s why the Subject May Be Withdrawn from the Study:** You may decide not to attend the interview if you wish. There will be no adverse consequence to you.

**Remuneration:** You will not be given any money or any reward for participating in the study. You will be doing this on your free will.

**Costs of the Study:** All costs, that is transport, stationery, data etc, will be borne by myself as the researcher

**Confidentiality:** The interview is completely anonymous and cannot be traced back to you or your institution. All information gathered will be kept confidential and used only for the purpose of this research.

**Research-related Injury**: No compensation, however you will not suffer any injuries because you are only attending an interview.

**Persons to Contact in the Event of Any Problems or Queries:** For any queries please contact me on 0764809130 or the study supervisors: Professor T Mgutshini on012 429 3377 or Dr. D. Sokhela on 0313732992 or the Institutional Research Ethics administrator on 031 373 2375. **Complaints can be reported to:** the Director: Research and Postgraduate Support Dr L Linganiso on 031 373 2577 or researchdirector@dut.ac.za.


**CONSENT**

**Statement of Agreement to Participate in the Research Study:**

- I hereby confirm that I have been informed by the researcher, Mr. N.A. Williams, about the nature, conduct, benefits and risks of this study Research Ethics Clearance Number:
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

| | | |
|---|---|---|
| **Full Name of Participant** | **Date** | **Signature** |

I, Neil Williams herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

| | | |
|---|---|---|
| **Neil Williams** | | |

## Annexure 5: Advert for recruiting Family

**Are you a parent of a child, diagnosed with Autism?**

**Has your child been admitted to a hospital?**

**Do you live in KwaZulu Natal ?**

If you answered yes to all the questions above, I would love to interview you for research I'm doing, to try and improve the in hospital nursing care of children with Autism.

If you choose to take part in this research, you will be required participate in a 30 to 60 minute, online interview (telephonic, on Whatsapp or on MS teams) and you will be reimbursed for the data used. I need your help to improve nursing care of children with Autism in hospital.

If you would like to participate, please contact Mr. Neil Williams on 076480930 or williams.neilarnold@gmail.com and more information will be sent to you.

## Annexure 6: Letter of permission from Action in Autism

ACTION in AUTISM

www.actioninautism.org.za

Inspire Advocate Empower

A Non-Profit Organisation (NPO)
Registration No. 047-002-NPO
Tel: 031563 3039 fax: 0865568973
E-mail Address: info@actioninautism.org.za
105 Haig Road, Durban North 4051

9 November 2021

To Whom it May Concern

**Re: PhD Research: Mr Neil Williams, student no. 19909436**

This is to confirm that the Executive Committee of Action in Autism has approved the application by Mr Neil Williams to make use of the Action in Autism database of autistic people, parents, professionals and our constituency in order to conduct research towards his PhD study, entitled An Interpretative Phenomenological Analysis of family involvement in the hospital nursing care of children with Autism Spectrum Disorder within eThekwini District.

Sincerely,

Kirsten Miller
Director
Action in Autism

Action in Autism is a non-profit organization created by parents of children with autism to improve the quality of life for people with Autism Spectrum Disorders and their caregivers by building partnerships between people with ASD, their families and the community to provide information, services, learning and research. Action in Autism's vision is that every child with autism in KwaZulu-Natal be enrolled in a school in 2021.

## Annexure 7: Letter of permission from Khanyisa Developmental Centre

KHANYISA
DEVELOPMENTAL CENTRE

To whom it may concern,

I, Amy Rodger, Centre Director of Khanyisa Developmental Centre hereby give permission to Neil Williams to recruit participants for his study from Khanyisa Developmental Centre. The Centre Speech Therapist, Prianka Parusnath, will assist in the recruitment process by sending project adverts to parents via email and the school correspondence application: ClassDojo.

Please do not hesitate to contact Prianka or myself should you have any questions.

Kind Regards,

Amy Rodger
Centre Director

Prianka Parusnath
Speech Therapist

KHANYISA
SCHOOL & THERAPY CENTRE
CNR MENDOZA DRIVE & HARBER CRESCENT
TEL: 031 561 1863
EMAIL: admin@khanyisacentre.co.za
Web: www.khanyisacentre.co.za
152/2015 (D) PBO No.: 930052273

KHANYISA
ARISE & SHINE

Tel: 031 561 1863 Email: admin@khanyisacentre.co.za Web: www.khanyisacentre.co.za Address: 5 Mendoza Drive, Umhlanga Rocks, 4316

**Annexure 8: Advert for recruiting registered nurses**

Are you a Registered or Professional Nurse?

&

Have you ever nursed a child, diagnosed with Autism in Hospital?

**If you answered yes to the above questions, I would love to interview you for my research, to try and improve the in hospital nursing care of children with Autism.**

**If you choose to take part in this research, you will be required participate in a 30 to 60 minute, interview (telephonic, on Whatsapp or on MS teams). You will be reimbursed with 1 Gig of data for the interview.**

**If you would like to participate, please contact Mr. Neil Williams on 0764809130 or williams.neilarnold@gmail.com and more information will be sent to you.**

## Annexure 9: Permission letter from KZN Department of Health

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email: [redacted]
www.kznhealth.gov.za

DIRECTORATE:
Health Research & Knowledge Management

NHRD Ref: KZ_202110_025

**Dear Mr NA Williams**
(DUT)

**Approval of research**

1. The research proposal titled **'An Interpretative Phenomenological Analysis of family involvement in the hospital nursing care of children with Autism Spectrum Disorder within eThekwini District.'** was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

   The proposal is hereby **approved** for research to be undertaken at Addington, Clairwood Inkosi Albert Luthuli Central, King Edward VIII, King Dinuzulu, Mahatma Gandhi, Prince Mshiyeni Memorial, RK Khan and St Aidans Hospital.

2. You are requested to take note of the following:
   a. *All research conducted in KwaZulu-Natal must comply with government regulations relating to Covid-19. These include but are not limited to: regulations concerning social distancing, the wearing of personal protective equipment, and limitations on meetings and social gatherings.*
   b. *Kindly liaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.*
   c. *Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.*
   d. *Provide an interim progress report and final report (electronic and hard copies) when your research is complete to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za*
   e. *Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.*

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

**Dr E Lutge**
Chairperson, Health Research Committee
Date: 09/11/2021

## Annexure 10: Letter of refusal from King Dinizulu Hospital

KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:
King Dinuzulu Hospital Complex

P.O. Dormerton, Sydenham, 4015
75 R.D. Naidu Drive, Sydenham, 4015
Tel: 031 2426000 Fax: 031 2099586

Enquires: Dr Z. Dlamini

Reference: RES 30/2021

28/01/2022

Dear Mr N.A. Williams

**RE: PERMISSION TO CONDUCT RESEARCH - AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF FAMILY INVOLVEMENT IN THE HOSPITAL NURSING CARE OF CHILDREN WITH AUTISM SPECTRUM DISORDER WITHIN ETHEKWINI DISTRICT**

Your request to conduct the abovementioned research has not been supported by King Dinuzulu Hospital Complex as we do not admit children in the Psychiatric wards.

Yours faithfully

**Dr Z. Dlamini**
**Acting C.E.O.**

GROWING KWAZULU-NATAL TOGETHER

## Annexure 11: Permission letter from IALCH

KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:
INKOSI ALBERT LUTHULI CENTRAL HOSPITAL
OFFICE OF THE MEDICAL MANAGER
Private Bag X03, Mayville, 4058
800 Vusi Mzimela (Bellair) Road, Mayville,4091
Tel: 031 240 1059 Fax: 031 240 1005 Email: Ursula.john@ialch.co.za

Reference: IREC 221/21
Enquiries: Medical Management

13 January 2022

Mr N A Williams
9 Lofthill Place
Hillgrove
Newlands West
4037

Dear Mr Williams

**RE: PERMISSION TO CONDUCT RESEARCH AT IALCH**

I have pleasure in informing you that permission has been granted to you by the Medical Manager to conduct research on: **An Interpretative Phenomenological Analysis of family involvement in the hospital nursing care of children with Autism Spectrum Disorder within eThekwini District.**

Kindly take note of the following information before you continue:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Kindly ensure that this office is informed before you commence your research.
4. The hospital will not provide any resources for this research.
5. You will be expected to provide feedback once your research is complete to the Medical Manager.

Yours faithfully

.....
**Dr L P Mtshali**
**Medical Manager**

## Annexure 12: Permission from a private hospital group

RESEARCH OPERATIONS COMMITTEE FINAL APPROVAL OF RESEARCH

Approval number: UNIV-2021-0058

Mr Neil Williams

E mail: Williams.neilarnold@gmail.com

Dear Mr Williams

**RE: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF FAMILY INVOLVEMENT IN, THE HOSPITAL NURSING CARE OF CHILDREN WITH AUTISM SPECTRUM DISORDER, WITHIN ETHEKWINI DISTRICT.**

The above-mentioned research was reviewed by the Research Operations Committee's delegated members and it is with pleasure that we inform you that your application to conduct this research at private Hospitals, has been approved, subject to the following:

i) Research may now commence with this FINAL APPROVAL from the Committee.

ii) All information regarding the Company will be treated as legally privileged and confidential.

iii) The Company's name will not be mentioned without written consent from the Committee.

iv) All legal requirements regarding patient / participant's rights and confidentiality will be complied with.

v) All data extracted may only be used in an anonymised, aggregated format and for the purposes of this specific study as specified in the proposal. The data may under no circumstances be used for any other purpose whatsoever.

vi) The research will be conducted in compliance with the GUIDELINES FOR GOOD CLINICAL PRACTICE IN HUMAN PARTICIPANTS IN SOUTH AFRICA (2016).

vii) The Company must be furnished with a STATUS REPORT on the progress of the study at least annually on 30th September irrespective of the date of approval from the Committee as well as a FINAL REPORT with reference to intention to publish and probable journals for publication, on completion of the study.

viii) A copy of the research report will be provided to the Committee once it is finally approved by the relevant primary party or tertiary institution, or once complete or if discontinued for any reason whatsoever prior to the expected completion date.

ix) The Company has the right to implement any recommendations from the research.

x) The Company reserves the right to withdraw the approval for research at any time during the process, should the research prove to be detrimental to the subjects/ Company or should the researcher not comply with the conditions of approval.

xi) APPROVAL IS VALID FOR A PERIOD OF 36 MONTHS FROM DATE OF THIS LETTER OR COMPLETION OR DISCONTINUATION OF THE TRIAL, WHICHEVER IS THE FIRST.

We wish you success in your research.

Yours faithfully

20/11/2021

Prof Dion du Plessis
Full member: Research Operations Committee & Medical Practitioner evaluating research applications as per Management and Governance Policy

Dr Shannon Nell
Chairperson: Research Operations Committee
**Date:** 9/12/2021

This letter has been anonymised to ensure confidentiality in the research report. The original letter is available with author of research

## Annexure 13: Permission from the Lenmed hospital group

lenmed
Embrace every day

Lenmed Head Office
2nd Floor, Fountain View House,
Constantia Office Park,
Cnr 14th Avenue & Hendrik Potgieter Road
Constantia Kloof.

2021/10/13

Mr. Neil Williams
Durban University of Technology,
Faculty of Health Sciences.

Dear Mr. Williams,

**Permission to conduct research in Lenmed Hospitals**

Thank you for your invitation to participate in your research: **An Interpretative Phenomenological Analysis of family involvement in the hospital nursing care of children with autism spectrum disorder within eThekwini District.** Before we can provide permission for you to continue with data collection, we require the following:

1. A 15 -minute power point presentation to our Group Nursing Standards Manager, Nurse Managers, and unit managers to outline the purpose, aim, duration and potential risks/benefits of your study. These virtual sessions would have to include the KZN hospitals in our Group which you intend to utilise in your study and would be conducted via Microsoft Teams. We also need to include a question-and-answer session to ensure all the participants have clarity on the process and requirements.
2. A Participant Information and Consent Document to ensure each staff member who agrees to participate is completely aware of the implications and commitment to participate in the study, and how their personal data will be utilised.
3. A detailed explanation of how you intend to protect the anonymity of the participants as well as the Lenmed Group, for example when publishing your data in an accredited journal.
4. A timeline for data collection – please, keep in mind that December is a very busy time for our hospital teams, which might negatively influence their willingness to participate. Could data collection be postponed to January 2022?

Please complete the below letter with your details. We will provide you with a signed copy to commence your data collection once we have the required information from you.
We look forward to working with you.

Regards,

Dr. Liezl Balfour
Group Nursing Standard Manager
Chairperson: Research Committee

**PERMISSION TO CONDUCT RESEARCH IN THE HOSPITALS IN THE LENMED GROUP**

**To:** Dr. Liezl Balfour
**Lenmed Group**

**From:** Mr. Neil Williams
**Principal investigator**

I am a researcher / student from Durban University of Technology, and request permission to conduct a study on **An Interpretative Phenomenological Analysis of family involvement in the hospital nursing care of children with autism spectrum disorder within eThekwini District**, in the LEHHC & Shifa Hospital Paediatric units of the Lenmed Hospital Group.

I would require access to the following data sources during my study:

1. The contact Information of Registered Nurses from the above Paediatric Units
2. _____
3. _____
4. _____

To facilitate your participation in my study, I, the researcher, hereby confirm that:

- I will not access any other data sources without the written permission of the Lenmed Group
- I intend to keep all personal information of participants confidential by _____
- I intend to keep the identity of the Lenmed Group confidential by _____
- I intend to share the findings of my study with the Lenmed Group for approval prior to dissemination of the results
- I intend to publish the findings of the study in a professional journal and/or at professional meetings such as symposia, congresses, etc., and provide the Lenmed Group with a copy of the publication
- I undertake not to proceed with the study without the approval of the Lenmed Group

Sincerely,
A Williams
Mr. Neil Williams

**PERMISSION TO CONDUCT THE RESEARCH IS HEREBY GRANTED, INCLUDING ACCESS TO THE REQUIRED DATA SOURCES**

**Signed: Dr. Liezl Balfour** Balfour LN

**Company stamp**

LENMED HEALTH (PTY) LTD
PO BOX 855 TEL: 087 087 0600
LENASIA
1820

info@lenmed.co.za | www.lenmedhealth.com

## Annexure 14: Full Approval from DUT IREC

**Institutional Research Ethics Committee**
Research and Postgraduate Support Directorate
2nd Floor, Berwyn Court
Gate 1, Steve Biko Campus
Durban University of Technology

P O Box 1334, Durban, South Africa, 4001

Tel: 031 373 2375
Email: lavishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics

**www.dut.ac.za**

23 November 2021

Mr N A Williams
9 Lofthill Place
Hillgrove
Newlands West
4037

Dear Mr Williams

**An Interpretative Phenomenological Analysis of family involvement in the hospital nursing care of children with Autism Spectrum Disorder within eThekwini District**
**Ethical Clearance number IREC 221/21**

The Institutional Research Ethics Committee acknowledges receipt of your notification regarding the piloting of your data collection tool.

Kindly ensure that participants used for the pilot study are not part of the main study.

In addition, the IREC acknowledges receipt of your gatekeeper permission letters.

Please note that FULL APPROVAL is granted to your research proposal. You may proceed with data collection.

Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the IREC according to the IREC SOP's.

Please note that any deviations from the approved proposal require the approval of the IREC as outlined in the IREC SOP's.

Yours Sincerely

Professor J K Adam
Chairperson: IREC

## Annexure 15: Important articles included in the literature review

| Author/Date | Title of paper/Aim of study | Key Findings |
|---|---|---|
| Mahoney *et al.* (2021) | Nursing care for pediatric patients with autism spectrum disorders: A cross-sectional survey of perceptions and strategies | Results: The participants involved 90 pediatric hospital nursing staff members providing direct care. Respondents demonstrated 90% accurate knowledge of the characteristics of ASD. Self-reported effectiveness in caring for children with ASD did not correlate with knowledge and significantly correlated with an increased number of strategies. Nursing staff with frequent interaction with people with ASD or those with previous training reported significantly more strategies to care for children with ASD. Only 35% of participants reported that they have adequate strategies to care for children with ASD in the hospital.<br>Practice Implications: Having more strategies was the factor associated with higher self-efficacy, so training for nursing staff should focus on increasing the number of strategies to use with children with ASD in the hospital and provide mechanisms to collaborate with other professionals to individualize strategies to meet each child's needs |
| Author/Date | Title of paper/Aim of study | Key Findings |
| Magalhães *et al.* (2020) | Nursing care to the autistic child: an integrative review | Nursing uses the empathy, holistic view and different strategies for the care to the autistic child; however, the professionals refer difficulties in clinical practice. The publications on the subject are scarce being necessary the development of clinical research. |
| Owen, Gary and Schnetter (2020) | Nursing care of patients with autism spectrum disorder | Successful assessment and delivery of interventions can be challenging when caring for patients with ASD. Sensitive nursing care and an understanding of sensory and communication difficulties are required. |
| Cooke, Smith and Brenner (2020) | Parents' experiences of accessing respite<br>care for children with Autism Spectrum<br>Disorder (ASD) at the acute and primary<br>care interface: a systematic review | This systematic review identified a number of barriers to respite care, of which the findings can be<br>used to inform future service development and further research. Knowledge of parental experiences in caring for a<br>child with an ASD is vital in addressing the need and type of respite care required for children with an ASD. |
| Author/Date | Title of paper/Aim of study | Key Findings |
| Yoo and Cho (2020) | Exploring the Influences of Nurses' Partnership with Parents, Attitude to Families' Importance in Nursing Care, and Professional Self- | To improve the quality of paediatric nursing care, it is necessary to provide a working environment in which paediatric nurses can work continuously. Hospitals should also develop a program that enables proper |

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| | Efficacy on Quality of Paediatric Nursing Care: A Path Model | collaboration between nurses and parents of hospitalized children and improves nursing professional self-efficacy. |
| Pillai, Makhetha and Aldous (2021) | A study reflecting the demographics and comorbidities of children diagnosed with autism spectrum disorder at initial presentation to the KwaZulu-Natal Children's Hospital | The study illustrated the demographic profiles and comorbidities of autistic children presenting to the KZNCH. However, the<br>medical and social shortcomings in KZN elucidated in this study reinforce the necessity for further research to be conducted and resources<br>to be invested to address the plight of children with ASD. |
| Author/Date | Title of paper/Aim of study | Key Findings |
| Mahery (2021) | The child's right to family and parental care during hospitalisation: Exploring legal obligations and policy standards for hospitals | All children are guaranteed the right to family or parental care in section 28 (1)(b) of the South African Constitution. This right also applies to hospitalised children who require support from parents and family during hospitalisation. The entitlements that stem from this right create various obligations for public and private hospitals. These include the obligation that hospitals should refrain from interfering with the hospitalised child's right to family and parental care, as well as their obligation to facilitate the enjoyment of this right in the best interest of all child patients. The effective implementation of existing and perhaps additional healthcare policy standards can assist hospitals in ensuring consistent and equal enjoyment of family and parental care for all hospitalised children |
| Kapur *et al.* (2019) | Health Disparities among Children with Autism Spectrum Disorders: Analysis of the National Survey of Children's Health 2016 | Utilizing the 2016 National Survey of Children's Health, this study illustrates that a child with ASD have nearly 4 times higher odds of unmet health care needs compared to children without disabilities, whereas children with other disabilities had nearly 2 times higher odds of unmet health care needs compared to children without disabilities. Applying Andersen's Behavioural Model of health care utilization, this study estimates that enabling factors (e.g., access to health insurance, quality of health insurance, access to family-centred care, family-level stress, exposure to adverse childhood experiences, and parental employment) improved prediction of regression model for unmet health care needs by 150%. Policy and program implications are discussed and a new framework for responding to observed disparities is discussed. |
| Argumedes, Lanovaz and Larivee (2018) | Brief Report: Impact of Challenging Behaviour on Parenting Stress in Mothers | Challenging behaviours are a known predictor of high parenting stress in families of children with autism spectrum disorders. However, few studies have evaluated the effect of reducing |

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| | and Fathers of Children with Autism Spectrum Disorders | challenging behaviours on parenting stress. The purpose of study was to (a) examine the impact of reducing the frequency and severity of challenging behaviours on parenting stress and (b) compare the effects of family-cantered support and parent education on changes in parenting stress. Both high severity of autistic symptoms and of challenging behaviours were predictors of parenting stress. Furthermore, receiving family-cantered support were associated with larger reductions in parenting stress. Overall, our results suggest that reducing challenging behaviours with family-cantered support may be preferable to produce collateral reductions in parenting stress. |
| Koyama *et al.* (2022) | Severe Outcomes, Readmission, and Length of Stay Among COVID-19 Patients with Intellectual and Developmental Disabilities | Patients with ASD and those with Down syndrome both had over a 40% longer mean Length of Stay (LOS). Patients with intellectual disabilities had a 23% (12-35%) increased odds of 30-day readmission. Conclusions: Results suggest that patients hospitalized with COVID-19 with IDD have a significantly in-creased risk of severe outcomes, 30-day readmission, and longer LOS. |
| Kilburn *et al.* (2020) | Group Based Cognitive Behavioural Therapy for Anxiety in Children with Autism Spectrum Disorder: A Randomised Controlled Trial in a General Child Psychiatric Hospital Setting | Cognitive Behavioural Therapy (CBT) programs adapted to children with autism spectrum disorder (ASD) effectively reduce anxiety when run in university clinics. Forty-nine children aged 8–14 years participated in a waitlist-controlled study in a general child psychiatric hospital setting. Post-treatment 30% of the children were free of their primary anxiety diagnoses and 5% were free of all anxiety diagnoses. No statistically significant difference between the two trial conditions were found on primary outcomes. However, statistically significant differences were found on secondary outcomes indicating clinically meaningful treatment responses. Together with high program satisfaction this study shows the CBT program to be feasible and potentially efficacious in treating anxiety in children with ASD in a general child psychiatric hospital setting |
| Wilder Research (2020) | Mapping the Journey of Families Who Have Children with Autism Through Social and Human Services, Medical, and Education Systems | This report maps the journey of families of children with ASD. |
| Morsy *et al.* (2020) | Assessment of the utilization of pharmacotherapy for paediatrics with autism spectrum disorder in Jeddah, KSA | Nowadays management of autism depends on a combination of behavioural management, pharmacotherapy, family and educational therapy for the best outcome. The most common pharmacological line used was SSRIs and kebra and about 75% of children who took drugs complained of side effects. |

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| Powell *et al.* (2021) | Health Status and Health Care Use Among Adolescents Identified with and without autism in early childhood — Four U.S. Sites, 2018–2020 | The findings provided in this report indicate that adolescents with autism had greater physical difficulties, had poorer physical and mental health, and experienced greater gaps in health care use and transition planning than did adolescents from the population control group. Potential strategies for improving health outcomes and reducing gaps in use of services for adolescents with autism include offering interdisciplinary training to professionals that promotes use of evidence-based interventions and increases provider comfort in treating adolescents with autism and other developmental disorders; improving delivery of care to be timely, coordinated, and family-centred; and promoting programs that facilitate successful health care transition for adolescents, including those with autism and other developmental disorders |
| Karpur *et al.* (2022) | Brief Report: Impact of COVID-19 in Individuals with Autism Spectrum Disorders: Analysis of a National Private Claims Insurance Database | Data from FAIR Health's FH® NPIC (National Private Insurance Claims) database, one of the nation's largest databases of private insurance claim records, were analysed to understand the experiences of individuals with ASD in the COVID-19 pandemic. Multivariate logistic regression models revealed that individuals with ASD+ID were nine times more likely to be hospitalized following COVID-19 infection and were nearly six times more likely to have an elevated length of hospital stay compared to those without ASD+ID. These findings point to the need for prioritizing access to vaccines to prevent COVID-19 infection and morbidities. This is the first study to illustrate a higher likelihood of hospitalization and elevated length of hospital stay from COVID-19 in individuals with ASD and other comorbidities. |
| Mol, Argent and Morrow (2018) | Parental satisfaction with the quality of care in a South African paediatric intensive care unit | The need for communication and support during the admission period, and the importance of environmental factors, proximity to the child, the attitude of medical staff and social support during the PICU stay emerged as common themes from the responses to the open-ended questions. Conclusion. Although parents were generally well satisfied with the quality of care, improving family involvement and providing adequate information in the PICU can contribute to quality family-centred care. |
| Author/Date | Title of paper/Aim of study | Key Findings |
| Mason *et al.* (2021) | Nurse Attitudes<br>A descriptive study of families' importance in inpatient nursing care | A descriptive cross-sectional design. This study examined inpatient oncology nurses' attitudes toward families' importance in nursing care. Nurses scored above the midpoint for all the items on the FINC-NA, suggesting that the nurses have a supportive attitude and place high importance on families and their involvement in nursing care activities. Two of |

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| | | the top three highest scoring items were from the family as a resource in nursing care subscale: “family members should be invited to actively take part in the patient’s nursing care” (highest) and “the presence of family members is important for the family members themselves” (third highest). The second highest scoring item, “it is important to find out what family members a patient has,” reflects the family as a conversational partner subscale. These findings are consistent with those from Blöndal et al. (2014) and Luttick et al. (2017). Valuing family presence and including family in conversations surrounding nursing care (Benzein, Johansson, Årestedt, & Saveman, 2008) are aspects of a patient- and family-centered care approach (Nickel et al., 2018). |
| Myers *et al.* (2021) | Family-Centered Care: How Close Do We Get When Talking to Parents of Children Undergoing Diagnosis for Autism Spectrum Disorders? | This mixed-methods study explored key elements of FCC from 31 parents of children recently diagnosed with ASD using parallel qualitative and quantitative measures. Parents rated highly their receipt of FCC and discussed ways providers demonstrated FCC. However, the majority of parents indicated that the period when their child was undergoing diagnosis was stressful and reported symptoms of depression and anxiety. The study points to ways in which health care providers can enhance FCC provided to families when a child is undergoing ASD diagnosis |
| Konradsen *et al.* (2022) | Comparison of Swedish nurses’ attitudes toward involving families in care over a decade | Overall, the nurses were positive towards involving families in care, both in 2009 and 2019. n Sweden, nurses’ attitudes toward involving families in care did not change over the studied decade, despite changes in nursing, healthcare-system, and society. |
| Morris, Muskat and Greenblatt (2018) | Working with children with autism and their families: pediatric hospital social worker perceptions of family needs and the role of social work | The information gained through this study draws attention to pediatric hospital social workers’ autism knowledge and experiences, as well as strengths and limitations of effective social work practice with these individuals and their families. The results of this study illuminate some barriers that social workers face in providing family-centered services for families of children with autism who visit the hospital and may support knowledge translation efforts such as the development of educational programs, and a compendium of resources for social work staff in the hospital. The value of social workers as professional collaborators in the healthcare system may be enhanced by increasing social worker knowledge and skills relevant to autism and emphasizing the benefits and value of the role of social work and may result in improved quality of patient and family-centered care and |

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| | | a higher satisfaction with healthcare services for children with autism and their families. |
| Phiri, Kafulafula and Chorwe-Sungani (2019) | Exploring Paediatric Nurses' Experiences on Application of Four Core Concepts of Family Centered Nursing Care in Malawi: Findings from a Resource Limited Paediatric Setting | Results: The findings showed that nurses were able to apply these core concepts in daily practice. Six themes emerged: Power and control, respect and dignity, information sharing and communication, family participation in care, Collaboration and partnership and Nurses impression family involvement. Conclusion: Registered nurses are knowledgeable and apply the four concepts of family centred care. However, the true application of core concepts of family centered care is constrained by lack of resources and absence of policy. These findings have implications for nursing management and research. |
| Alexanian *et al.* (2021) | Defining and Redefining Family Involvement in Practice: An Implementation Trial of a Locally Adaptable Patient-Centered Professional Development Tool in Two Ontario Intensive Care Units | In this study, the implementation of a FIT into two Ontario ICUs revealed that nurses were uncertain about the nature and extent of empowering family members to define and decide their involvement in their loved ones' care. Ongoing tensions about what appropriate family involvement should be stemmed from professional concerns about the quality of clinical care of the patients and the struggle to balance that against the nature offamily involvement in the daily care ofthe patient. Additional research that includes family member perspectives on their experiences in the ICU and, particularly, how language and socioeconomic barriers could affect their opportunities for family involvement is needed to illuminate the impact of the informal rules of health care professionals on family involvement in ICU patient care. This also points to the need for understanding and incorporating nursing concerns into interventions related to family involvement to best optimize facilitation by heath care professionals. A deeper understanding of this dynamic could then provide opportunities for tailored continuing professional development for health care professionals within the ICU to assist them in navigating their own perceived clinical care needs as providers, alongside the perceived needs of patient and family involvement in ICU care |
| Maaskant *et al.* (2021) | Strict isolation requires a different approach to the family of hospitalized patients with COVID-19: A rapid qualitative study | The communication with and involvement of family in hospital care changed enormously during the COVID-19 outbreak. Based on the identified themes, we formulated recommendations that may be helpful for family-centered care in hospitals during periods of restricted visiting policy. Nurses confirmed that communication with family was far less than before and that the physical condition of the patient was predominant. The |

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| | | involvement of family in care was limited to practicalities, although more involvement was described in end-of-life situations. Nurses experienced moral distress due to the visiting restrictions, though some acknowledged that they had experienced the direct patient care so intense and burdensome, that family contact simply felt too much. |
| Hsiao, Lu and Tsai (2019b) | Factors Associated With Primary Family Caregivers' Perceptions on Quality of Family-Centered Care in Mental Health Practice | This study provides tentative evidence that primary family caregivers' perceptions of quality of FCC in the presence of schizophrenia was inadequate in the provision of general and specific information. Younger and more educated primary family caregivers, having relatives with schizophrenia in acute wards, more negative attitudes of MHNs toward schizophrenia, and the importance of families in nursing care were related to poor aspects of quality of FCC. Given the impact of the nature of mental illness on the caregiving responsibilities that families continue to shoulder, there is a need to establish alliances between affected families and mental healthcare providers. Within the workplace context, assisting families to successfully carry out caregiving activities would in turn enhance patients' recovery. Results from this study direct our attention to the needs of affected families and the need to incorporate antistigma initiatives and a therapeutic family-centered approach into recovery-oriented mental healthcare practice to address their concerns. |
| Shibily *et al.* (2021) | The Perceptions of Nurses and Nursing Students Regarding Family Involvement in the Care of Hospitalized Adult Patients | This study used a quantitative descriptive cross-sectional design. The data were collected using a convenience sampling survey via social media. Conclusions: Nurses with more experience showed no support for family involvement in patient care. We have to consider the clinical barriers that affect nurses' support for family involvement in patient-centered care, such as hospital polices, guidelines, and the model used for family-centered care integration in the hospital system to facilitate the interaction between healthcare providers and family members. |
| Coats *et al.* (2018) | NURSES' REFLECTIONS ON<br>BENEFITS AND CHALLENGES OF IMPLEMENTING FAMILYCENTERED CARE IN PEDIATRIC INTENSIVE CARE UNITS | The main thematic finding was the nurses' descriptions of a "balancing act" to provide quality family-centered care. The balancing act was characterized by the interaction between 2 types of changes: (1) intensive care unit policies related to visitation hours and family presence at the bedside and (2) physical transformations in the intensive care unit from shared open space to individual private rooms. Conclusions All of the nurses viewed the transition to family-centered care as having benefits for families. They also described how changes had created new challenges for the |

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| | | delivery of nursing care in intensive care units, particularly regarding mentorship and the safety of patients and staff. |
| Abukari, Acheampong and Aziato (2022) | Experiences and contextual practices of family-centered care in Ghanaian nicus: a qualitative study of families and clinicians | Shared decision-making, counseling and education, as well as respect/dignity amongst clinicians, managers and families using a multidisciplinary approach are the fundamental concepts of FCC approach in Ghana. Acceptance and integration of FCC approach into neonatal intensive care units may reduce the burden of care as well as improve the quality of care. Further studies are needed to map out strategies and interventions for the integration of FCC into intensive care units. |
| Krajnc and Berčan (2020) | Family-centered care: a scoping review | identified five core characteristics of family-centered care: the importance of communication, involvement of patients and family members, support to family members, organisational aspects, and the importance of nurses' attitudes. We stressed that family-centered care proposes a systematic solution which strives to optimize the level of satisfaction of all included parties, because it perceives healthcare process as an intersubjective reality in which all of the involved parties mutually depend on each other. |
| Fraatz and Durand (2021) | Meeting the Needs of Children with Autism Spectrum Disorder and Their Families in Hospital Settings: The Perspectives of Certified Child Life Specialists and Nurses | Qualitative analyses yielded six themes that addressed ways to serve children who have ASD: partner with the family, individualize care, advocate for more education, understand ASD is a spectrum of differences, think psychosocially not just medically, and emphasize consistency in care. Findings illustrate the complexity of the ASD diagnosis in light of the limited training and education health care professionals receive and are discussed with regard to their implications for the ways that institutional policies, including those within the child life profession, can facilitate the delivery of optimal care for this population in hospital environments |
| Selvey, Stypulkowski and Waisbren (2019) | Surgical management of the patient living with autism | Results: The wide spectrum of symptoms associated with autism spectrum disorder pose unique challenges for surgical management. Early coordination with the patient and family optimizes the development of an effective care plan. Strategies include identifying triggers for anxiety as well as soothing mechanisms, performing surgery in the morning, completing preoperative paperwork prior to surgery, choosing appropriate analgesia and anxiolytics, and fast resumption of normal routines. Based on these findings a surgical checklist was created to aid in treating the patient with autism spectrum disorder. The checklist provides insight into navigating the surgical experience and emphasizes planning |

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| | | surgical interventions to most effectively fit individual patient needs. Conclusion: The surgical treatment of those living with autism spectrum disorder poses unique challenges for the health care team. The widespread adoption of such individualized approaches encompassing pre/intra/postoperative will become more important as these children grow into adults with increased needs for surgical services. |
| Benich *et al.* (2018) | Parental Perception of the Perioperative Experience for Children With Autism | The perioperative setting can pose unique challenges for children with ASD, especially in regard to their sensitivity to stimuli and communication difficulties. Children with ASD are likely to have comorbidities that often warrant evaluation and potential surgical intervention by otorhinolaryngologists. This qualitative analysis of the semistructured interviews of 12 parents or guardians of children with ASD provides insight into the common challenges faced by children and family members in the surgical setting. We used this information to construct a preoperative questionnaire to streamline the care of our patients. By examining frequently mentioned items pertaining to topics such as behavioral outbursts, tools for comfort, and communication, we hope to highlight the importance of considering the individual needs of children with ASD in otorhinolaryngology surgery. In this manner, we can aim to increase the comfort of and improve the surgical outcomes for these children in the future. |
| Cranley *et al.* (2022) | Nurses' Attitudes Toward the Importance of Families in Nursing Care: A Multinational Comparative Study | Results from this study indicated that country, age, gender, and practice areas were factors that were associated with nurses' attitudes toward the importance of family in nursing care. On average, nurses working in Hong Kong, China, had less positive attitudes compared with Ontario, Canada, and Sweden, with most of the difference in Hong Kong accounted for by stronger perceptions of family as a burden. Our study advances knowledge of nurses' attitudes toward the importance of family involvement in nursing care from a multinational perspective. Findings could lead to the development of education programs or interventions that tailor the nursing care offered to families. The identification of cross-national differences signals the need to investigate the role of culture and health care system-level factors that may contribute to nurses' attitudes toward the importance of family in nursing care |
| Clark, Whitt and Lyons (2019) | Improving Communication Between Health Care Providers, Families, and Children with Autism | The All About Me Passport is a tool that helps identify special needs and procedural history issues for children with ASD. Its use has fostered better communication between families and caregivers and the health care |

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| | Spectrum Disorder: The Linked Program | team throughout the perioperative areas. Families have expressed great appreciation that they are able to share their knowledge of what their children need. The Linked Program has been effective in helping our health care staff be more aware of the challenges facing families and their children with ASD in the perioperative setting while giving them the tools and skills necessary to meet their needs. |
| Wood *et al.* (2019) | CREATING A SENSORY-FRIENDLY PEDIATRIC EMERGENCY DEPARTMENT | Integrating current evidence, staff suggestions, community input, and expert advice allowed us to find creative solutions to the unique sensory needs of children who visit our emergency department. Modifying both the patient-care environment and the patient-flow process to accommodate for the needs of children with ASD/SPD created a more peaceful and healing environment for children and their families and gave nurses the support they needed to provide sensory-informed care. |
| Mimmo *et al.* (2019) | Partnerships for safe care: A meta-narrative of the experience for the parent of a child with Intellectual Disability in hospital | Eleven publications met the inclusion criteria. Data synthesis revealed three research traditions contributing to this meta-narrative: Paediatric Nursing Practice, Intellectual Disability Healthcare and Patient Experience. A total of five themes were identified: (a) being more than a parent, (b) importance of role negotiation, (c) building trust and relationships, (d) the cumulative effect of previous experiences of hospitalization and (e) knowing the child as an individual. |
| Hetland *et al.* (2018) | A qualitative study of factors that influence active family involvement with patient care in the ICU: Survey of critical care nurses | Patient care demands, the professional practice environment and a lack of resources for families hindered nursing family caregiver involvement. Greater attention to these barriers as they relate to family caregiver involvement and clinical outcomes should be a priority in future research. |
| Bourke *et al.* (2021) | Emergency mental health presentations in children with autism spectrum disorder and attention deficit hyperactivity disorder | Children with an underlying diagnosis of ASD and/or ADHD represent more than one-quarter of all children presenting to the ED with MH complaints. They experience high rates of ASBD and have higher acute crisis team utilisation. Future research is needed to co-design, implement and evaluate better approaches to managing these children in the ED and upon their return to the community, so as to reduce the future need for ED care |
| Nygård and Clancy (2018) | Unsung heroes, flying blind—A metasynthesis of parents' experiences of caring for children with special health-care needs at home | The enormous burden of care can weaken the parents' will to carry on and result in a decreased ability to provide care. This can have an impact on the parents' health, family functioning and the sick child's potential health outcomes. Nurses are in a unique position to help these families and should be better prepared for the role. |

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| Brødsgaard *et al.* (2019) | Parents' and nurses' experiences of partnership in neonatal intensive care units: A qualitative review and meta-synthesis | A successful relationship between parents and nurses can be achieved through co-creation of mutual knowledge and development of competencies and negotiation of roles. Neonatal intensive care unit nurses are in a position where they exercise power, but they can change the culture if they are aware of what seems to facilitate or create a barrier to a partnership with parents. |
| O'Connor, Brenner and Coyne (2019) | Family-centred care of children and young people in the acute hospital setting: A concept analysis | There is a lack of attention to cultural and societal changes, which impact on those receiving and delivering care. While we know that family-centred care is widely endorsed and enhances well-being, there is a lack of empirical evidence about the impact on health outcomes for children. While children's nurses have been applying some elements of family-centred care to their clinical practice for decades, the concept continues to evolve |
| Litwin and Sellen (2022) | Designing a Sensory Kit to Improve the Environment for Children with Autism Spectrum Disorder in the Pediatric Emergency Department | The kit was evaluated and iteratively improved based on observations of children using the sensory equipment, satisfaction surveys from their parents, and interviews with healthcare providers in the ED. Findings from this study can be used to guide other EDs in creating their own ASD sensory kit. |
| Aarthun, Øymar and Akerjordet (2019) | Parental involvement in decision-making about their child's health care at the hospital | This study gives unique insight into how parental involvement in children's healthcare decisions influence parents' ability to cope with the parental role at the hospital. The results showed that parents' competence and perceived influence and control over their child's health care appeared to affect how they mastered their role of involvement in decision-making. Individually tailored and respectful facilitation of parental involvement in these decisions by health professionals seemed to improve parents' influence, control and ability to cope with the parental role. Nurses should thus strengthen parents' sense of coherence enhancing the quality of health care. |
| Mendive Dubourdieu and Guerendiain (2022) | Dietary Intake, Nutritional Status and Sensory Profile in Children with Autism Spectrum Disorder and Typical Development | These findings confirm the need to consider the neurodevelopment, sensory profile, and type of diet to improve the ASD child's nutrition. Further long-term research is needed to explore their impact on health |
| Taghizadeh *et al.* (2019) | The experiences of children with autism spectrum disorder, their caregivers and health care providers during day procedure: A mixed methods study | Hospital attendance was often stressful. Participants identified a number of facilitating factors including good communication, clear explanations, and friendly attitudes of staff. Flexibility and individualized care of patients (such as avoiding unnecessary blood pressure measurements, and not changing into hospital gowns) were valued. Supportive aids (such as computers or special interest objects), use of social stories, and giving premedication were all considered helpful. Perceived barriers to |

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| | | care included prolonged waiting times for operation date as well as waiting on the day of operation, lack of private space, lack of noninvasive equipment such as cutaneous infrared thermometers, poor communication, and inadequate training of staff about autism spectrum disorder. |
| Nicholas *et al.* (2020) | Patient- and Family-Centered Care in the Emergency Department for Children With Autism | Results revealed the value of PFCC in autism-based ED care. Helpful attributes of care were a person-centered approach, staff knowledge about ASD, consultation with parents, and a child-focused environment. Conversely, a lack of staff knowledge and/or experience in ASD, inattention to parent expertise, insufficient communication, insufficient family orientation to the ED, an inaccessible environment, insufficient support, a lack of resources, and system rigidities were identified to impede the experience of care. |
| Dahav and Sjöström-Strand (2018) | Parents' experiences of their child being admitted to a paediatric intensive care unit: a qualitative study– like being in another world | The parents' experience when their child is admitted to a paediatric intensive care unit is fraught with a range of emotion and fear. There are indications that things such as good information, involvement and a positive experience of the transfer to the paediatric ward reduce the stress and anxiety associated with paediatric intensive care admission. The result of this study could be used as a basis for a post-paediatric intensive care follow-up service for the children and their families |
| Mahoney *et al.* (2021) | Nursing care for pediatric patients with autism spectrum disorders: A cross-sectional survey of perceptions and strategies | he participants involved 90 pediatric hospital nursing staff members providing direct care. Respondents demonstrated 90% accurate knowledge of the characteristics of ASD. Self-reported effectiveness in caring for children with ASD did not correlate with knowledge and significantly correlated with an increased number of strategies. Nursing staff with frequent interaction with people with ASD or those with previous training reported significantly more strategies to care for children with ASD. Only 35% of participants reported that they have adequate strategies to care for children with ASD in the hospital. |
| Oh *et al.* (2018) | Validity and Reliability of the Korean Version of the Families' Importance in Nursing Care-Pediatric Nurses' Attitudes Instrument | Of the 26 initial items, 24 were ultimately selected after evaluating content validity, construct validity, and reliability. The following 6 factors were included in the Korean version of the Families' Importance in Nursing Care-Pediatric Nurses' Attitudes (KFINC-PNA): family as a 'conversational partner', 'participant in care', 'supporter for the nurse', 'burden', 'recipient of empowerment', and 'its own resource'. |
| Walsh *et al.* (2020) | Barriers to Healthcare for Persons with Autism: A Systematic Review of the | In total, 31 articles were included in the review. The resulting taxonomy consisted of four themes: 1) Challenges Associated with |

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| | Literature and Development of A Taxonomy | Autism-related Characteristics; 2) Health-care Provider-based Issues; 3) Healthcare System Issues; and 4) Patient-related factors. Conclusions: Barriers to healthcare access for persons with autism are prevalent and occur at the patient, provider, and system levels. The taxonomy developed may facilitate measurement of barriers within health-care facilities and prompt identification of areas where interventions are warranted to improve care. |
| Wilson and Peterson (2018) | Medical care experiences of children with autism and their parents: A scoping review | The review indicated a number of challenges (e.g., parent-reported problems in parent-provider communication and overwhelming environments) as well as factors that facilitate positive experiences (e.g., providing positive reinforcement and explaining exam steps) during medical appointments. Children with ASD and their families are faced with many challenges while receiving care in medical settings. The present review identified many challenges families face, as well as facilitators of positive experiences. Understanding the unique experiences of patients with ASD and their parents will help to improve experiences in medical care settings for children, caregivers, and health care providers |
| Bevan *et al.* (2022) | Positive Healthcare Encounters for Children With Autism Spectrum Disorder: Accommodations During Surgical Procedures | This article describes a novel protocol developed by an anesthesia resource center to modify care for children with autism spectrum disorder and their families. This information serves as a template for perianesthesia nurses and advanced care providers to implement practice accommodations. Two case examples, based on parent interviews and chart review, are presented to exemplify this protocol. |
| Thom, McDougle and Hazen (2019) | Challenges in the Medical Care of Patients With Autism Spectrum Disorder: The Role of the Consultation-Liaison Psychiatrist | Strategies to optimize the care of patients with ASD in medical settings include pre-visit planning, anticipating and reducing sources of distress, facilitating a patient- and family-centered multidisciplinary approach, employing environmental interventions, and using psychopharmacologic treatments. |
| Mazurek *et al.* (2020) | Primary Care Providers' Perceived Barriers and Needs for Support in Caring for Children with Autism | The most common barriers related to lack of knowledge and resources for diagnosing and treating children with autism, and inadequate visit time and reimbursement |
| An, Chan and Kaukenova (2020) | Families in Transition: Parental Perspectives of Support and Services for Children with Autism in Kazakhstan | Focus group discussions with 17 parents raising children with ASD were conducted in two major cities of Kazakhstan. Focus group interview data were transcribed and analysed using open coding and axial coding procedures. The following main themes and categories were identified and discussed: delayed detection of ASD and multiple pathways to the diagnosis; challenges for |

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| | | families in accessing and receiving health care for children with ASD in the public health care system; obstacles to accessing special education and a lack of inclusive education programmes for children with ASD; limited public benefits and social services available for these families in their communities; the lack of support from professional service providers in aiding parents with children ASD; and low public awareness of the disorder in the society. Drawing on family caregivers' perspectives, recommendations for policy-makers and service providers are given to strengthen the care for children with ASD in Kazakhstan. |
| Garrick *et al.* (2022) | An Australian Cross-Sectional Survey of Parents' Experiences of Emergency Department Visits Among Children with Autism Spectrum Disorder | Children with autism presenting to the ED often have a range of comorbidities or behavioural challenges, and face a number of barriers to care within the ED. Parents and caregivers identified barriers that included the level of understanding of staff regarding ASD symptoms and comorbidities, communication between staff, parents and children, and escalating anxiety due to the physical ED environment. Atypical expression and communication of pain by the child was also identified as another barrier to care for children. Through ongoing consultation between families, health care providers and hospital administrators, continual gains can be made toward improving access to quality care for children with ASD, as well as efficient emergency department functioning |
| Ruthes *et al.* (2022) | Eating practices and behaviors of families of children with autistic spectrum disorder | Each family develops their eating practices based on their context, food and cultural identity, and the different demands of their children's eating behaviors and difficulties. Families need a support network to manage the organization of their daily routines. |
| Sohl *et al.* (2022) | Project Extension for Community Health Outcomes (ECHO) Autism: A Successful Model to Increase Capacity in Community-Based Care | The model teaches clinicians how to screen and diagnose ASD, as well as manage common co-occurring medical and mental health issues. ECHO Autism is particularly useful for addressing the complex needs of children with ASD and reducing disparities often present in rural and underserved communities. The model can be disseminated globally due to its flexibility in accommodating local and regional differences in social norms and constructs. This article provides an overview of the format of the ECHO Autism model, data supporting the model's efficacy, and discusses future research directions. |
| Weissheimer *et al.* (2021) | Information demands from families of children with Autism Spectrum Disorder | it was identified that families need information regarding the characteristics of Autism Spectrum Disorder (definition, cause, possibility of cure, prognosis and the probability of having another child with Autism |

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| | | Spectrum Disorder); child's routine and behavior; future rights and expectation |
| Powell *et al.* (2021) | Health Status and Health Care Use Among Adolescents Identified With and Without Autism in Early Childhood — Four U.S. Sites, 2018–2020 | Compared with a general population control group, adolescents with autism were 90% more likely to have additional mental health or other conditions and three times more likely to have unmet health care service needs. |
| Page *et al.* (2022) | Correlates of Feeding Difficulties Among Children with Autism Spectrum Disorder: A Systematic Review | Clinicians caring for children with ASD will likely encounter feeding difficulties. It is important to recognize that feeding difficulties are a significant and persistent problem for children with ASD. As they likely will not resolve spontaneously, early identification and treatment are necessary. Recognition that feeding difficulties are related to the child's sensory processing profile is critical to understanding the child's behaviors and guiding treatment recommendations. For example, an occupational therapist can specifically address the child's impaired sensory processing through sensory integration therapy. Children with feeding difficulties are more likely to exhibit challenging behaviors at mealtimes, which can increase parental stress. In addition to assessing the child's diet, clinicians should also ask about mealtime behaviors and support families in developing strategies to use at mealtime when maladaptive behaviors occur. Finally, feeding difficulties appear to be related to GI symptoms, especially constipation, in some individuals. |
| Thi Lan Anh and Nujjaree (2022) | Effectiveness of a Family Management Intervention Program among Families of Children with Autism: A Randomized Controlled Trial | The findings revealed that the participants in the intervention group had a significantly higher family quality of life and significantly lower caregiver burden than those in the control group after attending the intervention and remaining overtime. Results provided evidence that the family-management intervention program improved outcomes for families of children with autism. This program needs further testing. After this, nurses and healthcare providers responsible for families and children with autism can integrate this program as part of their services. |
| Matin *et al.* (2022) | Contributing factors to healthcare costs in individuals with autism spectrum disorder: a systematic review | This systematic review identified a range of factors, including lower SES and lack of health insurance, which are associated with higher healthcare costs in people with ASD. Our study supports the formulation of policy options to reduce financial risks in families of individuals with ASD in countries which do not have a tax-based or universal health coverage system. |
| Kouo and Kouo (2021) | A Scoping Review of Targeted Interventions and | The healthcare environment may be highly rigid and may not easily adapt to the unique |

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| | Training to Facilitate Medical Encounters for School-Aged Patients with an Autism Spectrum Disorder | needs of individuals with disabilities, especially those with ASD. It is necessary to continually examine whether such medical environments and those involved can be made more flexible and responsive to the individual needs of patients. This scoping review allows for a robust understanding of how medical professionals and those working closely with individuals with ASD have made impactful adjustments to hospital settings to be more conducive and to facilitate interactions with this growing and heterogenous population. However, more work must be done to ensure that these supports are available equitably across all medical settings and that the limitation and challenges identified are ameliorated. Enhancing the delivery of healthcare practices for individuals with ASD may have a universal impact, and could be beneficial for all patients with disabilities, or more broadly all patients may benefit for such interventions and greater partnerships with families to develop individualized medical care plans |
| Mohammed and Sunghee (2022) | Comparison of Intensive Care Unit Nurses' and Family Members' Priorities of Patient and Family-centered Care in Ghana | To render care that aligns with the care priority of families and patients in the ICU, nurses must plan care in consultation with their families. Respect and dignity of the families was the most import priority. |
| Reddy, Fewster and Gurayah (2019) | PARENTS' VOICES: experiences and coping as a parent of a child with autism spectrum disorder | he study identified two major themes namely experiences of ASD and coping with ASD. Dealing with ASD was characterised by significant challenges associated with resource limitations, poor guidance from health professionals, protracted diagnostic processes, reduced awareness of ASD and stigma for families. Parents were resilient and empowered themselves to cope with the tough journey, with support systems providing a buffer to families. Parents identified support, resources and awareness as pivotal needs. Positive ramifications from parenting a child with ASD were the development of positive personality traits, increased spiritual faith and a greater appreciation of life. The study emphasised the need for increased resources and support for families to cushion their experiences of ASD. |
| Gall *et al.* (2022) | Improving Care for Families and Children with Neurodevelopmental Disorders and Co-occurring Chronic Health Conditions Using a Care Coordination Intervention | over 2 years, this project provided care coordination to 84 children and their families, with an age range from 2 to 17 years. The care coordination intervention demonstrated positive impacts for children, families, and care teams and contributed to clinical efficiencies. Children had fewer visits to the emergency department and less frequent acute care use. Improvement in access to services, joint care planning and communication across providers, |

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| | | and better linkage with school supports were demonstrated. Families reported that the program decreased their stress around coordinating care for their child. Conclusion: This work demonstrated that intersectoral care coordination is attainable through innovative and collaborative practice for children with complex neurodevelopmental and medical needs. |
| De Beer and Brysiewicz (2019b) | Developing a theory of family care during critical illness | The theory of family care during critical illness was identified. The core concept of the theory is empowerment, informed by the underlying constructs of information sharing, proximity, garnering resources, and cultural and religious cooperation |
| Bono *et al.* (2022) | Assessing Interdisciplinary Trainees' Objective and Self-Reported Knowledge of Autism Spectrum Disorder and Confidence in Providing Services | Specifically, trainees in psychology had significantly higher levels of objectively measured ASD knowledge than trainees in physical/occupational therapy, social work, and non-clinical disciplines. Pre-service and professional development experiences predicted trainees' objectively measured ASD knowledge, self-reported ASD knowledge, and self-reported confidence. Implications and recommendations regarding interdisciplinary training to improve outcomes for individuals with ASD are discussed. |
| Williams *et al.* (2021) | Family-centredness of a provincial autism programme: A quality assurance evaluation using the Measure of Processes of Care | Over the 3 years of the evaluation of FCS for children with ASD and their families, the overall provincial MPOC scores have been consistent and relatively high, ranging from very good to excellent. The findings indicate that parents believe that their ABA-based services and supports agencies were succeeding in providing a family-centred environment, especially in areas related to service providers' interpersonal behaviours. This evaluation reflected a unique arrangement among university researchers, government ministry and community service provider agencies. |
| Naef, Schmid-Mohler and Ernst (2021) | Psychometric evaluation of the German version of the instrument: Families' Importance in Nursing Care – Nurses' Attitudes (FINC-NA) | The cross-cultural adaptation and psychometric testing of the German version of the FINC-NA resulted in a 19-item scale that measure nurses' attitudes towards the importance of families in nursing care. Further testing is needed to refine the structural validity and establish construct validity of the FINC-NA German version. |
| Coughlan *et al.* (2020) | Identifying and managing care for children with autism spectrum disorders in general practice: A systematic review and narrative synthesis | At one end of the continuum, there were GPs who had not heard of autism or endorsed outmoded aetiological theories. Others, however, demonstrated a sound knowledge of the conditions but had limited confidence in their ability to identify the condition. Many GPs and researchers alike called for more training and this might be effective. However, framing the problem as one of a lack of training risks |

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| | | silences the array of organisational factors that impact on a GP's ability to provide care for these patients. |
| Wilson and Peterson (2018) | Medical care experiences of children with autism and their parents: A scoping review | The review indicated a number of challenges (e.g., parent-reported problems in parent-provider communication and overwhelming environments) as well as factors that facilitate positive experiences (e.g., providing positive reinforcement and explaining exam steps) during medical appointments. Children with ASD and their families are faced with many challenges while receiving care in medical settings. The present review identified many challenges families face, as well as facilitators of positive experiences. Understanding the unique experiences of patients with ASD and their parents will help to improve experiences in medical care settings for children, caregivers, and health care providers. |
| Morris, Greenblatt and Saini (2019b) | Healthcare Providers' Experiences with Autism: A Scoping Review | (1) complexity beyond usual role, (2) limited knowledge and resources, (3) training/prior experience, (4) communication and collaboration, (5) need for information and training, and (6) need for care coordination and systemic changes. The results of this review have implications for future research and practice and should be considered when reflecting on opportunities to enhance research and service provision with individuals with autism. |
| Martinez-Torres *et al.* (2021) | Using the Ecological Validity Model to adapt parent-involved interventions for children with Autism Spectrum Disorder in the Latinx community: A conceptual review | Incorporating cultural components into parent-involved interventions will best support intervention implementation and dissemination in diverse communities. Research is needed into the process and outcomes of intervention programs in order to increase understanding of how specific cultural dimensions impact participation in and efficacy of parent-involved interventions for Latinx families of children with ASD. |
| Goh *et al.* (2021) | A qualitative study exploring experiences and support needs of parents of children with autism spectrum disorder in Singapore | Common themes were analysed using constant comparative method to generate results. Four themes emerged after 13 interviews: (1) adjusting psychologically, (2) changing lifestyle, (3) contending with hurdles to services and (4) needing informational, tangible and emotional support. |
| Acar, Chen and Xie (2021) | Parental involvement in developmental disabilities across three cultures: A systematic review | Each cultural group may have its own landscape that influences parent expectations and interpretations of child's behaviors, which in turn may affect parent reporting of developmental concerns during the EI/ECSE process. In this systematic review, we have drawn primarily on the empirical literature on parental involvement in EI/ECSE within the context of diverse cultures. We aim to provide more insight into parental involvement in |

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| | | EI/ECSE within the context of selected cultural contexts. Our review found sufficient evidence to suggest that some specific cultural elements are associated with parental roles in EI/ECSE. However, due to the relatively small number of studies in this area, these findings should be interpreted with caution. A majority of articles reported maternal involvement in EI/ECSE, and only a few studies included parents as intervention agents. Thus, our review highlights the need for future research to investigate effects of culture on parental involvement and develop culturally responsive methodical approaches to underpin meaningful parental involvement in EI/ECSE |
| Gautam (2020) | Autism Spectrum Disorder The Parental Experience | Primary care providers along with the U.S. physician workforce for patients with ASD are strongly encouraged to review their practices on early screening and diagnosis and have clearly planned out care for every child with a family centered approach. |
| Simpson, Schneider and Zlomke (2021) | Beyond Autism Severity: the Role of Medical Providers in Parenting/Caregiver Aggravation | Increases in ASD severity was associated with more child mental health concerns which, in turn, was associated with lower perceptions of family-centered care. This decrease in perceptions of family-centered care was associated with more caregiver frustration about getting access to services which, in turn, was associated with higher levels ofparenting aggravation with the child. Results provide future directions for additional research which could provide aid and support for providers and families of children with ASD. |
| Smith (2018) | Concept Analysis of Family-Centered Care of Hospitalized Pediatric Patients | Family-centered care of the pediatric patient in the hospital environment remains an abstract concept. It is recommended as a cornerstone of modern nursing practice, yet nurses report they lack sufficient education regarding its operationalization into practice. Elucidation of characteristics coupled with education regarding principles of the concept has the potential to augment further integration of family-centered care in the hospital environment. |
| Shimizu and Mori (2018) | Maternal perceptions of family-centred support and their associations with the mother–nurse relationship in the neonatal intensive care unit | Path analysis revealed that the relationship between mothers and nurses was linked to three factors related to the perinatal centres' support: consideration of parents' feelings, ability to deal with specific needs and coordination in dealing with situations that interact with provision of parent-friendly visual information. Separate path analyses for each perinatal centre showed the same pattern, although the standard coefficients were different. |
| Clarkson *et al.* (2019) | Cross-sectional survey of factors associated with | Fathers who had attended the delivery were more likely to bathe their infants than those |

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| | paternal involvement in the neonatal intensive care unit | who had not attended the delivery and fathers who performed kangaroo care felt more confident than those who did not. Compared to fathers who visited less often, fathers who visited more often were younger, had infants with a shorter hospitalisation time and lower acuity, and had fewer children in the family. |

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## Annexure 16: Editing certificate

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Re: **Neil Arnold Williams**
DUT PhD: **An Interpretative Phenomenological Analysis of Family Involvement in the Hospital Nursing Care of Children with Autism Spectrum Disorder within eThekwini District**

I confirm that I edited this thesis and the references for clarity, language and layout. I returned the document to the author with track changes so correct implementation of the changes and clarifications requested in the text and references is the responsibility of the author. The intellectual content of the document is the responsibility of the author. I am a freelance editor specialising in proofreading and editing academic documents. My original tertiary degree which I obtained at the University of Cape Town was a B.A. with English as a major and I went on to complete an H.D.E. (P.G.) Sec. with English as my teaching subject. I was a part-time lecturer in the Department of Homoeopathy at the Durban University of Technology for 13 years and supervised many master's degree dissertations during that period.

Dr Richard Steele
**11 August 2023**
*per email*

## Annexure 17: Interview from a nurse participant

**Transcript Notes for Nurse Participants 10**
**Date:** 21January 2022 **Time:** 16:10
**Institution:** Private Hospital -Paediatric ward **Participant Code:** Nurse Participant 10
**Private or Public institution:** Private Institute
**Demographic Information**
**Age**: 42 **Gender**: Female **Marital Status:** Married
**How many children do you have?:** 04 **Level of Education:** B Nursing Degree and B cur nursing sciences [Admin /Education]
**Years of Service: 16 years**
**Interview:**

1. **Tell me everything you know about Autism spectrum disorder.**

Communication is a challenge, especially the struggling to hear and talk, struggling with emotions, societal acceptance.
I have no training at all on Autism

2. **Have you nursed a child with autism Spectrum disorder, if yes describe that experience?**

Yes I nurses 2 children with ASD, I remember one was a 7 year old, was admitted for 3 days of antibiotics. The one child was fine, he was very forceful, his young Aunt was staying in hospital with him and he would tell her " you are not my mother". The other child had and orthopaedic procedure, it was the correction of some deformity done in theatre. He was mostly in bed and his mother was in hospital with him.

3. **What is the most important thing when nursing a child with Autism or any child?**

I would saty the safety of the child and safety of other children in the ward. I also think its important for the mother or parents to be counselled about child condition. The one childs who's mother stayed with him, she needed a counselling in my opinion, because all the other mothers would make comments about her and her child and seems to affect her badly.
0:0:0.0 --> 0:0:0.340 Neil A. Williams Like
0:0:0.280 --> 0:0:7.880 Nurse participant 10 And to understand and accept the condition of a child no matter what is said child to be different from the other children.
0:0:8.590 --> 0:0:9.30 Neil A. Williams yeah.
0:0:9.250 --> 0:0:10.180 Nurse participant 10 Yeah, yeah.
0:0:11.140 --> 0:0:11.560 Nurse participant 10 Yeah.
0:0:10.270 --> 0:0:14.980 Neil A. Williams So I I just realized I forgot to start the decoding, so I started it now.
0:0:15.200 --> 0:0:16.790 Nurse participant 10 I said oh OK.
0:0:16.310 --> 0:0:19.170 Neil A. Williams Yeah, and I've been writing all the time, so I've I've got.
0:0:18.800 --> 0:0:19.410 Nurse participant 10 Yeah, OK.
0:0:20.20 --> 0:0:20.520 Nurse participant 10 Alright.
0:0:20.190 --> 0:0:32.570 Neil A. Williams Then the next one says, what's the what is the role of the family when nursing the child in hospital. So what what do you expect the parents to do? What is their role in your opinion?
0:0:33.280 --> 0:0:34.110 Nurse participant 10 Sorry, let me just.
0:0:40.480 --> 0:0:40.840 Neil A. Williams Yep.
0:0:36.180 --> 0:0:41.410 Nurse participant 10 Um the family as an immediate family or I? I think it's just the support.
0:0:41.500 --> 0:1:7.380 Neil A. Williams Yeah, no, no. Whoever is with the child. So if the mother is staying with the child or even in this case the ante as well. So what role would you like them to play in hospital like? Do you expect them to come assist with nursing things like giving the medication

and that kind of thing? Or do you expect them to just do the other stuff? You know like changing the nappies or feeding the child away? So what? What do you think their role in hospital is when the child is admitted?
0:1:32.620 --> 0:1:32.890 Neil A. Williams Yeah.
0:1:37.340 --> 0:1:37.630 Neil A. Williams Yeah.
0:1:8.100 --> 0:1:38.10 Nurse participant 10 I, I think the the role of of the relative would be to support the child in a sense that these are all these changes. The nurses are all the strangers, so now that that is out of their normal environment, you know, I I, I think they need to support their child in a sense that they give the medication just to make sure that this child takes the medication. Remember that communication might be a bit of an issue with the child, but it.
0:1:45.770 --> 0:1:46.70 Neil A. Williams Yep.
0:1:38.170 --> 0:1:52.760 Nurse participant 10 Yeah, I don't know if there's quite a answering the question correctly, because with any other child it's it's better with her mother to give the medication you know, because it's a child, but I I feel that whatever is the normal.
0:1:53.360 --> 0:1:54.740 Nurse participant 10 Routine for a child.
0:1:55.390 --> 0:2:5.370 Nurse participant 10 It's a different environment. If the mother is there, then it's better for a child. Then the chart fills up. It appeared comfortable. If the mother does yet.
0:2:3.310 --> 0:2:6.240 Neil A. Williams Yeah, so mostly like emotional support.
0:2:6.640 --> 0:2:16.890 Nurse participant 10 Years emotional support and if the mother works with the nurses in terms of convincing the child that he has to take this medication.
0:2:17.340 --> 0:2:27.360 Nurse participant 10 Um, yeah and yeah for for better because the mother would know how better to communicate with this with with the child for effective communication and outcomes.
0:2:27.970 --> 0:2:34.870 Nurse participant 10 Um, yeah, the mother should be the for child support and communication.
0:2:35.600 --> 0:2:36.370 Neil A. Williams It's yeah.
0:2:36.310 --> 0:2:37.490 Nurse participant 10 Like easy, yeah.
0:2:38.340 --> 0:2:39.450 Neil A. Williams And then, um.
0:2:40.880 --> 0:2:49.850 Neil A. Williams Just, uh, just like another question after that. So if you have two identical had to put up an Ivy for these children, or give I and IMI or something.
0:2:50.850 --> 0:2:51.190 Neil A. Williams If.
0:2:50.780 --> 0:3:15.800 Nurse participant 10 Yeah, but we used IV mostly even though will not be very specific with him, but whenever the child was admitted in hospital we used to give Ivy antibiotics and whenever they didn't need there would be discharged unless the child had, you know, very difficult tripping. Then we would be on it but it was just one case in 5-6 months.
0:3:17.170 --> 0:3:17.590 Nurse participant 10 Awesome.
0:3:16.460 --> 0:3:20.120 Neil A. Williams OK, and then putting up the Ivy like with this aggressive child now.
0:3:20.560 --> 0:3:21.40 Nurse participant 10 Yes.
0:3:21.200 --> 0:3:22.740 Neil A. Williams How would you manage that?
0:3:23.700 --> 0:3:37.570 Nurse participant 10 Uh, we were very. I don't know if it was acceptable or legal or illegal, but we had our own way of doing the trips for the children who would wrap them in sheet.
0:3:38.890 --> 0:3:53.260 Nurse participant 10 Um, we had the health care worker who would help with holding the child. We would come as their mothers to wait outside, but obviously some wanted to be in D and then would give them the.
0:4:2.780 --> 0:4:3.50 Neil A. Williams Yeah.
0:4:9.480 --> 0:4:9.870 Neil A. Williams Yeah.
0:3:54.130 --> 0:4:19.870 Nurse participant 10 Prepare them and make them decide if they really wanted to be. There are main aim was to make sure that the child is still. We know it is traumatic for a child, but we didn't want to traumatise attacked more by poking and poking and poking because

the child is reading and and things we tried, we wrap the child in a sheet and we helped the so there was very good with holding so we were doing it that way.
0:4:20.550 --> 0:4:21.190 Neil A. Williams Yeah, OK.
0:4:33.510 --> 0:4:33.860 Neil A. Williams With it
0:4:20.890 --> 0:4:38.660 Nurse participant 10 So we never had much of problems and the nurses we had were very experienced. We had three nurses who had been phlebotomists, so we never had much of issues with trips such at all our pediatricians. They would only come for special cases. You know where we really could not.
0:4:39.860 --> 0:4:44.830 Neil A. Williams and then do you remember putting up ID for these children specifically these two?
0:4:46.460 --> 0:5:1.320 Nurse participant 10 Uh, uh, I cannot be very specific in remembering this, but in our end would be the only person to do this. Probably I did history they treats as well because if you are in the trips were yours.
0:5:2.230 --> 0:5:7.740 Neil A. Williams Yeah, and then the month is when they they assist you with holding the child and that candidate.
0:5:9.30 --> 0:5:9.370 Neil A. Williams Thanks.
0:5:10.450 --> 0:5:11.560 Nurse participant 10 Most of them didn't.
0:5:12.740 --> 0:5:30.140 Nurse participant 10 No, this ain't because that's the person I remember very well because she was with us couple of times and she never used to come in. She was a very uh person who wanted. He was a person who wanted to sit there on the sofa and then talk to him. That's when he gave he told he told.
0:5:32.270 --> 0:5:32.800 Neil A. Williams Yeah, OK.
0:5:31.110 --> 0:5:34.230 Nurse participant 10 Hold it right, yeah, but uhm.
0:5:41.900 --> 0:5:42.410 Neil A. Williams OK.
0:5:35.610 --> 0:5:44.160 Nurse participant 10 Yeah they yeah. The country member. Exactly what happened when we did his trip. But yeah, like I said it out and would do the trick.
0:5:44.990 --> 0:5:45.430 Neil A. Williams Then
0:5:45.90 --> 0:5:45.510 Nurse participant 10 Is it?
0:5:46.680 --> 0:5:47.930 Neil A. Williams then the next question.
0:6:6.740 --> 0:6:7.210 Nurse participant 10 Yes.
0:5:48.720 --> 0:6:18.490 Neil A. Williams And it says it well, what this question is based on, right? Is that when you when you look at the literature, when treat children and all that, and especially special needs children, it says that parents are vital. You know you, you can't nurse this child without the assistance and the help of the parents. And it depends. Must always be there and you must always involve them in whatever you're doing. This like you said, you know giving the medication you rather give it to them 'cause the child knows them and is comfortable.
0:6:19.80 --> 0:6:25.580 Neil A. Williams But but the literature also says, like there's no studies done in South Africa, mines will be one of the like the first studies, yeah?
0:6:25.0 --> 0:6:25.710 Nurse participant 10 The post that.
0:6:32.560 --> 0:6:32.960 Nurse participant 10 Yes.
0:6:26.280 --> 0:6:48.0 Neil A. Williams Like overseas when they've done, they said, you know, I've nurses know this you know they that they should involve the parents but for some reason they not involving the parents. So so that's why this next question is yeah it it says what do you believe prevents nurses from involving family in the nursing care of the child?
0:6:49.20 --> 0:6:55.830 Nurse participant 10 Um, from my experience with pediatric ward.
0:6:56.510 --> 0:6:56.840 Neil A. Williams Yeah.
0:6:57.170 --> 0:7:0.890 Nurse participant 10 Apparent will have something to ask you.
0:7:1.710 --> 0:7:6.490 Nurse participant 10 99% that you will get questions from the parents.
0:7:7.20 --> 0:7:7.320 Neil A. Williams Yeah.
0:7:7.420 --> 0:7:17.390 Nurse participant 10 So now you are in the world you it's busy and you really have got no time to stand for 2-3 minutes and answer the questions from the mother.

0:7:18.80 --> 0:7:18.530 Neil A. Williams OK.
0:7:24.0 --> 0:7:24.380 Neil A. Williams Yeah.
0:7:18.830 --> 0:7:37.360 Nurse participant 10 Number two is nurses, it's it's just my personal belief. Nurses do not have enough knowledge, so they actually don't want to up to two to receive any question from any parent, because this question might be kind of a challenge from, you know.
0:7:37.790 --> 0:7:38.240 Neil A. Williams Yeah.
0:7:37.960 --> 0:7:39.610 Nurse participant 10 For them from their mother.
0:7:41.460 --> 0:7:55.230 Nurse participant 10 And also a child you need to be a bit patient and take some time when you give medications like you can't say yeah and then you move on to the next patient. Discharged might be you know giving you some.
0:7:57.780 --> 0:8:4.410 Nurse participant 10 You need to be patient and take the necessary time that you would need for that specific case.
0:8:5.340 --> 0:8:15.810 Nurse participant 10 As an S you want to finish the whole of this room, you know, and you really don't have time and extra minutes to try and you know.
0:8:17.910 --> 0:8:23.960 Nurse participant 10 Ask convinced the child to give medication so if the mother is the sometimes.
0:8:25.290 --> 0:8:34.130 Nurse participant 10 The mothers are also not very cooperative, and now you want to be with us, right? Because you're a stranger to him. He is going to do what you want him to do.
0:8:34.740 --> 0:8:35.130 Neil A. Williams Yeah.
0:8:35.330 --> 0:9:6.190 Nurse participant 10 If these are mother, the child would keep on, you know, playing with you and things because their mother is there. And if the mother is not very assertive with the child, then it becomes very difficult, which is sometimes we would take the child into the treatment room whenever the mother would say that. I don't know what else to do, but the child doesn't want to take meeting, then we'll take the child and Dr the child and give the medication they and they turned it too. I think there were scared of the nurses kind of thing.
0:9:6.320 --> 0:9:9.70 Nurse participant 10 Wasn't just drink the medication in the treatment room and then you let him go.
0:9:9.920 --> 0:9:10.390 Neil A. Williams Of.
0:9:10.80 --> 0:9:12.240 Nurse participant 10 But in front of their mother, it would be difficult.
0:9:12.940 --> 0:9:13.250 Neil A. Williams Oh
0:9:13.530 --> 0:9:23.620 Nurse participant 10 Sometimes, but not all the cases, some parents are very assertively children and then they would actually help us. So the case is different, some parents.
0:9:24.480 --> 0:9:29.490 Nurse participant 10 Uh, they and they help, but most of the cases, yeah, they they.
0:9:30.430 --> 0:9:31.290 Nurse participant 10 Story is it.
0:9:32.300 --> 0:9:44.90 Neil A. Williams OK, then the next question, which is like this question it says, what's the best way in your opinion, what's the best way to involve family in the care of their child in hospital?
0:9:46.220 --> 0:9:48.470 Nurse participant 10 You don't need to explain to the parents.
0:9:48.990 --> 0:9:49.380 Neil A. Williams Yeah.
0:9:57.620 --> 0:9:58.30 Neil A. Williams Yeah.
0:9:58.310 --> 0:10:26.60 Nurse participant 10 They need some counselling kind of communications, some kind of you know. So just to let them know that this is the situation accepted and it is not the worst situation because sometimes the parents they themselves do not get to be cancelled and you know they don't get any support themselves. So if they're not supported how are we expecting them to be able to?
0:10:26.590 --> 0:10:28.500 Nurse participant 10 Uhm, support the child.
0:10:29.450 --> 0:10:41.420 Nurse participant 10 So I I I think it's mostly the communication. Even if the doctor is nursing the child the way that Dr communicates with the mother in terms of giving feedback in the prognosis of the child.

0:10:42.780 --> 0:10:50.70 Nurse participant 10 I I, I think it has to be more sensitive and more comforting and more sympathetic.
0:10:51.20 --> 0:10:54.40 Nurse participant 10 And being factual but sympathetic.
0:10:54.970 --> 0:10:57.560 Nurse participant 10 Just so that the mother can feel supported herself.
0:10:58.380 --> 0:10:58.790 Neil A. Williams Yeah.
0:10:59.150 --> 0:11:10.30 Nurse participant 10 Yeah, I think it's it's it's. It's a better communication skills among all the members that are involved, including their mother, their child, there, the doctor, nurses and everybody else. And also.
0:11:11.310 --> 0:11:19.470 Nurse participant 10 This autism is not very common. Like I said it in my years of nursing experience impedes I I remember only two.
0:11:20.260 --> 0:11:20.550 Neil A. Williams Here.
0:11:20.970 --> 0:11:33.690 Nurse participant 10 So I I think it needs to get to a stage where this condition is included in some kind of training or in-service education, or or you know.
0:11:33.750 --> 0:11:36.710 Nurse participant 10 So in in whatever platform there is.
0:11:37.510 --> 0:11:41.270 Nurse participant 10 It needs to be taken as one of the things that need to be, um.
0:11:44.830 --> 0:11:45.260 Neil A. Williams Yeah.
0:11:50.810 --> 0:11:51.110 Neil A. Williams Yeah.
0:11:42.430 --> 0:12:3.840 Nurse participant 10 Discussed by the health care workers. Because if if if I'm honest, like I said that the autism only saw it for the first time in hospital, Can you imagine how badly I, I, I did you know I am in terms of my nursing because, you know, understanding the child, that's aggressive and you're like taking things from allergy and it's for me.
0:12:3.890 --> 0:12:8.0 Nurse participant 10 They having no time to entertain all these, you know?
0:12:8.220 --> 0:12:9.170 Neil A. Williams Yeah, yeah.
0:12:9.280 --> 0:12:16.780 Nurse participant 10 So yeah, I could have given the very bad nursing came to the child.
0:12:18.370 --> 0:12:19.820 Neil A. Williams And The thing is now.
0:12:23.510 --> 0:12:29.270 Neil A. Williams Nowadays when you hear autism is very very common 'cause all the nurses I've interviewed.
0:12:29.600 --> 0:12:30.90 Nurse participant 10 Yes.
0:12:29.960 --> 0:12:40.20 Neil A. Williams If, like the last one, I just spoke to a little while ago, she said she's nursed so many 'cause they had a pediatric neurologist at their hospital. So they.
0:12:39.220 --> 0:12:41.970 Nurse participant 10 Oh OK OK oh.
0:13:5.500 --> 0:13:5.900 Nurse participant 10 Yes.
0:12:40.770 --> 0:13:11.330 Neil A. Williams So they nurse so many she's she's so experience you can see from the way she talks that she buy now she's nursed like literally, like maybe hundreds of of children like that 'cause the numbers are increasing quite dramatically now then the last very, very, very last question is fun. The doctors, you know when you do a doctor, you have to produce something. So my aim is to produce a framework on nursing, a child with autism in hospital.
0:13:12.410 --> 0:13:12.800 Nurse participant 10 Uh-huh
0:13:11.770 --> 0:13:21.110 Neil A. Williams So in your case it will be for nurses, uh, to guide them on nursing this chat. So in your opinion, what do you think should be included in the framework?
0:13:22.660 --> 0:13:23.410 Neil A. Williams Oh, the guideline.
0:13:27.0 --> 0:13:27.800 Neil A. Williams It's getting cold.
0:13:27.530 --> 0:13:32.160 Nurse participant 10 you mean in terms of who should we ask the chat or the structure?
0:13:29.660 --> 0:13:32.210 Neil A. Williams You think there's that as well, yeah?
0:13:33.320 --> 0:13:33.820 Nurse participant 10 Sorry.
0:13:33.150 --> 0:13:42.510 Neil A. Williams Yeah, like think of this nurse that has never nursing autistic child before and we give her this guideline to say this is what you should do or what you should know.

0:13:42.170 --> 0:13:42.540 Nurse participant 10 Uh.
0:13:45.970 --> 0:13:46.320 Nurse participant 10 Oh
0:13:43.630 --> 0:13:46.360 Neil A. Williams In order to nurse this child effective.
0:13:47.50 --> 0:13:48.660 Neil A. Williams Yeah, So what would be in it?
0:13:49.750 --> 0:14:17.640 Nurse participant 10 I think that the common signs and symptoms we need to to would be included because, you know, we are clinical. Sometimes we just observe and you know, have some idea about the patient or suspect something about the patient because you would. You would admit the patient and once you see those signs then you think to yourself it could it not be, you know.
0:14:17.790 --> 0:14:18.190 Neil A. Williams Yeah.
0:14:18.40 --> 0:14:23.170 Nurse participant 10 I think the nurses need to be, um, there. With that CUTLINE would include.
0:14:23.860 --> 0:14:38.350 Nurse participant 10 The measure of how do you? How can you quickly identify the child with autism? Number two, we need to look at, you know, the the specific nursing care for.
0:14:38.750 --> 0:14:42.330 Nurse participant 10 Um the child with autism, which would include.
0:14:43.300 --> 0:14:49.280 Nurse participant 10 A communication how we would communicate better with the tag and then.
0:14:49.920 --> 0:14:51.910 Nurse participant 10 Yeah, obviously the.
0:14:52.830 --> 0:14:56.30 Nurse participant 10 The the skill to obtain data.
0:14:56.700 --> 0:15:4.60 Nurse participant 10 Will also thabile need need will also need to be polished with an essence because if the nest can be able to take.
0:15:5.270 --> 0:15:14.170 Nurse participant 10 A proper data from the parent. Then you would understand the tiles habits better and you know, but the the the.
0:15:19.440 --> 0:15:19.810 Neil A. Williams Here.
0:15:15.660 --> 0:15:40.310 Nurse participant 10 Easy way to communicate with the child because children will not be the same but the parents know better about this chart. So the parent will know will tell you how to give this medication the medication to this child easily easily. So if you take enough data from the parent then you would you. You could be successful with nursing this child effectively.
0:15:41.580 --> 0:15:44.30 Neil A. Williams Uh, I'm guiding also asking.
0:15:50.120 --> 0:15:50.460 Nurse participant 10 It's.
0:15:52.280 --> 0:15:52.960 Nurse participant 10 Yes, yes.
0:15:58.710 --> 0:15:59.170 Nurse participant 10 Yes.
0:16:1.930 --> 0:16:2.290 Nurse participant 10 Yes.
0:16:5.760 --> 0:16:6.280 Nurse participant 10 Yes.
0:15:45.450 --> 0:16:7.790 Neil A. Williams How to involve the family you know to what can you do to involve the family? Anything you wanna add in for their 'cause you said it now you said communication with the family is important and then you said history. Taking a detailed history or taking specially the likes and dislikes of the child and what else would you say?
0:16:9.180 --> 0:16:24.980 Nurse participant 10 And also the the doctors because the ministration will send a child to the world like well. Yeah I won't send them either with the Porter or something. I think the the pediatrician without discriminating the case, but they also need to make the lenses away.
0:16:25.740 --> 0:16:26.10 Neil A. Williams So.
0:16:32.620 --> 0:16:32.860 Neil A. Williams Yeah.
0:16:25.680 --> 0:16:36.310 Nurse participant 10 Off the patient that's coming just like you would a phone for the patient with some kind of infection that you know some infectious communicable disease.
0:16:43.360 --> 0:16:43.700 Neil A. Williams Yeah.

0:16:36.800 --> 0:16:47.210 Nurse participant 10 Um, I I feel that with autism as well. It also has to notify the RN so that they can be prepared. Because if you don't know you tricked the gin.
0:16:48.880 --> 0:16:50.370 Nurse participant 10 Normally the same way.
0:16:50.780 --> 0:16:51.90 Neil A. Williams You
0:16:51.70 --> 0:16:52.580 Nurse participant 10 And then you know.
0:16:53.530 --> 0:16:53.850 Neil A. Williams yeah.
0:16:54.50 --> 0:16:58.850 Nurse participant 10 That that's when you find you get yourself to. Do you know?
0:17:1.860 --> 0:17:2.160 Neil A. Williams Yeah.
0:17:27.40 --> 0:17:27.480 Neil A. Williams Yeah.
0:16:59.950 --> 0:17:29.890 Nurse participant 10 Something wrong I think we need to. The doctor would need to phone and notified analysis that patient is coming with such special needs so that the message can be prepared even in terms of setting up the room and organizing the room for a child. Because this child does not for me does not need to be among the rest of the 20 children in this world can imagine because this child is going to corner Co.
0:17:39.710 --> 0:17:40.40 Neil A. Williams Yeah.
0:17:47.540 --> 0:17:47.770 Neil A. Williams Like
0:17:29.960 --> 0:17:48.300 Nurse participant 10 Run around, the others are running around, uh, but now you you know that you will be frustrating him. Maybe at home is not even used to having so many children and you can't even express themselves. Now to say something. Now he is going to become aggressive because the environment is not comfortable for him.
0:17:49.860 --> 0:17:52.690 Neil A. Williams OK, yeah. So the environment is important as well.
0:17:52.620 --> 0:17:56.430 Nurse participant 10 Yeah, so I think that also can also prepare.
0:17:57.210 --> 0:17:58.410 Nurse participant 10 They are in is well.
0:18:2.900 --> 0:18:3.680 Nurse participant 10 Yes.
0:17:59.350 --> 0:18:4.880 Neil A. Williams The preparation is well is important preparation of the environment and the and the nursing staff.
0:18:5.280 --> 0:18:5.970 Nurse participant 10 Yes.
0:18:7.530 --> 0:18:8.20 Neil A. Williams OK.
0:18:12.710 --> 0:18:13.50 Nurse participant 10 X.
0:18:10.60 --> 0:18:13.570 Neil A. Williams Alright, yeah, that's all. Thank you very much.
0:18:16.980 --> 0:18:17.490 Neil A. Williams At the end.
0:18:14.460 --> 0:18:31.950 Nurse participant 10 OK, makes sense. Thank you so much. Yeah, we we never had so many, you know because at the Bay, uh, we are so like far away in the pool in the bundle we used to transfer most of the case. I mean most of the neural cases. But we we we we nest these two. I remember these two.
0:18:32.760 --> 0:18:33.900 Neil A. Williams Yeah, nasty.
0:18:32.980 --> 0:18:40.290 Nurse participant 10 Especially the one who's mind here aren't all the time. You're not my mother and the way he was talking. You're not my mother, but anyway.
0:18:39.680 --> 0:18:41.120 Neil A. Williams Yeah, 'cause they have.
0:18:41.230 --> 0:18:48.100 Neil A. Williams That was what one is. The thing is indication is hard and also, um, they don't have. What do they call it?
0:18:58.250 --> 0:18:58.920 Nurse participant 10 Yeah.
0:18:48.820 --> 0:19:11.700 Neil A. Williams Uh, like they don't have a perception of tone of voice and body language and all. They can't read that and they can't interpret it either. You know, it's part of patient, normally like a normal neurotypical child. They they know when I raised my voice, it means them angry, like with a stick child. They say they don't have those. Those queues, you know those social cues.
0:19:12.570 --> 0:19:13.100 Neil A. Williams So they.
0:19:12.260 --> 0:19:13.370 Nurse participant 10 Yes.
0:19:25.490 --> 0:19:25.870 Nurse participant 10 Yes.

0:19:26.490 --> 0:19:27.150 Nurse participant 10 Yes.
0:19:13.720 --> 0:19:28.560 Neil A. Williams So like in artistic, yeah could speak in fairly loud. You know in the environment not knowing he's loud because he doesn't have those social cues. They call it that other children, you know it's it comes with communication and thinking.
0:19:28.810 --> 0:19:30.530 Nurse participant 10 Yes, the other lady.
0:19:30.590 --> 0:19:31.710 Nurse participant 10 We eat, but he's.
0:19:44.840 --> 0:19:45.180 Neil A. Williams Yeah.
0:19:33.90 --> 0:20:3.80 Nurse participant 10 In his 20s when I chatted with him at some stage, he would tell I I wasn't aware that it was autism at that time. Like I said that I was not aware of their condition by then, but she told me that my my child is my son is autistic, so she said I don't get. I don't allow any visitors into my house because he does not sleep. If there is someone he won't sleep even in his grandmother he won't sleep because now he is not.
0:20:3.120 --> 0:20:9.350 Nurse participant 10 He doesn't know this person, so he would not let anyone in his own house.
0:20:10.70 --> 0:20:10.790 Neil A. Williams Yeah it.
0:20:20.240 --> 0:20:20.690 Neil A. Williams Yeah, and.
0:20:9.970 --> 0:20:23.400 Nurse participant 10 So he would be oppressive for the whole night 'cause she said. So she never come. She was never welcome while coming to the visitors because of his son. He's she's, she said, at some stage he even broke the window.
0:20:24.190 --> 0:20:24.450 Neil A. Williams Yeah.
0:20:23.980 --> 0:20:26.930 Nurse participant 10 Uh, because he was fighting, trying to express himself.
0:20:28.310 --> 0:20:28.650 Nurse participant 10 So.
0:20:27.470 --> 0:20:35.170 Neil A. Williams Yeah, did you get me frustrated? And but then I always think even with my son 'cause he's nonverbal is completely non.
0:20:34.860 --> 0:20:37.390 Nurse participant 10 Oh yes, I remember you told me yes yeah.
0:20:43.650 --> 0:20:44.380 Nurse participant 10 Me.
0:21:2.680 --> 0:21:3.210 Nurse participant 10 Me.
0:20:36.820 --> 0:21:7.300 Neil A. Williams Yeah, so he also gets very frustrated. He gets very frustrated. Any any hits himself and sometimes he hits US and things but but the we and like in the moment you you sometimes get angry but you have to realize like he can't say anything so stems like he'll be showing me something that he wants you pointing and I'm not giving him the right thing. And then it be pointing and it'll be asking until he gets so frustrated 'cause I can't figure out what he wants and he knows what he wants but he can't.
0:21:7.760 --> 0:21:10.310 Nurse participant 10 He can tell you so now.
0:21:8.130 --> 0:21:15.740 Neil A. Williams
See you so he gets frustrated and that's and I understand that's that frustration that makes them aggressive like that.
0:21:27.90 --> 0:21:28.420 Neil A. Williams Yeah, yeah.
0:21:33.750 --> 0:21:34.50 Neil A. Williams Yeah.
0:21:15.890 --> 0:21:45.760 Nurse participant 10 So in that case you understand the fact that the mother herself needs to be given this information as to for her to understand the child's behavior herself. She needs to understand that because you would be patient with him, because now you've got better understanding and also you know for their mother. Now let's say the other mother in the room, the next mother in the room. She sees this child hitting you. Yes, he understands that the chat can't talk, but if she's got less information.
0:21:46.160 --> 0:21:46.490 Neil A. Williams Yeah.
0:21:52.330 --> 0:21:52.860 Neil A. Williams Yeah.
0:21:46.20 --> 0:22:1.790 Nurse participant 10 She won't think to herself that it's because they're spoiling in. Yes, he can't talk, but he should know if they you know he. Yeah they should be. He

should be. They should be able to control him. He can't be hitting them. You know they would think negatively, so yeah.
0:22:4.930 --> 0:22:5.620 Nurse participant 10 Yeah.
0:22:0.510 --> 0:22:11.110 Neil A. Williams Yeah, people don't understand is there's a lack of understanding, but I like what my son because he's he can't speak but he he makes sounds he makes like.
0:22:12.340 --> 0:22:13.330 Nurse participant 10 Yes, yes.
0:22:16.710 --> 0:22:17.90 Nurse participant 10 Yes.
0:22:11.330 --> 0:22:19.270 Neil A. Williams Ah, he's and he likes music and loves music and singing. It's like he's saying like he him like he hums.
0:22:19.660 --> 0:22:20.120 Nurse participant 10 Yes.
0:22:22.700 --> 0:22:23.80 Nurse participant 10 Uh.
0:22:27.220 --> 0:22:27.640 Nurse participant 10 Yes.
0:22:31.10 --> 0:22:31.940 Nurse participant 10 Me.
0:22:38.900 --> 0:22:39.410 Nurse participant 10 Yeah.
0:22:47.440 --> 0:22:48.170 Nurse participant 10 Absolutely.
0:22:20.180 --> 0:22:50.0 Neil A. Williams So when people hear that they kind of understand, OK, he's not. He's not a normal child, so they they don't really get, you know, upset with us, even loud noise and all that. But even if they get upset, I can't be bothered. I just tell them off if I need too, and I. But then my wife is very good, like I get very upset and if you tell me something I can get really, you know upset too quickly. But my child I can get.
0:22:49.570 --> 0:22:50.130 Nurse participant 10 Yeah.
0:22:57.110 --> 0:22:57.660 Nurse participant 10 Me.
0:22:59.570 --> 0:22:59.990 Nurse participant 10 It's.
0:23:3.390 --> 0:23:3.840 Nurse participant 10 You know?
0:23:8.210 --> 0:23:8.840 Nurse participant 10 Me.
0:22:50.680 --> 0:23:12.670 Neil A. Williams But my wife, she handles it very well. She talks to them nicely and she says you know what? He's a special needs child. He can't. It's like even now with the masks he doesn't understand he must wear mask so when you go past the security, the first thing they say is ways his mask or they talked to him and they'll say it's your mask. Then you have to stop them to say you know what?
0:23:13.890 --> 0:23:14.400 Nurse participant 10 Miller
0:23:13.480 --> 0:23:16.830 Neil A. Williams He's especially doesn't understand. You know you can't.
0:23:23.330 --> 0:23:23.880 Nurse participant 10 yeah.
0:23:24.530 --> 0:23:24.970 Nurse participant 10 Yes.
0:23:27.10 --> 0:23:27.510 Nurse participant 10 Yes.
0:23:17.860 --> 0:23:43.870 Neil A. Williams But then I see like we regulars, at some places, like by now they know him. You know, they know my son, so the security is don't even bother, they just and sometimes like the other day, I was surprised at Suncoast we went in and there was security guards ladies there and the one was about to say where's the mask? And then the other one stopped and I could hear in Zulu saying no, he's not, he's not right.
0:23:43.450 --> 0:23:46.420 Nurse participant 10 He's not, Oh yes, yes, yeah.
0:23:45.270 --> 0:23:53.940 Neil A. Williams Miss you all the time and then they just let us go so they I think it's people are getting to understand a little bit.
0:23:55.250 --> 0:23:55.730 Neil A. Williams Yeah.
0:23:53.540 --> 0:23:57.420 Nurse participant 10 Understand me.
0:23:56.610 --> 0:23:57.430 Neil A. Williams And the more you.
0:23:57.990 --> 0:24:3.210 Neil A. Williams They like him, he goes places 'cause he likes to go out so we take him to.
0:24:4.90 --> 0:24:11.330 Neil A. Williams And in people, eventually they kind of understand you know what is different and this is who he is and they OK with that I think.

0:24:29.310 --> 0:24:29.710 Neil A. Williams Yeah.
0:24:10.960 --> 0:24:35.130 Nurse participant 10 That's what we need in in in the wards. In the wards. That's what we need for for their mother now or their parents, her or himself to understand and accept the condition so that he or she can be able to tell the other parents you know, like your wife is telling them that she's specialty is special needs child. So if she is.
0:24:36.960 --> 0:24:56.330 Nurse participant 10 Once it ends in herself, you know to communicate, interact with the other mother. The next mothers. Then it will be better for her and for a child, and then SN K will continue when. But if the mother hasn't yet accepted it it you can you understand it? It would be so difficult.
0:24:56.520 --> 0:24:58.170 Nurse participant 10 Um, yeah.
0:24:56.950 --> 0:25:0.320 Neil A. Williams Yes, specially if it's new to them and it's the first time they lost.
0:24:59.680 --> 0:25:1.770 Nurse participant 10 Yeah, but yes.
0:25:7.220 --> 0:25:8.70 Nurse participant 10 Yes.
0:25:11.690 --> 0:25:12.630 Nurse participant 10 Yes.
0:25:14.90 --> 0:25:14.570 Nurse participant 10 Yeah.
0:25:1.150 --> 0:25:15.830 Neil A. Williams Because as you as you grow as a parent, it gets easier. You know 'cause you understand and you tell people and all that. But when you first dealing with this and you're dealing with a sick child and he's and there's other people, it's a lot. It's a lot.
0:25:16.110 --> 0:25:27.350 Nurse participant 10 Yes yeah, because yeah, in the world it it is really difficult. I still strongly believe that the parent has to be day even during the time of Covid or covered or not covered, the parent has to be there.
0:25:27.590 --> 0:25:29.180 Neil A. Williams Yeah yeah, yeah.
0:25:27.400 --> 0:25:34.790 Nurse participant 10 Hey uh, yeah she has to be day ** *** or he has to be allowed in you know too.
0:25:35.940 --> 0:25:53.130 Nurse participant 10 Uh, allow the nursing care flow you know to to to to to flow because the nurses you find this one are ending award these two ends and some parents having their children walking around and being normal. Come inverted commas normal.
0:25:53.350 --> 0:25:53.680 Neil A. Williams Yeah.
0:25:53.890 --> 0:25:56.820 Nurse participant 10 But they are so much attention seeking.
0:25:57.480 --> 0:25:57.910 Neil A. Williams Yeah.
0:25:58.240 --> 0:26:8.520 Nurse participant 10 They would do anything to get the nurses attention, you know, so you you find it balancing the attention for all the parents, especially the special needs child.
0:26:9.130 --> 0:26:10.440 Nurse participant 10 It becomes a challenge.
0:26:10.970 --> 0:26:11.350 Neil A. Williams Yeah.
0:26:25.270 --> 0:26:26.70 Neil A. Williams Was there, yeah?
0:26:36.740 --> 0:26:37.210 Neil A. Williams Yeah.
0:26:11.70 --> 0:26:41.580 Nurse participant 10 So, but if if the mother is there for the child, then you put no problem. I really preferred I was very happy that at netcare they would allow the models to be in because I felt that it was very easy to nurse the child if the mother was saying it was really. Yeah, it was really easy. Some of them would be difficult, but you know you you learn. You know I've had plenty of land to deal with a difficult matter, but it was really easy because you I would make that good communication with the mother relationship with the mother fast.
0:26:41.910 --> 0:26:45.460 Nurse participant 10 And then dealing with the baby was so it was very easy after that.
0:26:46.600 --> 0:26:47.210 Nurse participant 10 Yeah.
0:26:45.410 --> 0:26:55.200 Neil A. Williams Much easier, yeah? And that's something to do. I don't know why in government sometimes they still don't allow parents you know to stay all the time so that.
0:26:56.550 --> 0:26:56.810 Neil A. Williams Yeah.

0:27:7.810 --> 0:27:8.110 Neil A. Williams To.
0:27:13.180 --> 0:27:13.660 Neil A. Williams Yeah.
0:26:54.790 --> 0:27:24.730 Nurse participant 10 Their mother would be there. She will tell you if there's something wrong. If she suspects something wrong, she would tell you, you know you go to chat if the parent is not the the chat can shokane do anything you not even there to see you. You are the one hour and you're busy with other children. The next thing you'll come here, and it's not. It's not pretty, so it's it's I. I really liked the the the environment at Netcare because we had parents with their children, but at ngwelezane the two years that I worked there, we never allowed.
0:27:24.790 --> 0:27:26.360 Nurse participant 10 Parents so.
0:27:26.200 --> 0:27:27.50 Neil A. Williams Is is it?
0:27:27.630 --> 0:27:29.320 Nurse participant 10 No, the at Ngwelezane hospital.
0:27:29.380 --> 0:27:31.900 Nurse participant 10 It's probably not allowed. Parents were not allowed in.
0:27:39.860 --> 0:27:40.270 Nurse participant 10 Uh-huh
0:27:33.80 --> 0:27:42.730 Neil A. Williams Because yeah, it. It's it's stranger because I know, um, one of the parents are interviewed. She was talking about King Edward, which is also a government task.
0:27:43.320 --> 0:27:44.480 Neil A. Williams But she said she stayed with it.
0:27:45.390 --> 0:27:48.430 Neil A. Williams She she was there with the child all the time.
0:27:48.550 --> 0:27:56.130 Nurse participant 10 Mr. Probably they allowed him. Maybe they at King Edward. They do allow that, but in ways that we never allowed them.
0:27:56.740 --> 0:27:57.220 Neil A. Williams Yeah which.
0:28:10.370 --> 0:28:10.660 Neil A. Williams Yeah.
0:28:14.380 --> 0:28:14.680 Neil A. Williams Yeah.
0:28:17.210 --> 0:28:17.800 Neil A. Williams It's too long.
0:28:21.100 --> 0:28:21.620 Neil A. Williams Changes.
0:27:56.740 --> 0:28:22.340 Nurse participant 10 So even with the nappy rash it was easy for children to get the nappy rash, you know, because we would have routine to change them in the morning before breakfast and then the next thing you would change the the children just before the visitors came. You know if the child has got that yeah and peeing you know 3-4 hours is a long period of time. But if the mother is dead then they charged poops and then she changes the nappy right there in there.
0:28:23.70 --> 0:28:23.510 Neil A. Williams Yeah.
0:28:29.0 --> 0:28:29.550 Neil A. Williams Yeah.
0:28:43.760 --> 0:28:44.870 Neil A. Williams It's yeah.
0:28:23.150 --> 0:28:45.240 Nurse participant 10 Yeah, I think the parents need to be N for the Child Support. You know it's trauma over for the child. You've got your parents the whole time. At home. You play with them. You tease me. Do this and let you run around all of a sudden you not feeling well and now you must not have your parent with you. I I think it's it's not. Yeah so it needs to be revised.
0:28:46.650 --> 0:28:46.920 Nurse participant 10 Yeah.
0:28:45.520 --> 0:28:49.140 Neil A. Williams But it's a strange places strange environment, strange people.
0:28:48.960 --> 0:28:52.660 Nurse participant 10 Yeah, yes, yes you retired.
0:28:50.80 --> 0:28:54.130 Neil A. Williams And feeling bad, yeah, I know it's not true.
0:28:53.710 --> 0:28:56.830 Nurse participant 10 Yeah, no turn on for you all of a sudden.
0:28:57.70 --> 0:28:57.790 Neil A. Williams Yeah.
0:29:2.250 --> 0:29:2.560 Nurse participant 10 The.
0:28:58.560 --> 0:29:2.980 Neil A. Williams And you must eat this specific end anyway. Thank you very much.
0:29:4.150 --> 0:29:4.500 Neil A. Williams Hey.

0:29:5.890 --> 0:29:7.690 Neil A. Williams Thank you, OK.
0:29:4.360 --> 0:29:10.330 Nurse participant 10 OK Neil, no problem. Thank you all the best. All right bye.

## Annexure 18: Interview from a parent participant

**TRANSCRIPT OF PARENT PARTICIPANT 3**
Date (12th November 2021) 30th November 2021
Time 11:00 am to 12:00am
Participant code: Parent 03
**AGE** 28 **Gender** female **Marital status** Married
**Age of child** 6 years old **Relationship to child** mother
**Interviewer**: thank you for participating in the research just want to explain that I'm doing my doctorate research at DUT and was part of my studies I'd like to interview you as explained on the treatment of your child in hospital, I will be recording this interview, is this OK with you?
**Parent participant 3**: Yes, it is.
**1) Interviewer: t**hank you very much OK tell me about your child that has autism?
**1) Parent participant 3:** my son is an 18 year old boy, his name is Luyanda, diagnosed with Autism, He attends action in Autism Vocational training school. He lives with me; his father is not involved in his care at all. I work for SARS as an auditor.
**2) Interviewer**: OK tell me about the time when your child was admitted:
**2) Parent participant 3**about two years ago my son had a very bad meltdown at home he became very upset and very aggressive, and he punched a window with his hand and he cut his hand and sustained injuries to his hand. Since I'm on medical aid I rushed him to a private hospital in Durban called City Hospital. At City Hospital no one wanted to help me because he was a bit aggressive, they said they couldn't do anything without his consent, and they refused to even help. They came up to the car and they saw his hand was bleeding and they said they couldn't help him in any way because he they needed his consent. I then took him to King Edward hospital and when the guards at the gate saw him, they immediately restrained him they held him. There were two or three guards that held him and they took him by force to the psychiatric ward. He was admitted in the psychiatric ward for two nights. When I tried to explain to the nurses what happened and what is wrong with him and about autism they would not listen. The nurses assessed him, and they diagnosed him with bipolar depression and admitted him. I don't think the nurses and security guards are clued up at all about autism. they mix up autism with mental health issues. they put my son with other patients with mental health psychiatric issues. he was 16 years old at the time and was treated like a psychiatric patient.
**3) Interviewer** what was the perceptions of the nursing care you received while he was admitted to the hospital?
**3) Parent participant 3:** if the nurses knew what autism was, they would be better they need to attend a basic autism course. They made the situation worse my son thought that they were fighting with him and so he fought back. some tried to treat him like a psychiatric patient they did treat his hand eventually. I feel the nursing care is better in private and public hospital than private

hospital. They changed his medication without consulting with psychiatrists they did not know what medication to use. They just sedated him and locked him in a dark room they also put him with other psychiatric patients that are drug users and have other psychiatric problems my son was only 16 years old.
4) **Interviewer:** explain how you were involved in your childcare in hospital and post discharge and once they collaboration with you in your child's care?
4) **Parent participant 3:** They sedated him and locked him in a psychiatric ward I was not allowed to look after him at all I was not allowed to visit him for two days I did not see him I could not speak to him at all. I can imagine how afraid he was to be in this locked in this dark room without anyone that he knows with people he doesn't know and without me his mother.
5) Interviewer: how did you expect the nurses to involve you in your child's care in hospital?
5) **Parent participant 3:** they should have asked me about him. They should have asked about his history. They should have let me talk to him. They should have let me care for him tell me what to do and ask his permission. They should have informed him in his treatment. He loves KFC he knows pictures Spiderman and food they could have got him to do what you they want by bribing him**.**
6) **Interviewer:** What do you think is preventing you from being more involved in your child's care in in hospital?
6) **Parent participant 3:** the nurses lack knowledge of autism they can't differentiate between autism and bipolar disorder. They are short staffed there are too many patients and two little staff so they lack time with Patients.
7) **Interviewer** what is the best way to involve you and your spouse in the hospital care of your child.?
7) **Parent participant 3:** They must involve the patient; they must speak to the child and try to make him. understand. What they want him to do. They can even bribe the child with something he likes. The must also involve the parents, they must communicate with the parents and ask the parents for history and what they child likes and involve the parents in caring for the child.
The nurses must be educated on Autism and have some sort of in-service training on Autism.
Nurses must listen and be more caring.
They must have a special room for Autistic Children and not mix them with other Psychiatric patients. They can not mix our autistic children with drug-users and other dangerous Psychiatric patients.
The Psychiatric ward need more staff because they are short staffed.
The nurses need more education on Autism.

**Annexure 19 Letter to experts**


24 June 2023

Dear Sir/Madam

**Request for expert opinion on framework**

My name is Mr. Neil Williams, I am completing my Doctor of Nursing Degree at the Durban University of Technology. As part of this degree, I have developed a framework for the improvement of family involvement in the hospital nursing care of a child with Autism Spectrum Disorder (ASD).

I have identified you as an expert on my research topic and I would like your opinion on the framework. Please can you evaluate my framework using the attached checklist. I am requesting your help to improve my framework. It is a one page framework and checklist and therefore will not take much time at all.

I have invited other experts to also comment on the framework, so I may change the framework and send back to you for your opinion again, if necessary.

If you require any further information, please do not hesitate to contact me on 0764809130 or Williams.neilarnold@gmail.com.

Thank you for your time and consideration in this matter.

Yours sincerely,

Neil Williams

**Annexure 20: Delphi expert review of framework form**

**Introduction**: Good day, I have identified you as an expert on my research topic and I would like your opinion on a framework I developed as part of my Doctorate. Please can you evaluate my attached framework against the points below and there is a space provided for additional comments. I really appreciate your time and assistance.

**Title of the study:** An Interpretative Phenomenological Analysis of family involvement in the hospital nursing care of children with Autism Spectrum Disorder (ASD) within eThekwini District

**Framework being evaluated: "**The Neil Williams framework for improvement of family involvement in the hospital nursing care of a child with ASD

**Area of expertise: (Please Place an X in the appropriate box)**

| | | | |
|---|---|---|---|
| Child Nursing Science specialist | Professional Nurse working with children with ASD | Parent of child with (ASD) | Professional working with children with ASD |

**Review round:(Please Place an X in the appropriate box)**

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

**Evaluation:**

| Information | Appropriate | Amendments required | Comments/ Suggestions |
|---|---|---|---|
| Name of the Framework | | | |
| Colours of the framework | | | |
| Structure of the framework | | | |
| Language clarity | | | |
| Relevance of content | | | |

Additional comments:
.....
.....
.....
.....

Experts code …… Signatures:
……
Date: ……