دراسة
للاستشارات والدراسات والترجمة

خدمات أكاديمية

كفاءات وطنية

معايير عالمية

drasah1
www.drasah.com

00966555026526
00966560972772
info@drasah.com


TEST
TIME LEFT:
30 min

Mutah University
College of Graduate Studies

From Playgrounds to Rehabilitation Centers: A Qualitative Study of the Lived Experience of Children with an Amputation

Prepared by
Tahani Othman Al-Okaliy

Supervisor
Professor. Hala Obeidat

A Thesis Submitted to the College of Graduate the Studies
In Partial Fulfillment of Requirement for the Degree of
Master in Pediatric Health Nursing

Mutah University, 2023

Abstract

From Playgrounds to Rehabilitation Centers: A Qualitative Study of the Lived Experience of Children with an Amputation

Tahani Othman Al-Okaliy
Mutah University, 2023

Background: As a result of extremity amputation, children suffer from difficult conditions that adversely affect their anatomical, functional, psychological, and social status, and result in a low level of life quality.

Purpose: This study aimed to describe and explore the lived experiences of children with an amputation and describe the challenges and difficulties experienced by Jordanian children with an amputation.

Method: The study was conducted by using the qualitative phenomenological design, based on semi-structured interviews.

A purposive sample of (20) amputee children was interviewed, including those who received prosthetic devices at Al Bashir Hospital in Physical Medicine and Rehabilitation Center, and Farah Rehabilitation Center at the Royal Medical Services. The data were analyzed using Colaizzi’s method for qualitative data analysis.

Results: Five distinct themes captured the living experience of children who had amputation: (1) the Child's beliefs about his/her amputation, (2) In the same way as other children, I would like to attend school (school issue), (3) Psychological Impact, (4) child coping after amputation, (5) No one is incapable, but society hinders them.

Conclusion: This study concludes that children with an amputation are suffering from psychological (self-image problems, guilty, and low self-esteem), social isolation, and school problems; therefore, it is important for pediatric nurses and other members working at rehabilitation centers to encourage the families, school, and community members to help those children adapt positively to their condition and normalize their life.

Keywords: amputation, adaptation, lived experience, pediatric, phenomenological design.

الملخص

من ساحات اللعب الى مراكز التأهيل: دراسة نوعية للتجربة الحياتية للاطفال الذين تعرضوا لبتر في الأطراف

تهاني عثمان العقيلي

جامعة مؤتة، 2023

الخلفية: نتيجة بتر الأطراف الطرفية، يعاني الأطفال من ظروف صعبة تؤثر سلبًا على وضعهم التشريحي والوظيفي والنفسي والاجتماعي، فضلاً عن تدني نوعية الحياة.

الهدف: كان الهدف من هذه الدراسة هو وصف التجارب التي يعيشها الأطفال المصابون بالبتر.

المنهج: أجريت الدراسة بطريقة ظاهرية نوعية باستخدام المقابلات شبه المنظمة. تمت مقابلة عينة مقصودة من 20 طفلاً مع بتر، بما في ذلك أولئك الذين تلقوا أجهزة تعويضية في مركز البشير للطب الطبيعي وإعادة التأهيل ومركز فرح لإعادة التأهيل في الخدمات الطبية الملكية. تم تحليل البيانات باستخدام طريقة Colaizzi لتحليل البيانات النوعية.

النتائج: خمسة موضوعات مميزة استحوذت على التجربة المعيشية للأطفال الذين بترت أطرافهم: (1) معتقدات الطفل حول بتره، (2) كباقي الأطفال، أود الذهاب إلى المدرسة (قضايا مدرسية)، (3) التأثير النفسي، (4) تأقلم الطفل بعد البتر، (5) لا أحد عاجز ولكن المجتمع يعيقه.

الملخص: لخصت هذه الدراسة الأطفال الذين بترت أطرافهم يعانون من مشاكل نفسية (مشاكل في الصورة الذاتية ، وذنب ، وتدني احترام الذات)، وعزلة اجتماعية، ومشاكل مدرسية، لذا فمن المستحسن أن يكون ذلك مهمًا لممرضات الأطفال والأعضاء الآخرين العاملين في مراكز إعادة التأهيل لتشجيع الأسر والمدرسة والمجتمع التي يجب أن تساعد هؤلاء الأطفال على التكيف بشكل إيجابي مع حالتهم لتطبيع حياتهم.

الكلمات المفتاحية: البتر، التكيف، التجارب الحياتية، الاطفال ،التكيف، التصميم الظاهري.

Table of Contents

Content	Page
Dedication	I
Acknowledgments	II
Table of Contents	III
List of Tables	V
List of Appendices	VI
Abstract (in English)	VII
Abstract (in Arabic)	VIII
Chapter One: Introduction	1
1.1 Background	1
1.2 Statement of the Problem	4
1.3 Significance of the Study	5
1.4 The cultural context of the study	7
1.5 Purpose of the Study	7
1.6 Research Question	7
Chapter Two: Literature Review	9
2.1 Introduction	9
2.2 Physical impact of amputation on the growth and development of the child	9
2.3 Definition of Congenital and Acquired Amputation	10
2.4 Impact of Amputation on the Quality of Life	11
2.5 The Needs of Children with an Amputation	12
2.6 The complication of Amputation	12
2.7 Children with Amputation	13
2.8 Gaps in the Literature	14
2.9 Conclusion	14
Chapter Three: Methodology	15
3.1 Introduction	15
3.2 Research Design	15
3.3 Sampling	15
3.3.1 Inclusion Criteria	16
3.3.2 Exclusion Criteria	16
3.4 Setting	16
3.5 Ethical Consideration	17
3.5.1 Parental Consent Form of the Parental Permission for Children’s Participation in Research	17
3.5.2 Confidentiality	17
3.6 Data Collection Procedures	18
3.7 Data Analysis	20
3.8Trustworthiness of Data	22
3.9 Pilot Study	23

Chapter Four: Result Discussion & Conclusion 24
4.1 participant 24
4.2 Themes 25
4.2.1 Child's Beliefs about His/her Amputation 26
4.2.2 In the Same Way as Other Children, I Would Like to Attend School (School Issue) 27
4.2.3 Psychological Impact 30
4.2.4 Child Coping after Amputation 33
4.2.5 No One is Incapable, but Society Hinders Them 37
4.3 Summary 38
4.4 Discussion 38
4.4.1 Strengths 42
4.4.2 Limitations 42
4.4.3 Implication for Practice 43
4.4.4 Recommendations for Future Research 44
4.4.5 Summary 44
4.4.6 Conclusion 45
References 46
APPENDICES 53

LIST OF TABLES

Table	Page
Table (1) Sample Characteristics from Children Interviews (n=20)	24
Emerging Themes and Subthemes of Children with an Amputation Experience	25

LIST OF APPENDICES

Appendix **Page**

Appendix I: Ethical Approval 53
Appendix II: Consent Form (Arabic language) 57
Appendix III: Demographical Data and Questions to Guide the Interview (Arabic Language) 60

CHAPTER ONE
Introduction

1.1Background

A healthy child can physically, socially, spiritually, and cognitively develop during childhood (Jeanneret et al., 2012). Physical activity has increasingly become important for cognitive, physiological and neurological development during childhood, middle childhood, and adulthood (Mierau et al., 2014). During childhood, children perform physical activities through playing, which is essential for normal physical, cognitive, social, and emotional development (Navidi., 2016).

To be able to play, the child should have an integrated physical structure from birth throughout childhood, so that he or she can gradually develop motor and fine skills, starting from holding things in his or her hands, then crawling, walking, jumping, and so forth, to enable them to move and play (Berk., 2015). Children, who have experienced a congenital or traumatic injury, resulting in limb loss, may have a difficulty in facing the environmental challenges, since their functional ability is affected, and they are more dependent on others to accomplish their daily activities (Chhina et al., 2021).

Amputation in children has two main types as follows: congenital limb amputations and acquired amputations. A congenital amputation occurs from birth due to congenital malformation affecting either the upper or lower limbs. Occasionally, children may have multiple limb amputations. A congenital amputation can result in a complete absence of a limb, but it is more common to have a part of a missing limb, while the remaining portion does not normally develop (Belon &Vigoda, 2014). However, there are possible causes for congenital amputation, such as chromosomal abnormalities or different syndromes (Leung et al., 2015). On the other hand, acquired amputation is a surgical procedure for the removal of a limb resulting in anatomical, functional, psychological, and social consequences that can negatively affect children's quality of life (Ramstrand et al., 2021); it is considered as a disabling condition that affects children all over the world (Ziegler-Graham et al., 2008).

There are different reasons for amputations in children. Ogeng’O et al. (2010) concluded that trauma and tumors are the most common reasons, and that congenital anomalies are the main reason for amputation. Another related study conducted in the United States found that the main cause of amputation is accidents, as 5-year-old children and under were more likely to be amputated because of machinery, motor vehicle collisions, firearms, and off-road vehicles; making car injuries the most common cause of amputation among teens (Borne et al., 2017). Moreover, in older children, malignant tumors were found responsible for more than half of amputations, with the highest incidence occurring among (12- 21) years old group (Stricklin, 2020).

According to the Institute for Business Value Market Scan (IBVMS) (2021) commercial database, of the (36.5) million children in the Market Scan database, (14,038) had severe lower extremity loss with an estimated prevalence of (38.5) cases per (100,000) commercially insured children in the United States during the 7-year study period. Congenital malformations accounted for (84%) of cases, followed by (13.5%) related to trauma. Only (10.1%) had at least one prosthesis-related visit in (12) months after joining the cohort (McLarney et al., 2021).

According to the Centers for Disease Control and Prevention (CDC), each year, about (1500) US newborn are born with upper limb reductions (about 4 of every 10,000 newborns), and about (750) are born with lower limb reductions (about 2 of every 10,000 newborns) (Quinn &Mahat, 2019). In Aurora City in Turkey, there was a rate of (3.5 to 7.1) amputations per 10,000 births resulting from congenital deficiency, followed by amputations caused by disease and trauma (Rossi et al., 2019), while amputations among children under (18) years old accounted for (31.1%) cases of the total number in Turkey (Kocak et al., 2013).

A study conducted by Al-Worikat & Dameh to determine the demographic data among (120) Jordanian children with amputation found that (64) (53.3%) were males, while (56) (46.7%) were females. Male to female ratio was (1.15:1). The dominant level of amputation was trans-radial in (10) patients (15.62%) in the upper limb and trans-tibial in (18) patients (28.12%) in the lower limb. The dominant cause of amputation was a congenital deficiency in (56) patients (46.67%), followed by trauma in 48 patients (40%) (Al-Worikat & Dameh, 2008).

Normal children usually learn to roll over and stand with the help of their hands and feet. Compared to children born with congenital amputation or acquired amputation, where they need help from technicians, assistants, and therapists, in addition to artificial limbs to be able to grow and develop (Belon &Vigoda, 2014); therefore, they are exposed to physical problems and psychological challenges, including a change in lifestyle, change in self-concept, impairment in physical functioning, phantom pain, and phantom sensation (Mc Querry et al., 2019).

On the other hand, amputee children have a lower quality of life and emotional functioning (Quarry et al., 2015). This situation results in a long and expensive hospital stay in which the child experiences both physical and psychological effects (Khan et al., 2016). Furthermore, the amputation of limbs negatively impacts a child's happiness, physical appearance, movement, and athletic performance (Mc Querry et al., 2019).

Children with missing limbs should receive lifelong physical, psychological, and social care, requiring the services of professional prosthetists and therapists as well as specialized equipment, consumables, and coordinated healthcare (Ahmad et al., 2016). After amputation, prostheses were prescribed to replace missing bodily structures, restore function, and encourage activity and community participation; accordingly, prosthetic rehabilitation involves complex evaluation procedures, development of a treatment plan, designing, manufacturing of devices, fitting, alignment, gait training, and follow-up care (Lusardi et al., 2013). The differences in the appearance and function of amputee children's limbs discouraged the child from participating in recreational, social, and leisure activities, and thus leading to social, psychological, behavioral, emotional, and adjustment problems (Mc Querry et al., 2019).

Children with amputation suffer from many problems; one of these problems is physical problems that might have limitations with activities of daily living, mobility, balance, sports, recreational activities, and their adaptations for specific activities (Prigent et al., 2020). Also, those children may have a problem due to their concerns about the body image, shape, symmetry, size, and overall appearance of their limbs (Shaw et al., 2018); therefore, they could have self-esteem problems as well as difficulties in dealing with their problems (Prigent et al., 2020). Furthermore, Most of those children reported the negative effects of having a limb amputation on their school life. They discussed their limited participation in activities at school, having to miss school due to recurrent visits to the hospital, the isolation they felt at school, emotional and instrumental support from their friends and teachers, and some school-based environmental barriers (Chhina et al., 2021).

Considering these problems and the consequences of limb amputation, those children needed to adapt to the loss of a limb; however, the process of adaptation itself is an obstacle for them. Adaptation begins to restore complete self-sufficiency in daily activities (this means that the child performs his daily tasks without the need for assistance); this process takes a long time inside the hospital until the child is discharged to home and begins to receive education (Jo et al., 2021).

Accordingly, families significantly influence children's emotional and behavioral adjustment, and enhance their ability to use prosthetic devices. Therefore, parents must be informed and engage in the caring and rehabilitation process. They should recognize that they are an integral part to the team in developing and enhancing their child's rehabilitation (Le & Scott-Wyard, 2015).

1.2 Statement of the Problem

Studies conducted to understand the experience of children, who have lost a limb, concluded that the idea of accepting amputation depends on the reason for amputation. In children with osteosarcoma cancer, who suffer from pain caused by disease and chemotherapy, amputation was accepted better as compared to the children who suffered no pain. Even though they did not feel pain after the surgery, they showed strict denial after the operation when accepting their new situation (Gil et al., 2019). In psychological studies, it was observed that when told that one of their limbs should be amputated (before the amputation process), children felt fear, lost their appetite, struggled to satisfy themselves, and had difficulty sleeping at night (Kristianto et al., 2020). Then, after the amputation of their limb, the children faced a variety of psychological and medical stressors due to reduced physical function, the use of prostheses, discomfort, and changes in employment status (Kristianto et al., 2020). Children with amputation suffered from depression, anxiety, and behavioral problems, such as low self-esteem, and the lack of social support and peer acceptance from classmates led to depressive symptoms and low self-esteem (Le & Scott-Wyard, 2015). Amputation can affect a child's school life, since children may miss school life routines very much, have too limited participation in school activities, and have feelings of isolation (Chhina et al., 2021).

It is important not to neglect the family, as they may suffer from social and psychological problems, such as depression, guilt, anxiety, anger, and reluctance to accept the child's disability. If dealt with satisfactorily, it will be the best treatment for the child in the long run (Le & Scott-Wyard, 2015). In addition, the parents, the hospital staff, the physiotherapist, and the psycho and socio-therapist should devote a significant amount of time and perseverance to providing specialized care for children. Moreover, it was found that caring for children with amputations was expensive. A study on (74) patients reported an average stay of (11.3) days, with an average of (4) procedures costing up to ($22.0152) (Loder et al., 2004).

Adjusting to amputation in children is usually complex since they have many needs, including special medical care, physical therapy as well as psychological, social, and educational support. Despite having a prosthesis, these children had many obstacles, such as long-term follow-up, functional capabilities (balance, walking speed, comfort during walking, and walking outdoors), in addition to psychological problems that adversely affect their life (Griffet, 2016). In addition, it was essential to schedule the child's appointment at least twice a year to monitor his or her growth and how it affected the amputated limb over time (Griffet, 2016). The psychological adaptation of young children was better than that of adolescents, who felt distressed due to their differences. therefore, it is essential to begin early and continue psychotherapy (Jo et al., 2021).

At the local level of Jordan, the situation of Jordanian children with amputations from families with unemployed parents, who have not registered for social and health assurance, are liable to pay for any procedures that cause suffering to children. In government hospitals, Jordanian children generally receive artificial limbs, along with the efforts of the Ministry of Health (MOH) to develop its workshops for manufacturing artificial limbs. Furthermore, the Ministry of Health is interested in focusing and paying attention to continuing education and training in the field of prosthetics. These governmental hospitals are usually interested in installing prosthetics and providing rehabilitation; however, the psychological and social domains and the experience of these amputee children received little attention.

1.3 Significance of the Study

Through the researcher's experience at the pediatric ward, she noticed many challenges experienced by amputee children related to physical, psychological, and social problems, which may lead to stress, anxiety and depression symptoms, body image disturbance, as well as social isolation among those children.

Moreover, the researcher noticed that those children need frequent physical, psychological, and social rehabilitation to support and encourage them to normalize their lives.

Recent studies demonstrated that many factors play an important role in determining the child's experience and reaction to amputation, including the child's developmental level, his temperament, level of general stress, coping style, the parents' response, the extent of functional stress, and the physical deformity associated with the injury. These factors affect children's self-esteem and awareness of their appearance which, in turn, influences their adaptation to the loss resulting from amputation (AlSofyani et al., 2016).

The importance of this study lies in several factors, including the lack of knowledge and experience among the children with amputation regarding their physical, emotional, psychological, and school needs (Griffet, 2016).

This study may enhance the Jordanian health institution's policies regarding the amputation of children to provide them with adequate care that may normalize their life. This study aimed to describe the lived experience among the Jordanian children with amputation. A better understanding of this phenomenon may result in improved physical, psychological, and social care provided for those children and more support to their families. This study is considered as an attempt to raise the awareness among the community members regarding the amputee children and enroll them in suitable society institutions.

Describing the lived experience of amputee children may provide new insights and guide nurses and other healthcare professionals to better understand the limitations of loss and care management. This study may contribute to uncovering new venues and different coping strategies alongside with personal insights about children who have recently undergone an amputation. In addition, the data generated may use new knowledge to guide education, practices, and research for people affected by traumatic amputation.

Finally, this study is considered as a unique one because, as far as the researcher knows, no published Jordanian studies have explored or described the lived experience of Jordanian children with amputation.

The cultural context of the study

Through my experience as a pediatric nurse working in Al-Bashir Hospital, I met many amputee children and frequently provided health care to them. My experience helped me conduct better interviews with children and deal with them in a way that suits them so that I can collect data without making them feel pressured or uncomfortable. Through the interviews, I noticed that most children are from rural areas who attend public schools and live in families with parents who had not completed high school. It was found that congenital amputations were prevalent in most of the children in this study, where one of their parents was present during the interview with the child. During interviews with the amputee children, it was found that their parents usually overprotect them which, in turn, leaves them heavily reliant on their parents, or they are treated differently from their siblings because of their amputation as a form of pity. Despite this, society members treat them differently, as most of them are exposed to society's harmful curiosity and looks of pity. They are also exposed to bullying by their peers and have feelings of ridicule by others, which makes them feel powerless. However, Jordanian society is considered an Islamic society that follows the regulations of the Islamic religion; the view of Islamic law for amputees is based on the fact that there is no difference between the servants of God except by piety and righteous deeds and no difference between them and ordinary people, where it is necessary to respect them and not to make them feel embarrassed. Also, Islamic regulations view them as a category that has been subjected to affliction, and that they mustn't be mocked, and should have more care and attention.

1.4 Purposes of the Study

This study consists of two primary purposes:

1- To explore and describe the lived experience of Jordanian children with an amputation.
2- To describe the challenges and the difficulties experienced by Jordanian children with an amputation

1.5 Research Questions

The study aimed at answering the following questions:

1. What is the lived experience of Jordanian children with an amputation?
2. What are the challenges and difficulties experienced by Jordanian children with an amputation?

1.6 Conceptual Definitions

1.6.1 Lived Experience

It is a central methodological idea that aims to provide an in-depth understanding of how people experience, interpret, and feel about certain phenomena in their daily lives (Davies & Davies, 2007). Research interest is built on lived experiences since understanding a phenomenon requires taking into account the experience of the person who lives that phenomenon (Breuer, 2003).

1.6.2 Amputation

It is the removal or loss of a body part, such as a toe, finger, foot, hand, leg, or arm. It can be a life-changing experience affecting the child's ability to move, work, interact with others, and maintain the child's independence. Continuing pain, phantom limb phenomena, and emotional trauma can complicate recovery (Hauben, 2014).

1.6.3 Child

Refers to any person under the age of (18) who has rights regardless of who he is, where he lives, what language he speaks, what his religion is, what he thinks, what he looks like, is a boy or a girl, whether he has a disability, whether his family is rich or poor, and regardless of who his parents are, or what his parents or his family think or do (UNICEF, 2020).

1.6.3 Amputee Child

It refers to a child who has a missing part of his body due to congenital anomalies causes or acquired causes (Tabor, 2018).

1.6.4 Quality of life

It is a concept that aims to capture the well-being, whether of a population or individual, regarding both positive and negative elements within the entirety of their existence at a specific point in time. For example, common facets of QoL include personal health (physical, mental, and spiritual), relationships, education status, work environment, social status, wealth, a sense of security and safety, freedom, autonomy in decision-making, social belonging, physical surroundings (Barofsky, 2012).

1.6.5 Adaptation

It is a property of phenotypic features of organisms relative to the selection demands of the environment. Adaptive features have properties of form and function, permitting the organism to successfully maintain the synergies between a biological role of that feature and a stated selection force. The degree of goodness of the adaptation can be measured through the amount of energy needed to maintain the synergies, with less energy indicating better adaptation (Bock, 1980).

CHAPTER ONE
Literature Review

2.1 Introduction

Most of the research on the experience of amputation among children is related to individuals' reactions to their amputation, depending on factors, such as age, level of amputation (below or above the knee/elbow), and time since amputation. This literature review explores the lived experience of children with amputation from different aspects. It reviews the evidence for the experience of children, thanks to a comprehensive and rigorous literature search.

The author searched using a computerized search of MEDLINE, CINAHL, and PsycINFO, Google Scholar using keyword searches for the following terms: amputation children, quality of life for amputation children, the psychological and social impact for amputation, qualitative studies, and amputee children. The search covers the period (2014–2022). Major concepts found in the literature were studies regarding:

2.2 Physical impact of amputation on the growth and development of the child

(Belon & Vigoda,2014) conducted a study that found that during the early years of a normal child's life, they learn to roll over, crawl, stand, and walk. They learn how to grasp objects and use their arms and hands daily, while the child with an amputation using limbs and digits has lower abilities after amputation.

(Hall et al., 2020) conducted a study that found that training on artificial limbs for children is based on their growth and development and their amputated parts. This study found that children with upper limb amputations should receive training by the age of (5-7) months as they begin to sit, use both hands, support themselves, and crawl at this age, and by the age of two, they will have adapted to wearing a prosthesis. Children who have amputations in the lower limbs are usually trained on prosthetic limbs at the age of (10-14) months, which is the time when the child begins to crawl, stand and walk, as prostheses are installed at these ages so the family can do continuous physical therapy and work on adapting the child to this prosthetic.

(Ciocco et al., 2019) conducted a study that found that early fitting, if appropriate and desired by the family, is generally agreed to be recommended before two years old or within six months from the onset of trauma. Most important is to have a knowledgeable and comprehensive team to follow the child regularly and provide family education, so patients and parents can make informed choices

(Rossi et al., 2019) conducted a study that found that children born with congenital amputation use their limbs instinctively to interact with the environment as they discover new ways to do what they want no matter what amputation they have, especially children who have amputation in the upper limbs. Those children didn't prefer to use the prosthesis because they have adapted to the lack of an upper limb and found that their amputated limb works better than the prosthetic limb. In contrast, children who have amputations in the lower limbs need to walk, so they prefer to wear the prosthesis.

2.3 Definition of Congenital and Acquired Amputation

A congenital amputation refers to abnormal development. In most cases, abnormalities of the skeleton are clinically classified as failures or malformations of skeletal structure, but their embryonic origin is not always clear. A link between human mutations and embryonic processes, discovered in model organisms, has the potential to more precisely unravel the etiology of congenital anomalies, and advances in both, as they facilitate progress in this direction (Wolpert et al., 2015).

About (0.6) out of 1000 live births are affected by congenital limb defects. A major contributing factor to limb defects is prenatal exposure to drugs and environmental contaminants. In addition to Thalidomide, Warfarin, Valproic acid, Misoprostol, and Phenytoin, other well-recognized limb Teratogenic agents include Valproic acid and Valproic acid salts. Despite an increasing understanding of how these agents cause Dysmorphogenesis, the teratogenicity of many thousands of cases related to uncharacterized environmental factors (pollutants) remains unknown (Alexander et al., 2016).

Acquired amputations result from trauma or diseases, such as neoplasms or infections, with trauma occurring twice as frequently as the disease. Traumatic amputations can cause permanent damage and disability, psychological trauma and affect future functionality or goals (Le & Scott-Wyard, 2015). Another related study was conducted to quantify and interpret patterns in the global distribution and prevalence of acquired limb amputation by the causes, regions, and ages within the context of prosthetic rehabilitation and prosthetist education. Around (57.7) million people worldwide live with limb amputations due to traumatic reasons. Falls accounted for (36.2%), road injuries for (15.7%), other transportation injuries for (11.2%), and mechanical forces for (10.4%). In addition, the highest rates of traumatic amputations were registered in East Asia and South Asia, followed by North Africa, Western Europe, the Middle East, and high-income North America and Eastern Europe. The prevalence estimates indicated that (75.850) prosthetists are needed worldwide to treat traumatic amputations (McDonald et al., 2021).

2.4 Impact of Amputation on the Quality of Life

Many studies have examined the quality of life of amputees (Nurulain, 2016; Mc Querry et al., 2019; Knežević et al., 2015; Shaw et al., 2018; Birch et al., 2019; Demirdel & Ülger, 2021)

(Nurulain, 2016) conducted a retrospective study that aimed to investigate the outcomes of limb amputations among children with metastatic osteosarcoma. The results found that patients undergoing limb amputations reduced pain and improved mobility and emotional and psychological well-being. Amputations are likely to benefit children with limited life expectancy.

(Mc Querry et al., 2019) conducted a retrospective study that aimed to determine whether children with amputations had differences in subjective function based on amputation level. It was found that knee amputations negatively impacted physical performance more than ankle amputations, indicating that the higher the level of amputation, the worse the physical performance.

(Knežević et al., 2015) conducted a cross-sectional study that aimed to compare the quality of life of patients who had lower extremity amputations and those who had not undergone the procedure, where gender differences and level of amputation were taken into account. It was found that patients with lower extremity amputations faced many limitations as compared to patients who had not undergone the procedure, regardless of gender, while patients with lower amputations demonstrated better physical performance.

(Shaw et al., 2018) conducted an observational study in Tanzania that aimed to examine the causes and health-related outcomes of lower extremity amputations and socio-economic barriers to accessing prosthetics. The findings indicated that trauma is the main cause of amputations. Medical consequences of amputation include complications in (3 to 6) months following the operation, difficulties in acquiring prosthetic limbs for amputees, and poor quality of life for amputees, contributing to the poorer quality of life for amputees.

(Birch et al., 2019) conducted a study on children with fibular hemiplegia and investigated the effects of amputation or reconstruction and lengthening on functional and psychosocial outcomes two years after the amputation. The findings showed that children treated with amputation had lower quality of life in school and there were no significant differences in health-related quality of life between the two groups. Participants from both groups reported satisfaction with their treatment and functioning. The results revealed that there are no significant differences between the groups in terms of psychosocial adjustment or physical function.

(Demirdel & Ülger, 2021) conducted a cross-sectional study to investigate body image disturbance, psychosocial adjustment, and QOL in adolescents with amputation. The results found that body image disorder negatively affects the quality of life and the psychosocial adjustment of amputee adolescents was very poor.

2.5 The Needs of Children after Amputation

Children with amputations suffer from permanent disabilities and adverse psychological effects. Therefore, they should be treated following an amputation by a multidisciplinary team, which includes a physiotherapist, a nurse, a pediatrician, and a surgeon. Parents can also be supported during this process in a psychologically supportive way (Khan et al., 2016).

After a multidisciplinary team manages the patient, the prosthesis can be installed. In this context, the remaining length of the limb after amputation- a critical factor that needs to be evaluated according to the expected growth rate- was investigated (Griffet, 2016). The study aimed to increase the area of the maximum weight-bearing surface, eliminate skin friction caused by the prosthesis, and eliminate the effects of the level arm. The study objectives were achieved by introducing new materials on the market capable of improving the quality of the prosthetic limb which, in turn, had a significant effect on its function. This was accompanied by special management of psychological and social problems (Griffet, 2016).

(Jo et al., 2021) conducted a study that aimed to have a better understanding of the psychological characteristics of patients with limb amputations. The results revealed that during the amputation adjustment process, there could be psychological problems, such as depression, anxiety, and post-traumatic stress disorder. The psychological difficulties of patients with amputations are often accepted as normal responses that are often poorly recognized by patients, family members, and primary physicians. Therefore, early detection and treatment are important. Therefore, there is a need to have a multidisciplinary team that includes mental health professionals for comprehensive bio-psychosocial management, to help patients set realistic goals and use adaptive coping techniques, and psychological approaches that consider physical, cognitive, psychological, social, and spiritual functions as well as social support systems before and after amputation.

2.6 The complication of Amputation

(Le & Scott-Wyard, 2015) conducted a retrospective study that aimed to evaluate the amputation type and segment relationship with the use of prostheses in the pediatric population referred to the amputee rehabilitation clinic. The results indicated that there were several issues children face after an amputation, such as physical problems, which are usually manifested in terminal growth. The most common complications after an amputation usually presented with redness, warmth, and a painful bursa at the distal end of the residual limb. These children frequently visit rehabilitation centers and have to change their prostheses frequently.

(Horsch et al., 2022) conducted a retrospective study that aimed to describe the patterns of lower-limb amputation, indications, complications, and revisions for pediatric cases. The results revealed that the tumor was the most common indication for amputation (72.7%), and trans-femoral amputation was the most frequent level (68.2%). The results revealed that the complications occurred in (10) patients, mostly because of stump impalement or bony overgrowth. Of all the recorded patients requiring revision, (9) cases were regarding bone, and one case was regarding soft tissue.

(Prigent et al., 2020) conducted a case report study for a young adolescent male with a severe loss of function following foot trauma, where he underwent secondary trans-tibial amputation (17) months post-injury to describe how a structured multidisciplinary approach around the child and his family led to successful outcomes. The results revealed that children can suffer from limitations in daily life activities, mobility, balance, and sports, as well as limitations in their ability to adapt to specific activities. In addition, children's mental health may be adversely affected due to their body image, where they may feel distressed due to their amputated limbs, and how they will cope.

(Al-Adwan et al., 2017) conducted a study in Jordan to examine some variables (age, gender, level of amputation, kind of artificial limb, direction of amputation, site of amputation) related to prosthetic reactions and their relationship. The results showed that several factors affect the reaction to prostheses. This study found that several variables affect the relationship positively, such as the level of amputation and tenderness, while some others affect the relation negatively, such as the location of amputation and age. The results found that children were less acceptant of prosthetic limbs than adults and that the acceptance of prosthetic limbs increases with age.

2.7 Children with Amputation

(Hamill et al., 2010) conducted a study that aimed to identify the experiences of (8) amputee children whose amputation period exceeded (18) months. The study found that these children have a certain image of coping with amputations and their consequences through the process of identity renegotiation mediated by a wide range of decisions, media, and social factors.

On the other hand, several studies described children's experiences, but each aspect was explored separately.

(Quarry et al., 2016) conducted a study to measure self-esteem, quality of life, and emotional functioning among children with congenital and acquired limb loss compared to children without limb loss, and compare psychological adjustment among children with acquired limb loss with psychological adjustment in children with congenital limb loss. The results found that the congenital and acquired limb loss group had lower quality of life and emotional functioning than those without limb loss. However, self-esteem levels were not found to be lower and, in some cases, even higher. When comparing the congenital and acquired groups, very few differences were found; for example, those with acquired limb loss had more attention and concentration problems.

(Ali et al., 2021) conducted a study to assess the psychological issues following acquired limb amputation and the importance of positive self-esteem to psychological adjustment. The results found that there were several psychological issues associated with amputation. Male amputees generally have lower self-esteem and more severe adjustment problems than females, while young amputees exhibit more signs of maladjustment than older amputees. The regression analysis for self-esteem predicting psychological adjustment also revealed that there are noticeable differences in psychological adjustment levels as self-esteem changes. In addition, there was a strong positive relationship between self-esteem and psychological adjustment, and (77.5%) of the variance in the dependent variable (psychological adjustment) was caused by the predictor variable.

2.8 Gaps in the Literature

Previous studies examined the quality of life of amputee children and their reactions to amputation. However, within the researcher's knowledge and regarding previous studies, there were no published local and global studies on the lived experiences, challenges, sufferings, difficulties, and needs of children with amputations and their families.

2.9 Conclusion

The results concluded that there was a scarcity of studies exploring the challenges and difficulties experienced by Jordanian amputee children and their families. The literature concluded that there is a lack of information on amputee children's emotional and psychological social and physical experiences. Moreover, most studies were conducted using a quantitative design. Furthermore, there haven’t been any comprehensive studies in Jordan exploring and discussing the lived experiences of Jordanian children who have had a limb amputated.

CHAPTER THREE
Methodology

3.1 Introduction

In this chapter, the research's methodology and design, the participant selection process, the sample and setting, discussion of inclusion and exclusion criteria, data collection procedures, the description of data analysis, ethical considerations, and the trustworthiness of data are discussed.

3.2 Research Design

This study is based on a qualitative and phenomenological construct. According to the philosophical tradition of Husserl and Heidegger, phenomenology is an approach to understanding people's everyday experiences (Stannard, 2012). The phenomenological approach provides a deeper understanding of the experience, patterns, and themes exhibited by the study participants. A phenomenological inquiry, according to Moustakas (1994), aims at having a full understanding of the lived experiences and related perceptions and describing these experiences in people's words. Descriptive phenomenology is an approach used to study the essence of human experiences (Sloan & Bowe, 2014).

In phenomenology, the qualities or essence of an experience through interviews, stories, or observations of people who undergo the experience under study are examined. In a phenomenological study, the approach used and how it fits the purpose of the study should be also clearly stated. This approach uses fewer participants, but in greater depth, than would be possible in a survey or other type of research (Patočka, 2019).

Against this, the current study aims to explore and describe the lived experiences of Jordanian children with an amputation. Qualitative descriptive phenomenology is the most appropriate design, as it allows a better understanding of the lived experiences of children with an amputation. In a phenomenological study, children's experiences and how they react to amputation are explored. Also, this research approach is adopted to describe the challenges and difficulties experienced by those children.

3.3 Sampling

It is common for phenomenologists to work with small samples of participants. The selection of a phenomenological study sample is governed by two principles. The first principle is that all participants must have experienced the phenomenon, while the second principle is that all participants must be capable of articulating the lived experience.

Purposive sampling, also called judgment sampling, is the deliberate selection of a participant based on his or her qualities (Battaglia, 2008). This technique does not require underlying theories or a set of participants (Etikan, 2016). It is the task of the researcher to determine what needs to be known and then sets out to find people who can willingly provide the information. In addition, this sample will focus on candidates with similar characteristics. This study utilizes a purposive sample of (20) participants; (8) females and (12) males aged from (8-18) years old.

3.3.1 Inclusion Criteria

The participants are selected using the following inclusion criteria: children between the ages of (8-18), who have undergone amputation, are included in this sample because children at this age can express themselves; children, who have suffered from an amputation for more than a year, can speak more clearly about their experience; the Jordanian children who suffer from acquired or congenital amputations (with or without prosthesis).

3.3.2 Exclusion Criteria

The study excluded children with mental health problems, children with neuro-developmental delays, and children who did not desire to complete the study.

3.4 Setting

This study was first conducted at Al-Bashir Hospital affiliated with the Ministry of Health. Then, more interviews were conducted at Farah Rehabilitation Center in the Royal Medical Services military sector. The selected hospitals are considered central hospitals in Jordan and receive patients from all governorates and provide healthcare to all age groups.

Data were first collected from the Physical Medicine and Rehabilitation Center at Al-Bashir Hospital. In addition, there has been a new, large physiotherapy and rehabilitation center built in the hospital with clinics for (20) doctors and a physical, occupational, and electrical therapy department with (35) physiotherapists, along with exercise rooms for men, women, and children approximately reviewing (150) patients per day. Additionally, there are about (10) prosthetic technicians who examine approximately (50) patients a day and (10) nurses who work in physiotherapy and prosthetics.

The main objective of providing physical therapy is to achieve the maximum possibilities to restore the patient's wellness, allow them to return to their everyday lives as much as possible, and provide them with a treatment service at a high level that gains approval and acceptance from patients. Many professionals are involved in this process, including doctors, physical therapists, technicians, and nurses.

The second setting is a Unit for prosthetics and amputation rehabilitation in Royal Medical Services, which consists of two floors and covers an area of (2.600) square meters. It contains rehabilitation clinics for amputees and paralyzed individuals and foot care, physiotherapy, occupational therapy training rooms, laboratory examination, and training step, a variety of workshops for the manufacture of traditional and modern limbs for the upper and lower limbs, rehabilitation and amputation clinics, blacksmithing, carpentry, weaving, and crafts that employ about (9) doctors, as well as a physical, occupational, and electrical therapy department with (50) physiotherapists.

3.5 Ethical Consideration

As part of this study, the ethical approval from Mu'tah University Academic Research Committee (IRB number: 0096232370706), the Research 23 Committee at JRMS (Jordanian Royal Medical Services), and the directors of the targeted hospitals (see Appendix I) are obtained to ensure the maintenance of ethical standards and protect the rights of the study participants. Furthermore, informed consent was obtained from the parents of participants in this study (see Appendix II).

3.5.1 Parental Consent Form of the Parental Permission for Children's Participation in Research

The researcher ensured getting ethical permission from the parents by signing the consent form and taking the permission from children verbally, and then explaining to the parents that the children's privacy and the confidentiality of their data will be protected by keeping their identity confidential, as only pseudonym, rather than names, was used for protection and security. All data collected were kept strictly confidential, and names were not used in any presentation or texts. All information “records, transcripts, written materials, and consent forms” were kept in password-protected electronic files that no one could access except for their researcher and her assistants. Parents reported their cooperation and acceptance of the order to allow their children to participate in this study (See Appendix **II).**

3.5.2 Confidentiality

Participants were informed that the researcher will keep the information of the subject for at least three years after the research completes. Participants' identities were kept confidential, and no data were directly linked with them. Moreover, the confidentiality of the data is ensured by not requiring participants to reveal their names to protect their anonymity and by refusing to share the data with anyone not authorized to access those data. It is also ensured to minimize any harm caused to the respondents by ascertaining at the outset whether they have any objections to participating in the study or see that participation in this study can negatively impact them.

3.6 Data-Collection Procedures

Having obtained permission from the facility managers, technicians, doctors, and nurses to conduct the study, they were informed about the inclusion and exclusion criteria. Among the inclusion criteria were that the child must be a Jordanian citizen between (8) and (18) years old who had an amputation done at least a year ago, and have a congenital or acquired amputation. It is important to note that all children who did not meet the inclusion criteria and who had severe health or mental problems were excluded. Due to this, the semi-structured face-to-face interviews were conducted at a convenient time and place.

Semi-structure Interview

The children have been interviewed at the rehabilitation center at Al-Bashir Hospital and Unit for prosthetics and amputation rehabilitation at the Royal Medical Services. Before meeting them, arrangements were made based on their scheduled appointments in the hospital, where the researcher went repetitively to the limbs department and checked the dates for limb fittings, and sometimes the workers at the limbs department notified the researcher of new appointments. Following that, the researcher introduced himself as a master's student and explained the aims of this study which are to describe the lived experience of amputation children and ask them questions about their experiences, tell them how long the interview takes, and then interviewed the child.

Additionally, this interview was manually recorded, and the answers to the questions were recorded by either the researcher or another assistant researcher who registered the responses manually. We use this method of recording because some participants refused tab recording. Therefore, to protect their rights and confidentiality, the researcher recorded the interview manually. Participants were ensured that any information they give is kept very confidential and used only for research purposes by the researchers. In this case, the participants were also informed that the interview takes place at the appropriate time for them, either while waiting for treatment or after treatment in a rehabilitation center. Then, parents' consent was obtained to invite their children to participate in the study by signing those parents' consent forms and getting the permission from child verbally.

Interviews took place in both hospitals' private and quiet rooms for nurses within the limb department. During the interview, either the father or mother was present with the child so that he or she would not feel strange and could express themselves better in their native Arabic dialect.

The responses were written in the text base of the interview question. Indeed, the presence of the parents during the interview was helpful to the researcher as they encouraged the child to talk about his experiences. They understood better because they were asked in Arabic, and the interview lasted between (30) and (50) minutes. To prevent tiredness or boredom, the participants were given a break of (5) to (10) minutes. The subjects were changed to something the child was interested in, such as talking about his or her favorite games and programs. Also, if the researcher noticed that the child has become more attentive, they returned to the original topic to better understand the situation and the participants' views about their experience. During the participant's talk, the researcher minimized interruptions.

Therefore, the researcher turned off the phone and has the participants do the same. As part of the research, the researcher made supportive gestures, agreement, and so on, since it is more appropriate than verbalization, which can distract the child and lead him in unproductive directions. Furthermore, establishing a relationship of empathy and affection with the child was necessary to get better information by giving him some beautiful phrases like (I heard that you're old, smart, and you hear the words, so you'll know how to answer any question I ask, or I was asking about his favorite programs in a shorter period). Ideally, during the interview, the children were asked about their experiences, which may arouse the affection of the parents. If either the parent or the child cried, it was the researcher's responsibility to calm them and ask if they could complete the interview. Furthermore, the behavior and features of the child's face were observed when he or she talked about the experiences he or she had experienced, judging his or her emotional state based on his non-verbal gestures. The open-ended questions that allow them to speak freely were also asked. Data were collected from participants over (4) months, from August 8th, 2022 to December 12th, 2022. Throughout conducting the study, (20) interviews were made over (4) months. It was noticed that the same themes repeatedly come up from the participants. Despite interviewing more and more participants, it was found difficult to find any new themes, opinions, patterns, or ideas. As a result of conducting (20) interviews, data saturation was reached.

Interview Question

The semi-structured and open-ended questions in the interview were conducted to allow participants to elaborate on their responses. Due to their semi-structured nature, they allowed for probing and a more conversational approach rather than a rigid question-and-answer format (Langdrige & Hagger-Johnson, 2009). The interview lasted between (30) and (50) minutes in a private isolated room in a hospital. The researcher designed and developed interview questions based on the following studies, pieces of research (Liu et al., 2010; Ramstrand et al., 2021), and based on the researcher's experience. At the starting interview, the demographical data, including the child's age, gender, academic performance, family income, parent's educational level, reason and type of amputation “congenital or acquired”, duration of amputation, use of the prosthetic device and the type of prosthetic were collated as required. Then, the following questions were asked:

1. Could you tell me about yourself?
2. Where do you live, and with whom?
3. Who is closest to you in your family?
4. When did you have the amputation?
5. What caused amputations?
6. When did the physician tell you that you must receive an amputation? What were your feelings at that time?
7. What was your reaction after the amputation took place?
8. After the amputation, what were your biggest fears?
9. What changes did the amputation add to your life in terms of the following: family, study, physical appearance, dependency, and community treatment?
10. Tell me more about the amputation’s effect on you, your daily life, and your family?
11. Are you wearing a prosthesis? When was it installed?
12. Please describe your experiences of wearing prostheses.
13. How did you feel about the particular experiences of living with amputation and what did it mean to you?
14. When placing the prosthesis, do you experience physical or psychological pain?
15. Who helped you in doing your daily activities? Or do you do it yourself?
16. How long have you become self-reliant following your amputation?
17. Do you have any views regarding the health services provided to children who have lost limbs?
18. Have you been differently treated from other family members at school, or when going into a public place?
19. What are the difficulties and the challenges facing you?
20. Who supports you?

3.7 Data Analysis

Colaizzi's method of data analysis was used to explore the experiences of amputee children. To understand the structure of an experience, Husserl's descriptive phenomenology aimed to extract its essence (Welch, 2014). Husserl intended to discard the accepted ways of "doing philosophy" and look "back to the things themselves" with a detailed description to determine the nature of things themselves (Husserl, 1970). In 1978, Colaizzi developed a seven-step analytical approach to discover the fundamental structures of data influenced by Husserl's descriptive phenomenology by providing clear, logical, and sequential steps used in phenomenological research, and thus increased the reliability and dependability of the results. Unlike other phenomenological data analysis methods, it requires participants to validate findings to ensure that they are accurate and credible (Wirihana et al., 2018).

There are seven steps in Colaizzi's method of data analysis. According to Colaizzi (1978), researchers should be flexible within these steps, as pursuing the meaning and essence of a phenomenon should not require a rigid set of steps, but a deeper and thorough investigation of meaning. For this reason, the following steps are taken into account to analyze the data: Reading and rereading the transcript, extracting significant statements about children's experience with an amputation, formulating meanings from significant statements, aggregating formulated meanings into theme clusters and themes, developing an exhaustive description of children's experience with amputation of the essential structure or essence, a description of the fundamental structure of the children's experience with an amputation is subsequently generated, and the analysis is completed by validating the study findings through participant feedback. According to Colaizzi (1978), this helps to put aside their perceptions of a phenomenon and scientifically understand the experiences of participants. Understanding the experiences of others provides previously unavailable insights (Wirihana et al., 2018).

Data analysis based on Colaizzi's (1978) method is rigorous and robust, making the results of this method credible and reliable. Within this framework, emergent themes and the connections between them are easily identified. This method provides a clear and logical process through which the fundamental structure of an experience can be explored by researchers using a descriptive phenomenological approach (Morrow et al., 2015). The Arabic language interviews, concurrent with analyzing the qualitative data, are conducted and translated into English after transcribing it. To support the interpretation, the transcripts from the interview discussion were read and reread to identify shared meaning from the participants' responses. Next, the interpretations of the similarities, differences, and consistency between the various forms of color data collection were compared and analyzed, ensuring that no phrases were lost during translation.

Following each interview, the participant data were collected, sorted out, and analyzed using Colaizzi's method. Colaizzi's method is used to analyze the data and identify similar ideas based on the participant's experiences and perspectives. To ensure the accuracy of the information, color index coding is used to organize and label data, meaning that the various relationships and themes were identified by organizing and labeling the information. Using a thematic analysis, the patterns of themes, topics, ideas, and meanings that repeatedly appeared in the data could be developed. To validate the findings, several verbatim quotes supporting the interpretations and themes identified in the participants' responses were incorporated. Narratives were also created to tell a cohort story about data. The non-verbal expressions were also relied on during the interview, such as facial expressions, voice tones, body language, and sensations. Reflection and interpretation began once the themes were identified.

3.8 Trustworthiness of Data

The method used for analyzing qualitative data is essential for establishing standards of rigor, reliability, and credibility. To establish trustworthiness in qualitative research, Cope (2014) suggested that the four criteria of Lincoln and Guba (1985) must be met: credibility, dependability, conformability, and transferability.

(1) Credibility: A study's credibility depends on trusting that the information presented in the course of the study represents facts and figures (Lincoln & Guba 1985; Polit & Beck 2014). A study's credibility refers to its trustworthiness, while validity refers to the extent of the accuracy that reflects or evaluates the concept or ideas investigated. Each of these criteria was explained, and the procedures that are typically followed were illustrated. The qualitative approach was used in this study to establish credibility to trust in the study results. When conducting qualitative studies, any presuppositions they may have about the phenomenon in mind before they start the study are kept away; as a researcher, I considered the children's narrative rather than my experience.

(2) Dependability: As part of a qualitative research study, dependability can be achieved by accurately documenting the processes (Armstrong et al., 1997). This detailed documentation allowed the reader to ascertain whether appropriate research methods were followed and provided future researchers with the information needed to replicate the study (Shenton, 2004).

To ensure data reliability over time and conditions, reviewers are requested to review and examine the research process and data analysis; among them was my supervisor, who checked the data analysis step by step. The reviewers confirmed that the current study's findings are consistent and replicable. Furthermore, a code-recode procedure throughout the analysis process is promoted. Then, the same data were coded and recorded within (2) weeks to evaluate the required results.

(3) Conformability: It is the qualitative counterpart of objectivity and refers to the agreement between two or more independent auditors regarding whether a given set of data is meaningful, relevant, and accurate (Wirihana et al., 2018). The way decisions were made in qualitative research should be transparent (Krefting, 1991). Research notes were kept for every decision made by the researcher and every analysis performed as the study progressed. The participants were also consulted and confirmed that the themes were accurate by member-checking. After several months of semi-structured interviews, participant or respondent validation is achieved by returning the data to the participants, allowing them to interact with them alongside the interview data. Once the study was completed, the results of the organ examination with the relevant participants were shared, allowing them to evaluate the results critically. Studying abstracts either reflects the experiences of the participants or does not. When participants confirmed accuracy and completeness, the study had credibility. Although these checks were not error-free, they reduced the chance that incorrect data will be captured and interpreted. The purpose of this process is to deliver results that are authentic, reliable, and trustworthy. The main idea of the texts was read by the researcher from a sample of randomly selected participants during the phone interview. After obtaining the participant's consent for the texts, several questions were asked. Afterward, the texts were individually read to each participant and feedback was received about the texts.

(4) Transferability: A study's transferability refers to its ability to be applied in different situations and populations (Elo et al., 2014). The reader must then determine whether the findings and conclusions reflect their context and experiences (Shenton, 2004).

A generalization of the results of this study cannot be made for all amputee children. However, this study will focus on amputee children who receive care at Al-Bashir Hospital and Farah Center of the Royal Medical Services because these hospitals serve all Jordanian governorates as central hospitals.

3.9 Pilot Study

Pilot studies are mini-versions of full-scale studies known as feasibility studies and include specific pre-testing of research instruments, such as questionnaires and interview schedules. Pilot studies are an essential part of any study design. Pilot studies do not guarantee success in the main study, but they do increase the chances. Research pilot studies have several important functions and can provide valuable insights for other researchers. In the current study, the interview schedule was tested by conducting an interview experiment with three participants who are qualified for the study, asking them about the interview questions and determining whether they are understood. Then, the participants were interviewed at the location where the interviews were conducted, along with assessing their suitability for the study. In carrying out this pilot study, the experience in conducting interviews with participants and conversing with them is also gained, along with making early suggestions about the research.

CHAPTER FOUR
Result Discussion & Conclusion

In this chapter, the results of the study are presented, along with a description of the sample. Throughout this chapter, the themes identified are based on the research questions discussed in the objective and aims section.

RESULTS
4.1 Participants

The study participants were communicated over the telephone and interviews were scheduled with them based on their hospital appointments. As no new patterns of information emerged after interviewing about (20) participants; (8) females and (12) males, the majority of the causes of amputation among the participants were congenital (n=16). Once the saturation point was reached, the interview process ended.

Regarding the data collection, it was completed without any withdrawal of consent by participants. Table (1) shows the demographic data of the interviewees, where each child was given a pseudonym, and none of the mentioned names corresponded with the names of the participants in the study, as they were given these pseudonyms to notify the reader that they are people.

Table 1

Sample Characteristics from Children Interviews (n=20)

Child Symbols	**gender**	**age**	**Residency**	**Type of amputation and level of amputation**	**School attendance and self-evaluation**	**Present of prosthetic**
Ahmad	*BOY*	*18*	*urban area*	*Congenital, below elbow*	*Yes, very good*	*Yes*
Lara	*Girl*	*18*	*rural area*	*Acquired, above knee*	*Yes, excellent*	*Yes*
Mohammad	*Boy*	*15*	*Rural area*	*Congenital, above knee*	*Yes, acceptable*	*Yes*
Mays	*Girl*	*14*	*Urban area*	*Acquired, above knee*	*Yes, excellent*	*Yes*
Saher	*Boy*	*9*	*Rural area*	*Congenital, below knee*	*No*	*No*
Basel	*boy*	*8*	*Rural area*	*Congenital below knee,*	*Yes, very good*	*Yes*
Tala	*Girl*	*17*	*Rural area*	*Congenital, above knee*	*No*	*Yes*
Oday	*Boy*	*17*	*Rural area*	*Acquired, below elbow*	*Yes, acceptable*	*No*
Ali	*Boy*	*12*	*Urban area*	*Congenital, below knee*	*Yes, excellent*	*Yes*

Child Symbols	**gender**	**age**	**Residency**	**Type of amputation and level of amputation**	**School attendance and self-evaluation**	**Present of prosthetic**
Hamzah	*Boy*	*10*	*Rural area*	*Congenital, below knee*	*Yes, good*	*Yes*
Ayman	*Boy*	*15*	*Rural area*	*Congenital, both leg*	*No*	*No*
Yaser	*Boy*	*10*	*Urban area*	*Congenital, below knee*	*Yes, good*	*Yes*
Eyad	*Boy*	*15*	*Rural area*	*Congenital, below knee*	*Yes, good*	*Yes*
Rama	*Girl*	*10*	*Urban area*	*Congenital, above elbow*	*Yes, excellent*	*Yes*
Belal	*Boy*	*14*	*Rural area*	*Acquired, Above knee*	*Yes, acceptable*	*Yes*
Osama	*Girl*	*9*	*Rural area*	*Congenital, below elbow*	*Yes, very good*	*Yes*
Yaqeen	*Girl*	*13*	*Rural area*	*Congenital, below knee*	*Yes, good*	*Yes*
Laith	*Boy*	*8*	*Rural area*	*Congenital, below ankle*	*Yes, good*	*Yes*
Yasmeen	*Girl*	*10*	*Rural area*	*Congenital, above elbow*	*Yes, very good*	*Yes*
Salma	*Girl*	*9*	*Rural area*	*Congenital, above knee*	*Yes, acceptable*	*Yes*

4.2 Themes

The essence of the phenomena is illustrated as five-theme clusters and (11) themes that captured the life experiences of children who had amputation:

Table 3

Emerging Themes and Subthemes of Children with an Amputation Experience

Themes	**Subthemes**
The child's beliefs about his amputation.	(1) The child's feeling that he does not belong to humans and that he is a stranger to them.
In the same way as other children, I would like to attend schoo1l.	(1) The child's frequent absence from school and the decline in academic performance due to frequent visits to the hospital. (2) The child's relationship with his peers. (3) School activities that the child was denied due to amputation.
Psychological suffering	(1) Feeling of loneliness “feeling that the child was rejected” (2) Feeling guilty (3) Poor body image and low self-confidence.

Themes	Subthemes
Child coping after amputation.	(1) Family and its role (2) The child's self-reliance in performing his daily tasks after amputation. (3) The child adapts to the prosthesis and considers it a part of his body or refuses. (4) Limited awareness of amputation due to the age of the child.
No one is incapable, but society hinders them.	

4.2.1 Child's Beliefs about His/ Her Amputation

Participants reported a category of experiences related to this broader theme: The child's feeling that he does not belong to humans and that he is a stranger to them.

4.2.1.1 The Child's Feeling that he does not belong to Humans and that He is a Stranger to them:

Several participants refused to accept their amputations, leading them to believe that they were not humans and described themselves as strangers to their peers. In addition, they believed that the absence of a part of their body made them completely different, whether from their brothers or other people, where one of them thought that he looks like a monster in fairy tales and is called (the man whose feet were skinned); for example:

Lara said "Every time I think of myself, I ask myself, why am I like this? Why am I different from the rest of my brothers?"C2
I had a difficult childhood during which I wondered why I was the way I was. Why am I different from the rest of the students in my class? I always felt different, and I talked about why I was different.

Tala said "I didn't live the stage of childhood because I used to see girls and, my brothers and sisters used to go to my second sister's house and go to the market. I would only look at them, but I could not go out with them, so I felt like something was missing from me since I did not live like them." C7

Hamzah said "In my mind, I imagined myself becoming like the man whose feet were skinned if I cut off my legs. Do you know him? We always hear about this from our people." C10

In contrast, several participants were of the opposite opinion, believing the amputation to be a normal occurrence, for example:

Ahmad said "I have been like this since I was young. Amputation is normal for me, and this amputation is God's will. It is normal for me, and I thank God for everything. It feels like I'm a normal person, and I have a prosthetic leg. What does that mean? I have adapted to the situation and it *is very normal for me. I feel the same way as my relatives and friends. There is no difference between us."C1*

While some participants believed that despite amputations, they were better off than others because they could walk and do many things that others could not for example:

Mohammad said "Despite this, I live like other children and do all the activities that children my age do. Furthermore, there were many disabled students in my class and my situation was better than theirs." C3

The children described their beliefs about the amputation they had based on their experiences.

4.2.2 In the same way as other children, I would like to attend school (school issue)

Children between the ages of (6 and 18) spend most of their time at school. This is an important aspect of their lifestyle, so this study aims to learn more about their experiences with amputation. Due to this, it is significant to mention school-related issues and their experiences regarding amputation within the school. Therefore, school difficulties emerge as a significant theme consisting of three sub-themes: 1- The child's frequent absence from school and the decline in academic performance due to frequent visits to the hospital, 2- The child's relationship with his peers, and 3- School activities that the child was denied due to amputation.

4.2.2.1 The child's frequent absence from school and the decline in academic performance due to frequent visits to the hospital

As a result of one of the child's limbs being amputated, the child is required continuing visiting the hospital for physical rehabilitation, prosthetic limb installation, and reviews by the Prosthetics Department, which requires the child to miss school frequently and to review his academic performance. Here are a few examples:

> *Lara said "I was delayed for a whole year by my classmates because of the amputation, even though I was one of the first in my class when I had the operation. Due to my absences from school for three months, my principal kept me in my class."*

While the child achieved excellent academic results, the amputation process caused her to be late for an academic year. This caused her to fall behind her peers, affecting her psychological health.

> *Mohammad said that "He academically suffered because of the many operations and hospital visits, leading to his declining academic performance. Because of the financial situation, and my family couldn't enroll me in a private school."*

In another case, the child's academic performance declined despite remaining in the same class as his peers. As a result of his frequent absences from school and many surgeries, his performance was rated as acceptable. His health condition occupied all of the family's attention, causing them to neglect his academics, in addition to not having the financial ability to send him to a specialized school for rehabilitation.

In contrast, some parents did not send their children to school to prevent their health condition from getting worse, or because they did not have anyone to help them, for example:

> *Tala said "As a result of my condition, my father did not want me to attend school because of the position of my two legs. But my older sister taught me how to write and read, so now I can spell and read any word, and I know the numbers. Because I was tired while at home and my legs hurt, they did this to me out of fear for me. Since I was at home and was getting tired and my legs hurt when I didn't get out, how things would be if I went to school?" C7*

In contrast, some of the children expressed their love for the school and its excellent academic performance, noting that amputation did not affect their grades.

> *Ali said" I am a smart and excellent student, and I love studying. When God takes something from me, he replaces it with something else." C9*

It was shown that children with amputations had various academic performance levels, ranging from acceptable to excellent. Some children argued that their academic performance was acceptable or good because they were frequently absent from class as a result of frequent hospital visits and surgeries. Therefore, their academic performance declined as a result. Although the children who had excellent academic performances argued that despite his amputation, his family taught him everything he missed during his hospital stays and followed him up continuously; they are still smart despite the amputation they have. There were also a few cases when children did not receive any education, which was the result of a lack of resources at school as well as parents' fears that their condition would worsen.

4.2.2.2 The child's relationship with his peers

To identify how amputee children deal with their peers, they were asked to describe their relationships with their peers. In addition, they were asked to describe their assistance to each other. Most of the study participants reported that bullying was a frequent occurrence at school, while in others; cooperation and assistance characterized their relationship with their peers. Here are examples in which she described being bullied by her classmates at school:

> *Lara said "In school, I have suffered from bullying sometimes. They made comments and mocked me for my legs, and I felt different, but this was a long time ago. Maybe it still exists, but I no longer care, because I have grown up and matured."C2*
>
> *Oday said "During that time, I experienced severe bullying. Some children talked to me in an ugly way, telling me had no hands." C8*

However, several children indicated that they had good relationships with their peers and had a lot of love among them and they helped each other in many ways as well, for example:

> *Ahmad said, "My relationship with my friends was like a brotherhood, and I joked with them and laughed with them rather than being grumpy."*
>
> *Mohammad said, "Whenever I play with the rest of the students, I was usually a cheerful person who communicates with his colleagues amicably, and I have a close friend."*
>
> *Mays said "At school, I am friendly with all my school colleagues, not just my friends who are with me in the class. I have never been subjected to bullying, since whenever I mention that I have a prosthetic limb, people are surprised because it doesn't look like a leg at all, and no one has ever explained why your leg is that way."*

A child's reaction to his peers differed from child to child, so each one had a different perspective on his peers. Despite having an amputation, some of them have made many friends and described it as something normal. However, some of the children had a different opinion, as they had been bullied by their classmates. The reason they were bullied is because they didn't have a side and looked different from most of their peers. This caused them to feel like outcasts and different from their peers.

4.2.2.3 School activities that the child was denied due to amputation

As children in school, many physical activities were carried out routinely, beginning with attending school and ending with returning home; walking to school in the morning, standing in the morning line, participating in the school radio, and participating in sports classes. However, there were some children excluded from doing these activities because of their amputated limbs. This context calls for a discussion of the experiences of amputee children with physical activities.

Lara said that "The girls wanted to go on a school trip, but I could not go with them. I wanted to participate in the sports class, but I couldn't go. It was difficult for me to participate and stand in the morning line, so I stayed in class. Even during recess, I stayed in class, and the girls in the classroom bought me from the canteen. In terms of fatigue and transportation, I had to go to school by taxi and at my own expense, *because I could not walk to school, which was financially costly to me and my parents.”*

Mohammad said, “I was excluded from school physical activities, but now it is normal, my situation improved, and I started playing with the rest of the students.”

Basel said “I cannot ride most of the games that I love in the city of games, so I watched my friends climb them. On the trips I used to go on, I did not walk. I used to stay by the bus and didn’t walk much.”

In contrast, some children continued to do many physical activities despite their amputations, and they didn't feel restricted. For example:

Mays said “Whenever I go on school trips and if there are games that I want to ride, I ride them normally, even if my friends do not want to play them. I also play running games at school. I do not get tired even when walking long distances.”

Oday said “At school, I was not deprived of anything. I participated in school trips and sports activities. I stood during the morning assembly. I was treated the same as the rest of my friends by the teachers.”

We conclude from the foregoing that amputation for some children is a physical barrier. This is because they cannot participate in many physical activities, which has a profound effect on their lives. This amputation prevented them from participating in physical school activities and recreational activities considered appropriate for children of school age.

However, amputation for some children was a natural thing and it did not have a physical effect on them. Therefore, they practiced their lives and activities normally and were not prevented from doing any activities. On the other hand, they did additional activities, such as going to the gym. Some of them learned to drive a car to get their license when they reached the age of (18). Some of them participated in swimming activities despite having an amputation.

4.2.3 Psychological impact

One of the objectives of this study is to describe the experience of amputee children, so we need to describe the challenges faced by those children by describing the psychological state of amputee children and discovering the effect of the psychological state on their lives, where this theme consisted of subthemes: 1- Feeling of loneliness “feeling that the child has been rejected”, 2- low self-confidence, 3- Poor body image, and 4- Feeling guilty.

4.2.3.1 Feeling of loneliness (feeling that the child has been rejected)

The researcher interviewed the study participants to determine how amputation has affected their lives and their feelings about it. A small number of children expressed feeling rejected because they had difficulty seeing themselves in a positive view and seeing themselves differently from others, where they thought that the other children are better than them, in addition to the ridicule presented by other children over their amputation, leaving them feeling isolated. For example:

Lara said that " Sometimes they teased me for my legs, and I felt like an outcast and different from them."

Oday said that "My first time out, I get annoyed by people's looks, so I want to go back home, and I don't want to stay outside. In this case, I don't want to go out, I don't want to be with anyone, and I don't want to see anyone."

In contrast, some of the children expressed different opinions, as they were far from being isolated, and it was quite the opposite, due to their strong integration into society, their school and neighborhood peers, as well as their great social mixing. Some parents kept their children at home so that they can study. However, some children spent their time outside playing, not interested in studying, but rather playing in the lane with their peers.

When I asked about his relationships with his neighbors, Belal said "Their family punished him because he played with his friends for long periods while abandoning his lessons."

4.2.3.2 Feeling guilty

A child born into a family, and needs health care, affects all family members, causing them to suffer financially or morally, affecting the child himself, as he believes that he was the main cause of his parents' suffering, whether financially or morally, making him feel guilty for the amputation's existence. For example:

Hamzah said "Isn't it appropriate that amputees shouldn't be an ordeal for our families, but rather a gift? Why don't you secure a salary for a person with a disability? As a result of his situation, I think this person will be a burden to his family."

The opposite was found in some cases, since the family played a major role in this, atopic which will be discussed later in this thesis. Here, it was the environment around them and the family that caused some children not to feel guilty about an amputation. For example:

Mays said, "I am not affected at all, as my family doesn't make me feel the deficiency, nor do people outside my home, nor do my relatives, and I've been in this situation for a while, so I'm not affected."

From the foregoing, we conclude that children involved in the suffering of their parents feel more guilt and that they are responsible for this suffering. A sense of guilt can be triggered by the amputee's family or the society in which he lives, by telling him either directly or indirectly that he is helpless and depends on them for his survival.

4.2.3.3 poor body image and low self-confidence

As part of this discussion, children's experiences with their external appearance after amputation and how that affected their self-esteem are discussed. Some children reported that the amputation affected their external appearance since they had to wear long and wide clothes to conceal the amputation or the prosthesis. When these children stood in front of the mirror, they expressed sadness over the fact that they had an amputation, in addition to the way they thought, and their constant question of why they didn't have a natural party, and why they weren't like their brothers. These experiences affected their self-confidence, as most of them refused to go out because of the amputation they had and the shape of their bodies that differs from their peers as a result of the amputation, in addition to their fear of being mocked. For example:

Oday said " As I stood in front of the mirror, I told myself that I needed a prosthesis, and I thought about my situation and others of my age. In front of a mirror, I was annoyed with myself and asked why I was like this."

Lara said that "Since the amputation, I had to wear long, loose clothes to hide my prosthesis and change my way of walking. I could not walk as others do."

The experiences of children in this study suggest that children who have amputations may lack self-confidence due to their external appearance, which they perceive as a deficiency in themselves, and that as a result of this deficiency, they are different from their peers, where they view their peers as better than them because they do not have this deficiency. Other children had self-confidence despite their amputations and external appearances, expressing that they do not differ from their peers when it comes to their appearance. For example:

Mays said, "As for me, this has become a matter of trust, since I consider myself normal, and whoever says I don't care about him should know that I live with amputation and I have confidence in myself beyond what is usual."

Regarding this, children with amputation suffer from psychological problems, such as low self-esteem due to body image disturbance, which makes them feel rejected by their peers, so they isolate themselves.

The experiences of children in this study differ from one child to another, as each child grew up in a different environment than the other, and each child had his surrounding environment from the family and society, playing an important role in accepting his appearance and shape, as well as in his self-confidence, more details about their role later are provided in the next sections.

4.2.4 Child coping after amputation

When determining whether the child has adjusted to amputation, it was important to know the child's family role, his or her self-reliance, and whether he or she has a prosthetic limb. All of these factors can play a part in determining whether the child has adapted well to amputation. Due to the foregoing, this theme has been divided into subthemes: Family and its role, the child's self-reliance in performing his daily tasks after amputation, the child's adaptation to the prosthesis and considering it as a part of his body or refusal to accept it, and limited awareness of amputation due to the age of the child.

4.2.4.1 Family and its role

The love a parent has for their child cannot be measured, and seeing their child ill, diagnosed with a disability, or needing life-changing surgery is their worst nightmare. The most significant thing is that parents find the strength to move forward, so their children can have a safe and happy childhood. It is especially true for children who have undergone an amputation.

The parent and family members play a major role in the child's adaptation to amputation; they help the child prove himself to himself and others, they contribute to not making him feel inferior, treating him like the rest of his siblings without excessive sympathy and pity feelings towards him, in addition to encouraging him to accept his amputation and accept his physical appearance, so that others will accept him as well.

Conversely, some children suffer excessive parental protection, where their parents differentiate them from their siblings, show extra interest in them, make their siblings do their tasks, and help them with all of their work, so that the amputee children become dependent on their family and are seen as a helpless individual who cannot do anything without assistance. Several children in this study said that their family played a significant role in their adjustment to amputation, as most of them agreed that the family supported them financially and morally and encouraged them in many ways. Along with reassuring the child and giving him a feeling of warmth and fear for his feelings, the family does everything possible to provide him with the appropriate environment and education.

In some cases, the family plays a positive role in the child's development. In this case, the family convinced "Mays" that she was not deficient in any way. She should also understand that she is not different from others, but rather that she is better. This idea had been established for her, so she convinced herself and others around her of it until she became a beloved child both inside and outside her home

Mays said "Since I am the only girl and the youngest member of my family, I am the most pampered one of them. Even if there is no amputation, they will pamper me. My grandfather's house is complete, as well as my family's; it's not just because I have a prosthetic limb. It is normal for me to have a prosthetic limb (I am a normal girl)."

Also, parents' words played a crucial role in the lives of their children, which they viewed as responses to every situation for example:

Ali said "My mother tries not to show anything for me; every time I tell her that this amputation annoys me, she tells me it's from God. She also tells me there are other things God gave you that others don't have. You're smart."

However, some parents, who are a minority in this sample, fear excessively for their children and do not want to let their child enter school and learn, so they prevented him from attending school. It is not out of deprivation, but rather from fear of his health deteriorating, and fear that no one will help them get to school and move within it.

Tala said "Because of my condition, my father does not want me to go to school, because the position of my two legs is not good. He does this out of fear for me, because while I am at home, I am getting tired and my legs are hurting while I don't go out, so how will things be if I go to school?"

From these children's experiences, we conclude that the family is the child's first supporter, as the child's positive adaptation to amputation depends on his family. As a result of the family's support and encouragement, the child becomes more confident despite his amputation. Often, parents' desire to protect their amputee children results in insecurity, low ambitions, and low self-confidence.

4.2.4.2 The child's self-reliance in performing his daily tasks after amputation

In this study, many of the children who said that they needed help after the amputation process, were unable to serve themselves and needed their parents to assist them with going to the bathroom, wearing clothes, and eating. However, after some time had passed since the amputation operation, they began to rely on themselves in a way that allowed them to become self-reliant, although most still need assistance. For example:

Mays said "I have been self-reliant since I was in the third and fourth grades, and now I'm completely independent, doing everything around the house myself. My mother does nothing but cooking since I'm the only girl in the house."

Based on the data above, it is concluded that children initially find it difficult to rely on themselves after the amputation, but with time they begin to adapt, especially after installing the prosthesis, which we will discuss later concerning its role in the child's adaptation process after the amputation. As in the previous case, when "Mays" needed to rely on herself immediately after the amputation, gradually she was able to do other household tasks despite her amputation.

In some cases, children were so dependent on their parents from childhood that they were kept at home by their parents out of fear for them and because no one could help them, so they could not attend school. Since these children are usually accompanied outside the house, they are unable to attend school.

C11Ayman said that "The only time I leave the house is when my brother takes me shopping with him. My mother is the one who does everything because I can't walk."

In the previous case, the sad thing was that he had a younger brother who had the same congenital amputation and the same suffering, where his family kept him and his brother at home, and they went out with their older brother or one of the parents because they needed help. Also, they spent most of their time either watching TV or using the phone in the house.

The dependency of amputee children on themselves ranges from the presence of completely self-reliant children and children who are partially dependent on their parents, who may, if they grow up, become fully self-reliant, in addition to the children who are completely dependent on their families due to the amputation they have.

4.2.4.3 The child adapts to the prosthesis and considers it a part of his body or refuses it

In most cases, prostheses are installed within a period after the amputation process is completed, once the child has completely recovered from the amputation. When a child is brought in for an initial visit to determine the length of the prosthetic limb, the child is then contacted after a month or two to install the new prosthetic limb, and this is the attitude of most children who have installed artificial limbs.

In the first few days after installing the prosthesis, most of the children found it difficult to use the prosthesis because it seemed strange and heavy to them. They also described their experience with the prosthesis as a difficult one, since they found it difficult to wear it and found comfort in taking it off, then with time they gradually got used to wearing it permanently. For example:

Ahamd said "In the beginning, I disliked wearing the prosthesis. If I wanted to wear it, I would either wear it only once or twice a week, or I wouldn't wear it at all. Sometimes it would hurt me or bother me, or my hands would swell. Then, after wearing it for a while, I started wearing it daily, and I was sleeping in it as well. Now that I am used to it, it doesn't hurt anymore, and I wear it normally."

In contrast, some children were very young when they fitted their prosthetic limbs, some fitting them at the age of one and a half years, so they were unaware of what it feels like to have a prosthetic limb for the first time; therefore, they have adapted to the prosthetic limb since childhood, considering it as an integral part of their bodies. For example:

Ali said "My prosthesis became a part of my body when I was young, and I got used to wearing it all the time and taking it off only when I slept"

Although most children in this study had prosthetic limbs, very few children did not have prosthetic limbs despite their amputations. Although they expressed a need for a prosthetic limb, they were informed that they would be contacted if industrial materials became available. For example:

Oday said, "To be honest, since I was young, I went to the prosthetics department to put the limb, and I am now 17 years old and until now, the hospital told me to contact you if there are materials available."

Based on the interviews, the researcher found that the children without a prosthetic limb struggled with coping with the amputation since they expressed their dissatisfaction with not having a prosthetic limb installed and stating that their lives would be better if they had the prosthetic limb, as opposed to the children whose prosthesis gradually became part of their bodies and showed their gradual adaptation to it.

Awareness of amputation due to the age of the child

Theme summarizes the child's awareness when he performed amputation and his knowledge of amputation and what is it. Additionally, did he have a role in deciding to amputate, and what he had suffered following the operation? As a result, was he affected by the loss of his limb?

Several participants said that they were unaware of the amputation when it was performed since the amputation was performed while he was unconscious. Therefore, he did not understand what an amputation is and what it means to lose a limb, so he had no freedom in making the decision. The following is an example of what one participant said:

Ahamd said "When I asked him, what was your reaction to being told that you would need an amputation? He said I was young at the time and wasn't aware that I had a congenital defect."

Basel said, "Despite not knowing what the operation is and why it is performed, he tells his mother that he remembers when he was taken for the surgery and he was crying as she deposited him at the door."

If a child has had amputation since childhood, but has not been aware enough to remember the details, and wasn't accustomed to having a limb, this may be beneficial to them, since they did not experience the pain of losing a body part or the feeling of losing a limb.

In some of the interviews, participants described how they felt during the time of the amputation and recalled what happened for example:
Tala said "It was very difficult for me. I asked what would happen if I amputated it. Will I crawl on the ground if I want to amputate it? Since I want to walk, the doctor told me I don't even know what amputation is, or that prosthetic limbs exist. You will walk and play football, too. You will find it difficult at first, but you will adapt to it over time. I am encouraged by the doctor's words, following my leg amputation, I experienced a difficult psychological state. After losing my limbs, I began considering how I would move and what I would do."

Because he was used to the presence of the limb, and because he liked the movement, he believed that the amputation would worsen his condition. Mays said "*Before the amputation, my mother told me that your leg caused you a lot of pain; now that it has been damaged, we would like to replace it with a new one. My mother kept telling me that the new foot would be better than the old one and that it wouldn't bother me. All that mattered to me was the fact that I wanted to rest and was not afraid."*

Furthermore, the child's awareness of amputation was a positive aspect, since it showed that he understood the concept and that it might relieve pain caused by disease and chemical exposure.

4.2.5 No one is incapable, but society hinders them

There are many ways through which society members treat these children, including ridiculing and bullying them or expressing curiosity towards them, as they are asked questions to find out why their legs were amputated. Also, some people stared at them for a long time and interfered with their privacy, which made them withdraw and shy. Therefore, providing help and assistance to amputee children should not be associated with compassion and kindness, so as not to impose an inferior image on them or hurt their feelings. For example:

Hamzah said "The feeling of inadequacy was evident, particularly in the looks and interactions with others. If someone treats you out of pity, this in itself will cause a negative reaction, not because this is your right, but because he pities you."

Mays said "If anyone asks me about my legs, I say I am still a child, what do you understand? If I saw any child with a side like me, I would ask him, because it is normal to ask."

An amputee's mental health is influenced by society's attitude towards him, whether this is a negative or a positive attitude. It negatively impacts both his adaptability to himself and society.

Regarding the challenges and difficulties experienced by Jordanian children with an amputation, some acute and long-term challenges are experienced by the children and their families; these are post-traumatic limb amputations manifested by stress, anxiety, depression, and social isolation. On the other hand, there were physical and financial challenges related to lack of financial availability and support, since those children need prosthetic devices and frequent hospital visits. Also, the lengthy and costly hospital stays of children post-amputation result in physical suffering related to pain and psychological implications, leading to significant morbidity and continuous suffering.

4.3 Summary:

This study aimed to describe the lived experience of Jordanian children with an amputation and discover the challenges and difficulties experienced by Jordanian children with an amputation. Participants who have amputation volunteered to complete semi-structured interviews.

Five distinct themes captured the lived experience of children with amputation: :(1) the Child's beliefs about his/her amputation, (2) In the same way as other children, I would like to attend school (school issue), (3) Psychological Impact, (4) child coping after amputation, (5) No one is incapable, but society hinders them.

The data taken from the amputee children revealed that the adaptation of the amputee children varies according to the cause of the amputation, as it was found that the children who had amputation since birth were more adaptable than the children whose amputation was acquired. The data taken from the children also revealed that most of their experiences were in the form of the difficulties they faced. The results revealed that amputee children faced physical problems that prevented them from physical and recreational activities and resulted in a decline in their academic evaluation due to frequent visits to the hospital. In addition to the psychological impact of amputation on these children, they suffered from frequent bullying and poor body image, which resulted in their feeling of rejection, loneliness, and lack of self-confidence.

4.4 Discussion

In this chapter, the researcher will discuss and describe each of these themes in detail and compare the results of the current study with literature on amputee children's experiences. Furthermore, the researcher will discuss the limitations of this study and its effects on amputee children, as well as future recommendations for research on amputee children. This study used a qualitative phenomenological approach to develop a comprehensive understanding of the lived experience of Jordanian children with an amputation and describe the challenges and the difficulties experienced by the Jordanian children with an amputation, which were collected manually by the researcher using data from semi-structured and individual interviews conducted with amputee children. A description of the experiences of amputee children was the purpose of the study.

The current study revealed that amputee children have many life experiences, which could represent more challenges than experiences due to their amputations. Several themes were identified through the data collected from various sources. The experiences of amputee children were categorized into (5) themes, including (1) Child's beliefs about his/her amputation, (2) In the same way as other children, I would like to attend school (school issue), (3) Psychological impact, (4) Child coping after amputation, (5) No one is incapable, but society hinders them.

In this study, according to the children's beliefs about amputation, children who were amputees described themselves as strange to their peers and as not human. Some of them described themselves as monsters without limbs because of their amputations. The results of this study disagree with those (Andregård & Magnusson, 2017), which suggested that the beliefs of the children are based on the beliefs of the community since the community classified them as devils living in human bodies and that this amputation resulted from witchcraft, making those children believe in this.

The majority of participants believed that they were normal children, who were not different from their peers, and that they were used to living with their amputations. This confirmed what was found in (Griffet, 2016), which found that children adjust better to amputations than adults. Throughout this study, the theme of "In the same way as other children, I would like to attend school" summarizes how amputee children expressed their desire to attend school without facing barriers since most of these children suffer from a decline in academic performance as a result of their amputation. As a result of frequent hospital visits and rehabilitation centers, they have to miss school. Similarly, this result matches with what was reported in this study (Hocking et al., 2018; Chhina et al., 2021), showing that repeated absenteeism from school caused by cancer and amputation is a major obstacle to academic success.

As this study shed light on children deprived of school as a result of amputations and a lack of assistance in schools, it is somewhat similar to (Chhina et al., 2021), which found that amputee children who have congenital limb amputation have difficulty adjusting to school due to environmental obstacles, such as climbing stairs, especially those on wheelchairs.

In this study, the relationship of amputee children with their peers differed, as the majority of children were ridiculed and bullied at school because of the amputation they had. This finding agrees with (Calder et al., 2017) who found that amputee children were bullied by their peers due to their condition. Despite this, some of the children in the study had good relationships with their peers and had good friends who helped them despite their amputations. Indeed, those children were encouraged to engage with their friends and form relationships with them. This finding agrees with the findings of a study conducted by (Rosenbaum & Gorter, 2012), which suggested that children with amputations should be encouraged to establish contact with peers and participate in a peer group.

This study found that some children with amputated limbs suffered physically as a result of the amputation, and so many participants described their experiences with physical activity. In addition to the difficulty of moving due to their inability to walk long distances without pain, these children were deprived of many physical and recreational activities. This finding agrees with the study conducted by (Chhina et al., 2021), which showed that amputee children had limited ability to balance, perform sports, and engage in recreational activities. They also experienced pain when walking or running long distances. A group of participants were living their lives naturally, without assistance, in addition to their regular activities like swimming, exercising, and participating in recreational activities. In a similar vein, (Matheri & Frantz, 2009) found that children with amputees are more likely to remain physically active if they are confident in their abilities.

The theme of "psychological impact” demonstrated how amputation affects children psychologically, as amputee children felt lonely. After all, they believed they were different from the other children, and that these children were better than them because they did not have amputations, which caused them to feel alone and isolate themselves from other children. This result agrees with (Chhina et al., 2021) which found that children feel isolated and lonely, especially when asked to go and play with their peers.

Despite this, some children in this study were able to play with their peers without feeling rejected or lonely, since they were participating in activities with their friends, whether they were at school or playing with their friends in their neighborhood. This result agrees with (Kanagasabai et al., 2018) which found that some amputee children experienced fun, challenge, achievement, and independence. The researcher found that some children felt guilty about their amputations since their families suffered financially and morally as a result. Although there are no studies supporting this, a study (Harvey et., 2020) found that parents are usually the ones who feel guilty because they are the ones responsible for their children's conditions and unable to help them.

After the amputation, the child's perception of himself changed. The researcher found that most children are embarrassed about their appearance because they had to wear wide and long clothes to cover the prosthesis and the amputation, as well as feeling sad about seeing themselves in the mirror. As a result, they did not feel confident about themselves. A study conducted by (Chhina et al., 2021) demonstrated that children were forced to wear specific clothes to hide amputated body parts, and they were unable to wear whatever they wanted. Additionally, due to their concerns about their body image, they discussed how their amputation-related problems affected their self-confidence and self-esteem.

Concerning the theme of “child coping after amputation", adaptation to amputation in a child depends largely on the role that his family plays in dealing with the amputation as well as the child's awareness of the time at which the amputation was performed and the time at which the prosthetic limb was placed. Additionally, the child's self-responsibility plays a large role in the child's adaptation. As a result of this study, amputee children are more likely to be accepted by others if they grow up in families that provide them with continuous support and help them prove themselves in society. Those children should not be shown excessive interest in them, but they should be encouraged to accept their amputations. In this way, children will be able to adapt to their amputation. This finding agrees with (Oliver et al., 2020), which described the role of parents in supporting their children with prosthetic limbs, where parents described their experiences, and stated that they provide support for their children, contain them, and protect them and that they are always careful not to inform them that they differ from the rest of their peers.

Despite this, there are children whose families prevented them from going to school because of their fear of them, claiming that they need help, and this is known as negative positivity. This finding agrees with (Andregård & Magnusson, 2017) who found that some participants were told by their families that they could not attend school because of their disabilities. As a result of the amputation, children who lost limbs at an early age did not suffer from the loss of their limbs and were unaware of the amputation, and their acceptance of their physical appearance also differed from that of children who lost limbs at an age when they were aware of the amputation and experienced the suffering that comes with losing them. This result agrees with (Demirdel & Ülger, 2021), which found that children who commonly amputate their limbs at an early age and experience body change due to amputation feel less discomfort than adolescents.

After the amputation operation, the researcher found that most of the children needed help in all aspects of their lives, and they may continue to need help for years to come. As they age, they become more independent and rely on themselves, especially when they are fitted to their prostheses. This result disagrees with (Bloemen et al., 2015), which revealed that children and adolescents with physical disabilities faced specific barriers with their increasing age.

According to this study, a prosthetic limb is one of the important ways through which children adjust to amputation since it was found that children putting the prosthesis on at an early age are more adaptable to an amputation. A person who rejects the limb at first, but gradually becomes accustomed to it and considers it a part of themselves has been proven by a study (Braaksma et al., 2018), which concluded that prostheses are more successful among children than in adults. Despite this, several children were unable to obtain prostheses, either due to a lack of materials in the hospital or due to a lack of money. This result agrees with the (Andregård& Magnusson, 2017), which revealed that the participants suffered and were forced to crawl on earth as a consequence of their financial inability.

Regarding the theme “No one is incapable, but society hinders them". This study found that most participants felt that society was not on their side and was not supportive of them most of the time. Indeed, community members showed excessive curiosity about the amputation, and thus the children expressed frustration with society's treatment of them. They continued to ask them about the reason for the amputation, which caused them to become embarrassed. They expressed frustration with society's behavior toward them. They also showed excessive pity towards them, which makes them feel inferior, and this was confirmed in a (Stricklin, 2020) study, which revealed that children are usually surrounded by curious people who ask them about their amputations. Another study showed that participants felt they were treated negatively by society, as they were mocked and looked at with contempt, which caused them to feel unimportant (Andregård & Magnusson, 2017).

4.4.1 Strengths

This study provides a comprehensive view of amputee children's experiences since it discusses their psychological, physical, and social aspects. It is the first study that examines the experience of children with amputations in Jordan. A few studies focused only on the psychological aspect, while others emphasized the social aspect and the existence of qualitative research versus quantitative research. Additionally, the researcher included (20) children in this study, which allowed them to describe and discover their suffering closely, and the existence of parents during the interview were motivating to the child to describe his experience. In addition, Colaizzi's (1978) method was used to analyze data, which is rigorous and reliable, so the results can be trusted. Researchers can also identify emerging themes and their connections. Because most of the research is based on the experiences of amputee adults, there is very little quantitative research on amputee children.

4.4.2 Limitations

One of the limitations of the current study is that the researcher conducted this study on only two rehabilitation centers in military and governmental hospitals. However, the researcher did not interview children attending rehabilitation centers in private hospitals; this impedes the ability to consider the sample as a representative sample. In addition, the representation was for the children only, where there were no representations from other perspectives, such as parents and family. The perceptions of parents and family members are missing from this study. Direct interviews with parents of amputee children and their family members would have enriched the findings. In addition, they would offer a great understanding of their experience from their viewpoints. Additionally, this study used qualitative research focusing on phenomenological description, rather than statistical generalization, Finally, we don’t have a registry for the number of children with acquired or congenital amputation in Jordan.

4.4.3 Implication for Practice

Given the results of this study, it is emphasized that medical staff, including doctors, nurses, and technicians should work together to develop a comprehensive program for amputee children, including the amputee child, his family, and society. Also, for successful rehabilitation and care for children, there is a need for a multidisciplinary team approach involving the child's parents, physiotherapist, play therapist, and a child psychiatrist. On the other hand, there is a need to increase awareness among amputee children, introducing them to their amputations, helping them become more receptive to it, and spreading awareness to their families which, in turn, teaches parents how to deal with the child, support him, encourage him to accept the amputation, and make him an active family member who performs his tasks rather than being dependent on others. Furthermore, psychological support for children and their parents should be included in the program to prevent psychological problems, such as isolation and lack of self-esteem, as well as depression and anxiety associated with amputations.

Moreover, the data generated from this study helps plan strategic policies and programs at different community levels for prevention, treatment, and distribution of resources to care for children with amputation to ensure better health care and opportunities in life. We should not ignore the importance of the community, since this program should contain educational programs which, in turn, will help spread awareness among the community members regarding amputee children and integrating them into the community, along with preventing society from ridiculing them, treating them humanely, and accepting them as an important member in society. As a final note, the school plays a significant role in the lives of amputee children, since most of their time is spent there. Therefore, school nursing must continuously educate the school community about the importance of integrating amputee children into school and sports activities and fostering their peer relationships.

Additionally, this study has implications in the flowing nursing field:

1- Nursing practice: this study will build a structural nursing intervention for pediatric nurses that considers amputee children, their difficulties, and their needs.

2- Nursing education: this study seeks to develop an educational curriculum that considers amputation children, their challenges, and their need in nursing colleges and universities, in addition to directing undergraduate nurses on how to provide care when they meet those children regarding their challenges and their needs.

3- Policymaker: this study will provide conclusions and recommendations to policymakers to find strategic planning on the family, hospital, and community levels to help amputee children to normalize their lives.

4- Nursing community: this study will assist nurses in building an education program that engages all medical teams in a hospital to provide an appropriate education for children and their parents and rehabilitate them physically and psychologically. The study also aims to build an educational program that engages all teachers in a school to help amputee children inside the school, enroll those children with other children, prevent bullying on those children, deal with them as important students in school, and encourage them to be better.

4.4.4 Recommendations for Future Research

Conducting quantitative studies is necessary to generalize the results to the amputee children in Jordan. Also, we need qualitative studies to be conducted in private hospitals to compare these children's life experiences according to their different social classes to representative samples; it will enable us to discover the quality of life for these children. In addition, there is a need for further research to examine the experiences of parents of amputee children and their role in supporting them and examine the role of society in supporting amputee children.

4.4.5 Summary

This study aimed to highlight each of the five themes arising from interviews with amputee children. The amputee children's experiences, beliefs about amputation, and perspectives of themselves were examined to determine the best understanding of the experiences of amputee children. Moreover, a focus is given on the suffering of these children, whether physical, psychological, or social suffering and how it affects their adaptation to amputation.

4.4.6 Conclusion

This study is the first Jordanian study about the lived experience of children with an amputation. It concluded that children with an amputation suffer from psychological (self-image problems, anxiety, and stress), social isolation, and school problems. Therefore, we recommend pediatric nurses and other members working at rehabilitation centers to encourage the families, schools, and community members to help those children adapt positively to their condition to normalize their life.

References

Abdulraheem-Mustapha, M. A., & Abdulraheem-Mustapha, M. A. (2020). International and Regional Legal Framework on Child Justice Administration. *Child Justice Administration in Africa*, 129-154.

Ahmad J, Gupta AK, Sharma VP, Kumar D, Yadav G, Singh S. (2016). Traumatic amputations in children and adolescents: A demographic study from a tertiary care center in Northern India. J Pediatr Rehabil Med. Nov 30;9(4):265-269. doi: 10.3233/PRM-160398. PMID: 27935565

Al-Adwan, M., Najjar, Y., Hdaib, M., & Al-Khateeb, M. (2017). Variables Affecting the Amputees' Reactions Artificial Limbs in the Kingdom of Jordan. *Journal of the American Academy of Special Education Professionals*, 140–154.

Alexander, P. G., Clark, K. L., & Tuan, R. S. (2016).Prenatal exposure to environmental factors and congenital limb defects. *Birth Defects Research Part C: Embryo Today: Reviews*, *108*(3), 243-273.

Ali, S., Waqar, M., Anwar, M., Zahid, M., Sattar, A., &Arif, M. (2021). Self-Esteem as a Predictor of Psychological Adjustment to Limb Loss: A Case Study of Acquired Limb Amputation. *Journal of Gandhara Medical and Dental Science*, *8*(3), 53-59.

AlSofyani, M. A., AlHarthi, A. S., Farahat, F. M., & Abuznadah, W. T. (2016). Impact of rehabilitation programs on dependency and functional performance of patients with major lower limb amputations. *Saudi Medical Journal*, *37*(10), 1109–1113. https://doi.org/10.15537/smj.2016.10.16033

Al-Worikat, A. F., & Dameh, W. (2008). Children with limb deficiencies: Demographic characteristics. *Prosthetics and Orthotics International*, *32*(1), 23–28. https://doi.org/10.1080/03093640701517083

Andregård, E., & Magnusson, L. (2017). Experiences of attitudes in Sierra Leone from the perspective of people with poliomyelitis and amputations using orthotics and prosthetics. *Disability and Rehabilitation*, *39*(26), 2619–2625. https://doi.org/10.1080/09638288.2016.1236409

Armstrong, D., Gosling, A., Weinman, J., &Marteau, T. (1997). The place of inter-rater reliability in qualitative research: An empirical study. *Sociology*, *31*(3), 597-606.

Barofsky, I. (2012). Can quality or quality-of-life be defined? *Quality of Life Research*, *21*(4), 625–631. https://doi.org/10.1007/s11136-011-9961-0

Battaglia, M., Sampling, N., &Lavrakas, P. J. (2008).Encyclopedia of survey research methods. *Publication date*.

Belon, H. P., & Vigoda, D. F. (2014). Emotional adaptation to limb loss. *Physical Medicine and Rehabilitation Clinics of North America*, *25*(1), 53–74. https://doi.org/10.1016/j.pmr.2013.09.010

Berk, L. (2015). *Child development*.Pearson Higher Education AU.

Birch, J. G., Paley, D., Herzenberg, J. E., Morton, A., Ward, S., Riddle, R., Specht, S., Cummings, D., & Tulchin-Francis, K. (2019). Amputation Versus Staged Reconstruction for Severe Fibular Hemimelia. *JBJS Open Access*, *4*(2), e0053. https://doi.org/10.2106/jbjs.oa.18.00053

Bloemen, M. A. T., Backx, F. J. G., Takken, T., Wittink, H., Benner, J., Mollema, J., & de Groot, J. F. (2015). Factors associated with physical activity in children and adolescents with a physical disability: A systematic review. *Developmental Medicine and Child Neurology*, *57*(2), 137–148. https://doi.org/10.1111/dmcn.12624

Bock, W. J. (1980). The Definition and Recognition of Biological Adaptation. *American Zoologist*, *20*(1), 217–227. https://doi.org/10.1093/icb/20.1.217

Borne, A., Porter, A., Recicar, J., Maxson, T., & Montgomery, C. (2017). Pediatric traumatic amputations in the United States: a 5-year review. *Journal of Pediatric Orthopaedics*, *37*(2), e104-e107.

Borne, A., Porter, A., Recicar, J., Maxson, T., & Montgomery, C. (2017). Pediatric traumatic amputations in the United States: a 5-year review. *Journal of Pediatric Orthopaedics*, *37*(2), e104-e107.

Braaksma, R., Dijkstra, P. U., & Geertzen, J. H. B. (2018). Syme Amputation: A Systematic Review. *Foot and Ankle International*, *39*(3), 284–291. https://doi.org/10.1177/1071100717745313

Breuer, F. (2003). Subjekthaftigkeitdersozial-/wissenschaftlichenErkenntnistätigkeit und ihre

Calder, P., Shaw, S., Roberts, A., Tennant, S., Sedki, I., Hanspal, R., & Eastwood, D. (2017). A comparison of functional outcome between amputation and extension prosthesis in the treatment of congenital absence of the fibula with severe limb deformity. *Journal of Children's Orthopaedics*, *11*(4), 318–325. https://doi.org/10.1302/1863-2548.11.160264

Chhina, H., Klassen, A. F., Kopec, J. A., Oliffe, J., Iobst, C., Dahan-Oliel, N., &Cooper, A. P. (2021). What matters to children with lower limb deformities: an international qualitative study guiding the development of a new patient-reported outcome measure? *Journal of Patient-Reported Outcomes*, *5*(1), 1-12.

Ciocco, R., Hsia, M., & Konieczny, T. (2019). Pediatric hand therapy-prosthetics and training. In *Pediatric Hand Therapy*. Elsevier Inc. https://doi.org/10.1016/B978-0-323-53091-0.00006-3

Cope, D. G. (2014, January). Methods and meanings: credibility and trustworthiness of qualitative research. In *Oncology nursing forum* (Vol. 41, No. 1).

Davies, B., & Davies, C. (2007).Having, and being had by,“experience” or,“experience” in the social sciences after the discursive/poststructuralist turn. *Qualitative inquiry*, *13*(8), 1139-1159.

Demirdel, S., & Ülger, Ö. (2021). Body image disturbance, psychosocial adjustment and quality of life in adolescents with amputation. *Disability and Health Journal*, *14*(3). https://doi.org/10.1016/j.dhjo.2021.101068

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., &Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE open*, *4*(1), 2158244014522633.

Etikan, I. (2016). Comparison of Convenience Sampling and Purposive Sampling. *American Journal of Theoretical and Applied Statistics*, *5*(1), 1. https://doi.org/10.11648/j.ajtas.20160501.11

Gil, S., Fernandez-Pineda, I., Rao, B. D., Neel, M. D., Baker, J. N., Wu, H., Wu, J., &Anghelescu, D. L. (2019). Role of Amputation in Improving Mobility, Pain Outcomes, and Emotional and Psychological Well-Being in Children with Metastatic Osteosarcoma. *American Journal of Hospice and Palliative Medicine*, *36*(2), 105–110. https://doi.org/10.1177/1049909118791119

Griffet, J. (2016). Amputation and prosthesis fitting in paediatric patients. *Orthopaedics and Traumatology: Surgery and Research*, *102*(1), S161–S175. https://doi.org/10.1016/j.otsr.2015.03.020

Hall, M., Cummings, D., Welling Jr, R., Kaleta, M., Koenig Jr, K., Laine, J., & Morgan, S. (2020). Essentials of Pediatric Prosthetics: Current Concept Review. *Journal of the Pediatric Orthopaedic Society of North America*, *2*(3).

Hamill, R., Carson, S., &Dorahy, M. (2010). Experiences of psychosocial adjustment within 18 months of amputation: an interpretative phenomenological analysis. *Disability and rehabilitation*, *32*(9), 729-740.

Harvey, C. (2020). The uncanny effect of disability: Uncomfortable maternal love for a disabled child. *Contemporary psychoanalysis*, *56*(1), 1-28.

Hauben, D. J. (2014). *OF*. *July*.

Hocking, M. C., Paltin, I., Belasco, C., & Barakat, L. P. (2018). Parent perspectives on the educational barriers and unmet needs of children with cancer. *Children’s Health Care*, *47*(3), 261–274. https://doi.org/10.1080/02739615.2017.1337516

Horsch, A., Gleichauf, S., Lehner, B., Ghandour, M., Koch, J., Alimusaj, M., ...&Putz, C. (2022). Lower-Limb Amputation in Children and Adolescents—A Rare Encounter with Unique and Special Challenges. *Children, 9*(7), 1004.

Husserl, E. (1970). *The crisis of European sciences and transcendental phenomenology: An introduction to phenomenological philosophy*. Northwestern University Press.

Jo, S.-H., Kang, S.-H., Seo, W.-S., Koo, B.-H., Kim, H.-G., & Yun, S.-H. (2021). Psychiatric understanding and treatment of patients with amputations. *Yeungnam University Journal of Medicine*, *38*(3), 194–201. https://doi.org/10.12701/yujm.2021.00990

Kanagasabai, P. S., Mulligan, H., Hale, L. A., & Mirfin-Veitch, B. (2018). "I do like the activities which I can do…" Leisure participation experiences of children with movement impairments. *Disability and Rehabilitation*, *40*(14), 1630–1638. https://doi.org/10.1080/09638288.2017.1303093

Khan, M. A. A., Javed, A. A., Rao, D. J., Corner, J. A., & Rosenfield, P. (2016). Pediatric Traumatic Limb Amputation: The Principles of Management and Optimal Residual Limb Lengths. *World Journal of Plastic Surgery*, *5*(1), 7–14. http://www.ncbi.nlm.nih.gov/pubmed/27308235%0Ahttp://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC4904133

Knežević, A., Salamon, T., Milankov, M., Ninković, S., Jeremić-Knežević, M., &Tomašević-Todorović, S. (2015). Assessment of quality of life in patients after lower limb amputation. *Medicinskipregled*, *68*(3-4), 103-108.

Kocak, S., Ertekin, B., Erdemir, E., Giriskin, A. S., & Cander, B. (2013). Demography and Clinical Consequences of Trauma-Related Amputations in the Emergency Department Short. *Journal of Academic Emergency Medicine*, *12*(4), 205–210. https://doi.org/10.5152/jaem.2013.34735

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American journal of occupational therapy*, *45*(3), 214-222.

Kristianto, B., &Setiawati, Y. (2021). Multidisciplinary Team Support for Psychological Aspect of Osteosarcoma Amputation in Children: A Case Report. *ScientiaPsychiatrica*, *2*(4), 170-176.

Langdridge, D., & Hagger-Johnson, G. (2009). *Introduction to research methods and data analysis in psychology*. Pearson Education.

Le, J. T., & Scott-Wyard, P. R. (2015). Pediatric Limb Differences and Amputations. *Physical Medicine and Rehabilitation Clinics of North America*, *26*(1), 95–108. https://doi.org/10.1016/j.pmr.2014.09.006

Leung, K. Y., Poon, C. F., Teotico, A. R., Hata, T., Won, H. S., Chen, M., Chittacharoen, A., Malhotra, J., Shah, P. K., & Salim, A. (2015). *Recommendations on routine mid-trimester anomaly scan*. *41*(5), 653–661. https://doi.org/10.1111/jog.12700

Liu, Y., Han, S., & Li, H. (2010). Understanding the factors driving m-learning adoption: a literature review. *Campus-Wide Information Systems*, *27*(4), 210-226.

Loder, R. T., Dikos, G. D., & Taylor, D. A. (2004). Long-term lower extremity prosthetic costs in children with traumatic lawnmower amputations. *Archives of pediatrics & adolescent medicine*, *158*(12), 1177-1181.

Lusardi, M. M., & Bowers, D. M. (2013). Motor control, motor learning, and neuro plasticity in orthotic and prosthetic rehabilitation. *Orthotic Prosthetic Reh*, *3*(4), 38-71.

Matheri, J., & Frantz, J. M. (2009). Physical activity levels among young people with physical disabilities in selected high schools in kenya and their perceived barriers and facilitators to participation. *Journal of Commmunity and Health Sciences*, *4*(1), 1–8.

McDonald, C. L., Westcott-McCoy, S., Weaver, M. R., Haagsma, J., & Kartin, D. (2021). Global prevalence of traumatic non-fatal limb amputation. *Prosthetics and orthotics international*, 0309364620972258.

McLarney, M., Pezzin, L. E., McGinley, E. L., Prosser, L., & Dillingham, T. R. (2021). The prevalence of lower limb loss in children and associated costs of prosthetic devices: A national study of commercial insurance claims. *Prosthetics and Orthotics International*, 0309364620968645.

Mc Querry, J., Gammon, L., Carpiaux, A., Talwalkar, V., Iwinski, H., Walker, J., ...& Muchow, R. (2019). Effect of amputation level on quality of life and subjective function in children. *Journal of Pediatric Orthopaedics*, *39*(7), e524-e530.

Medicine, S. M., Gandhi, M., Rac, M. W. F., & Mckinney, J. (2019). Amniotic Band Sequence. The American Journal of Obstetrics & Gynecology, 221(6), B5–B6. https://doi.org/10.1016/j.ajog.2019.09.020

Mierau, A., Hülsdünker, T., Mierau, J., Hense, A., Hense, J., &Strüder, H. K. (2014). Acute exercise induces cortical inhibition and reduces arousal in response to visual stimulation in young children. *International Journal of Developmental Neuroscience*, *34*(1), 1–8. https://doi.org/10.1016/j.ijdevneu.2013.12.009

Morrow, R., Rodriguez, A., & King, N. (2015). Colaizzi's descriptive phenomenological method. *The psychologist*, *28*(8), 643-644.

Moustakas, C. (1994). *Phenomenological research methods*.Sage publications.

Navidi, U. (Ed.). (2016). *The role of play in children's health and development*. MDPI AG.

Nurulain T. Zaveri. (2016). Role of Amputation in Improving the Quality of Life, Mobility, and Pain Outcomes in Children with Metastatic Osteosarcoma. *Physiology & Behavior*, *176*(10), 139–148. https://doi.org/10.1177/1049909118791119.Role

Ogeng'o, J. A., Obimbo, M. M., King'ori, J., &Njogu, S. W. (2010). Pattern of limb amputation among rural Kenyan children and adolescents. *JPO: Journal of Prosthetics and Orthotics*, *22*(3), 157-161.

Oliver, J., Dixon, C., & Murray, C. D. (2020). Being the parent of a child with limb difference who has been provided with an artificial limb: an interpretative phenomenological analysis. *Disability and Rehabilitation*, *42*(14), 1979–1986. https://doi.org/10.1080/09638288.2018.1543462

Patočka, J. (2019). What Is Phenomenology? *Husserl: German Perspectives*, *19*(2), 84–109. https://doi.org/10.5422/fordham/9780823284467.003.0004

Prigent, M., Brochard, S., Thepaut, M., Cornic, T., Cariou, M. T., Le Rouzic, C., Le Moine, P., Pons, C., & Houx, L. (2020). Improvement in activities and participation in an adolescent following secondary foot amputation. *Journal of Pediatric Surgery Case Reports*, *59*, 101544. https://doi.org/10.1016/j.epsc.2020.101544

Quarry, C., Holloway, J., Murray, J., & O ’callaghan, E. (2015). *Self Esteem and Emotional Functioning in Children*.

Quinn, M., &Mahat, G. (2019). Congenital upper limb deficiency: a case report. *Contemporary PEDS Journal*, *36*(3).

Ramstrand, N., Maddock, A., Johansson, M., &Felixon, L. (2021). The lived experience of people who require prostheses or orthoses in the Kingdom of Cambodia: A qualitative study. *Disability and Health Journal*, *14*(3), 101071.

Rosenbaum, P., & Gorter, J. W. (2012). The “F-words” in childhood disability: I swear this is how we should think. *Child: Care, Health and Development*, *38*(4), 457–463. https://doi.org/10.1111/j.1365-2214.2011.01338.x

Rossi, R., Alexander, M., Eckert, K., & Cuccurullo, S. J. (2019). Pediatric Rehabilitation. In *Physical Medicine and Rehabilitation Board Review, Fourth Edition*. https://doi.org/10.5014/ajot.40.6.436a

Shaw, J., Challa, S., Conway, D., Liu, M., Haonga, B., Eliezer, E., Morshed, S., &Shearer, D. (2018). Quality of life and complications in lower limb amputees in Tanzania: results from a pilot study. *The*

Lancet Global Health, *6*, S18. https://doi.org/10.1016/s2214-109x(18)30147-5.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, *22*(2), 63-75.

Sloan, A., & Bowe, B. (2014). Phenomenology and hermeneutic phenomenology: The philosophy, the methodologies, and using hermeneutic phenomenology to investigate lecturers' experiences of curriculum design. *Quality and Quantity*, *48*(3), 1291–1303. https://doi.org/10.1007/s11135-013-9835-3

Stannard, D. (2012). Essentials of Nursing Research: Appraising Evidence for Nursing Practice. In AORN Journal (Vol. 95, Issue 2).https://doi.org/10.1016/j.aorn.2011.10.009

Stricklin, N. (2020). Pediatric Acquired Amputation: A Personal and Professional Viewpoint. *Journal of Life Care Planning*, *18*(1).

Tabor, C. (2018). The Impact of Prosthetics on Amputee Quality of Life.

Trautwein LC, Smith DG, Rivara FP. Pediatric amputation injuries: etiology, cost, and outcome. J Trauma. 1996 Nov;41(5):831-8. doi: 10.1097/00005373-199611000-00011. PMID: 8913212.

UNICEF, (2020). The Convention on the Rights of the Child: The children's version. *New York: UNICEF*.

Welch, C., &Paavilainen-Mäntymäki, E. (2014). Putting process (back) in: Research on the internationalization process of the firm. *International Journal of Management Reviews*, *16*(1), 2-23.

Wirihana, L., Welch, A., Williamson, M., Christensen, M., Bakon, S., & Craft, J. (2018). Using Colaizzi's method of data analysis to explore the experiences of nurse academics teaching on satellite campuses. *Nurse Researcher (2014+)*, *25*(4), 30.

Wolpert, L., Tickle, C., & Arias, A. M. (2015). *Principles of development*. Oxford University Press, USA.

Ziegler-Graham, K., MacKenzie, E. J., Ephraim, P. L., Travison, T. G., &Brookmeyer, R. (2008).Estimating the prevalence of limb loss in the United States: 2005 to 2050. *Archives of physical medicine and rehabilitation*, *89*(3), 422-429.

APPENDEX I

ETHICAL APPROVAL

جامعة مؤتة
كلية الدراسات العليا

MUTAH UNIVERSITY
College ofGraduate Studies

الرقم :ك.د.ع/ل ١٠/٩٧/١٠٢٦
التاريخ : .... هـ
الموافق: ٩/٦/٢٠٢٢ م

Re.................
Date:...................

السادة مديرية الخدمات الطبية الملكية مركز التأهيل الملكي المحترمين

تحية طيبة وبعد،،،

ارجو التكرم بتسهيل مهمة الطالبة تهاني عثمان عبيدالله العقيلي الرقم الجامعي (620201203005) والتي تدرس في جامعة مؤتة ماجستير / تخصص تمريض صحة الطفل وذلك من اجل الحصول على المعلومات والبيانات لاعداد دراستها والموسومة بـ" **From Playgrounds to Rehabilitation Centers: A Qualitative Study of The Lived Experience of children with an Amputation)** " والتي تقوم بها استكمالاً لمتطلبات الحصول على درجة الماجستير.

شاكرين لكم اهتمامكم وحرصكم على التعاون مع جامعة مؤتة، ودعمها لتحقيق أهدافها في خدمة هذا الوطن في ظل حضرة صاحب الجلالة الهاشمية الملك عبدالله الثاني ابن الحسين المعظم يحفظه الله ويرعاه.

وتفضلوا بقبول فائق الاحترام ،،،،

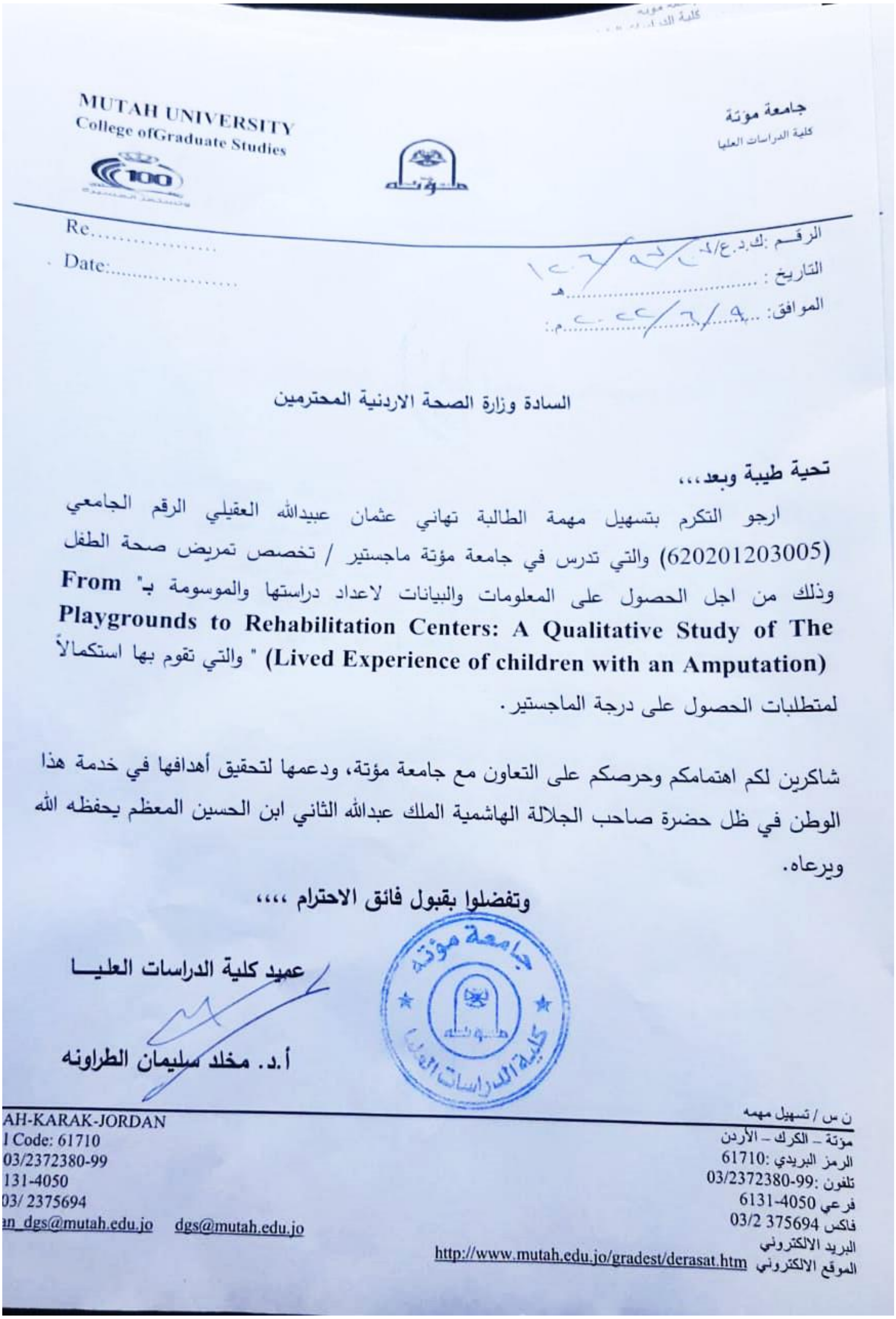
عميد كلية الدراسات العليـــا

أ.د. مخلد سليمان الطراونه

ن س / تسهيل مهمه

مؤتة – الكرك – الأردن
الرمز البريدي :61710
تلفون :03/2372380-99
فرعي 6131-4050
فاكس 03/2 375694
البريد الالكتروني
الموقع الالكتروني http://www.mutah.edu.jo/gradest/derasat.htm

MUTAH-KARAK-JORDAN
Postal Code: 61710
TEL :03/2372380-99
Ext. 6131-4050
FAX:03/ 2375694
dean_dgs@mutah.edu.jo dgs@mutah.edu.jo



جامعة مؤتة
كلية الدراسات العليا

MUTAH UNIVERSITY
College ofGraduate Studies

Re.................
Date:....................

الرقـــم :ك.د.ع/٧/٢/٥٧/١٢٠٦
التاريخ : ....هـ
الموافق: ٩/٦/٢٠٢٢ م

السادة وزارة الصحة الاردنية المحترمين

تحية طيبة وبعد،،،

ارجو التكرم بتسهيل مهمة الطالبة تهاني عثمان عبيدالله العقيلي الرقم الجامعي (62020120305) والتي تدرس في جامعة مؤتة ماجستير / تخصص تمريض صحة الطفل وذلك من اجل الحصول على المعلومات والبيانات لاعداد دراستها والموسومة بـ" **From Playgrounds to Rehabilitation Centers: A Qualitative Study of The (Lived Experience of children with an Amputation)** " والتي تقوم بها استكمالاً لمتطلبات الحصول على درجة الماجستير.

شاكرين لكم اهتمامكم وحرصكم على التعاون مع جامعة مؤتة، ودعمها لتحقيق أهدافها في خدمة هذا الوطن في ظل حضرة صاحب الجلالة الهاشمية الملك عبدالله الثاني ابن الحسين المعظم يحفظه الله ويرعاه.

وتفضلوا بقبول فائق الاحترام ،،،،

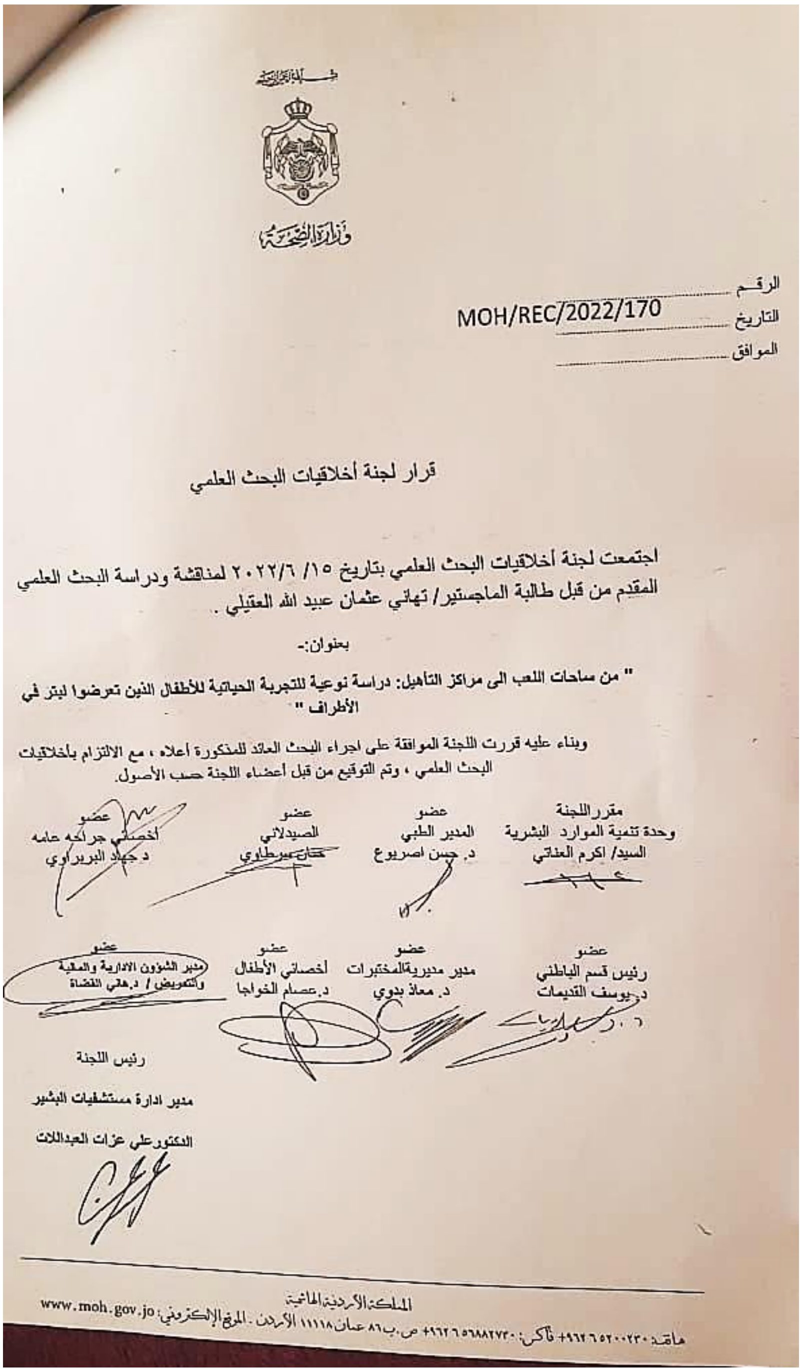
عميد كلية الدراسات العليـــا

أ.د. مخلد سليمان الطراونه

ن س / تسهيل مهمه

مؤتة – الكرك – الأردن
الرمز البريدي :61710
تلفون :03/2372380-99
فرعي 6131-4050
فاكس 03/2 375694
البريد الالكتروني
الموقع الالكتروني http://www.mutah.edu.jo/gradest/derasat.htm

AH-KARAK-JORDAN
l Code: 61710
03/2372380-99
131-4050
03/ 2375694
an_dgs@mutah.edu.jo dgs@mutah.edu.jo



بسم الله الرحمن الرحيم

وزارة الصحة

الرقم ....

التاريخ MOH/REC/2022/170

الموافق ....

قرار لجنة أخلاقيات البحث العلمي

اجتمعت لجنة أخلاقيات البحث العلمي بتاريخ ١٥/ ٢٠٢٢/٦ لمناقشة ودراسة البحث العلمي المقدم من قبل طالبة الماجستير/ تهاني عثمان عبيد الله العقيلي .

بعنوان:-

" من ساحات اللعب الى مراكز التأهيل: دراسة نوعية للتجربة الحياتية للأطفال الذين تعرضوا لبتر في الأطراف "

وبناء عليه قررت اللجنة الموافقة على اجراء البحث العائد للمذكورة أعلاه ، مع الالتزام بأخلاقيات البحث العلمي ، وتم التوقيع من قبل أعضاء اللجنة حسب الأصول.

مقرر اللجنة وحدة تنمية الموارد البشرية السيد/ اكرم العناتي	عضو المدير الطبي د. حسن اصريوع	عضو الصيدلاني غسان عبرطاوي	عضو أخصائي جراحه عامه د جهاد البربراوي
عضو رئيس قسم الباطني د. يوسف القديمات	عضو مدير مديرية المختبرات د. معاذ بدوي	عضو أخصائي الأطفال د.عصام الخواجا	عضو مدير الشؤون الادارية والمالية والتعويض / د.هاني القضاة

رئيس اللجنة

مدير ادارة مستشفيات البشير

الدكتور علي عزات العبداللات

المملكة الأردنية الهاشمية

هاتف: ٠٢٣٠ ٦٥٢٠٠٢٣٠ +٩٦٢ فاكس: ٠ ٦٥٦٨٨٢٧٣٠ +٩٦٢ ص.ب ٨٦ عمان ١١١١٨ الأردن . الموقع الإلكتروني: www.moh.gov.jo

APPENDEXES II

Parental Consent Form (Arabic language)

Parental Permission for Children Participation in Research

من ساحات اللعب الى مراكز التأهيل: دراسة نوعية للتجربة الحياتية للاطفال الذين تعرضو لبتر في الأطراف

موافقة مسبقة

رقم الدراسة:

تاريخ الموافقة:

عنوان الدراسة:من ساحات اللعب الى مراكز التأهيل، دراسة نوعية لتجربة الحياة التي يعيشها الاطفال المبتورين

مقدمة

الغرض من هذا النموذج هو تزويدك (بصفتك والد أحد المشاركين المحتملين في دراسة بحثية) بالمعلومات التي قد تؤثر على قرارك فيما يتعلق بالسماح لطفلك بالمشاركة في هذه الدراسة البحثية أم لا. سيقوم الشخص الذي يقوم بإجراء البحث بوصف الدراسة لك والإجابة على جميع أسئلتك. اقرأ المعلومات الواردة أدناه واسأل أي أسئلة قد تكون لديك قبل أن تقرر ما إذا كنت ستمنح الإذن لطفلك بالمشاركة أم لا. إذا قررت السماح لطفلك بالمشاركة في هذه الدراسة ، فسيتم استخدام هذا النموذج لتسجيل إذنك.

الغرض من الدراسة

إذا وافقت ، سيُطلب من طفلك المشاركة في دراسة بحثية حول[من ساحات اللعب الى مراكز التأهيل، دراسة نوعية لتجربة الحياة التي يعيشها الاطفال المبتورين]. الغرض من هذه الدراسة هو استكشاف التجربة الحياتية للاطفال الذين تم بتر احد اطرافهم في الأردن باستخدام تصميم ظاهري نوعي. تهدف الدراسة إلى الإجابة على ثلاث اسئله رئيسيه وهي :

ما هي التغيرات الحياتية التي واجهها الطفل بعد البتر ؟
ما هي الصعوبات التي واجهها الطفل بعد البتر ؟
كيف تم التعامل مع البتر من الناحية الجسدية والنفسية والاجتماعية؟

الخطورة من الدراسة:

لا يوجد أي خطورة متوقعه من هذه الدراسة ومع ذلك إن شعرت بالقلق أو بعدم الراحة في أي وقت أثناء الدراسة لك الحرية بالانسحاب.

فـوائد الدراسة:

ستعود هذه الدراسة بالفائدة على الطفل والاهل والمؤسسة الصحية باكملها، وذلك عن طريق اكتشاف تجارب الاطفال المبتورين ومساعدتهم في التكيف مع هذا البتر ومواجهة العقبات التي قد تواجههم.

ماذا سيطلب من طفلي أن يفعل؟

إذا سمحت لطفلك بالمشاركة في هذه الدراسة ، فسيُطلب منه إجراء مقابله للاجابه عن عدة اسئله متعلقه بالدراسه [المقابلة ستكون في المركز وجهًا لوجه مع اتخاذ الاحتياطات اللازمة للوقاية من عدوى فيروس كورونا.]. ستستغرق هذه الدراسة للمقابلة الواحدة من 40- 60 دقيقة وجهاً لوجه ، سيتم إجراء مقابلة شبه منظمة مع الطفل بشكل فردي، في المكان الذي سيتم الاتفاق عليه بين المشارك والباحث. سيتم تسجيل المقابلة رقميًا واستخدامها في جمع البيانات.

هل يجب ان يشارك طفلي؟

لا ، مشاركة طفلك في هذه الدراسة تطوعية. قد يرفض طفلك المشاركة أو الانسحاب من المشاركة في أي وقت. لن يؤثر الانسحاب أو رفض المشاركةبأي حال من الأحوال. يمكنك الموافقة على السماح لطفلك بالمشاركة في الدراسة الآن وتغيير رأيك لاحقًا دون أي عقوبة أو تأثير على خطة

العلاج أو الخدمات التي يتلقاها الطفل.

ماذا لو لم يرغب طفلي في المشاركة؟

بالإضافة إلى إذنك ، يجب أن يوافق طفلك على المشاركة في الدراسة. إذا كان طفلك لا يرغب في المشاركة ، فلن يتم تضمينه في الدراسة ولن تكون هناك عقوبة. إذا وافق طفلك في البداية على أن يكون في الدراسة ، يمكنه تغيير رأيه لاحقًا دون أي عقوبة.

كيف ستتم حماية خصوصية طفلك وسريته إذا شارك في هذه الدراسة البحثية؟

ستتم حماية خصوصية طفلك وسرية بياناته من خلال إبقاء هويتهم سرية ، حيث سيتم استخدام الرموز فقط ، بدلاً من الأسماء ، لتوثيق إجاباتهم على أسئلة الباحث. سيتم استخدام المجهولية للحماية والأمن. سيتم الاحتفاظ بجميع البيانات التي تم جمعها في سرية تامة. مع عدم استخدام اسمه في أي عرض تقديمي أو نص أو دراسة أو منشور. سيتم الاحتفاظ بجميع المعلومات (السجلات ، والنصوص ، وجميع المواد المكتوبة ، واستمارات الموافقة) في ملفات محمية لا يمكن لأي شخص الوصول إليها، باستثناء الباحثة ومشرفيها.

للاتصال والسؤال:

إذا كنت ترغب بالتواصل مع الباحث في مناقشه الدراسة والمعلومات الواردة أعلاه أو أي سؤال عن الدراسة يمكنك الاتصال بالباحث على الرقم 0792087540 ويمكنك الاتصال على البريد الالكتروني

Tahani.alakele@mail.ru

يشير توقيعك أدناه إلى أنك قد قرأت المعلومات الواردة أعلاه وقررت السماح لهم بالمشاركة في الدراسة. إذا قررت لاحقًا أنك ترغب في سحب الإذن الممنوح لطفلك للمشاركة في الدراسة ، فيمكنك التوقف عن مشاركته أو مشاركتها في أي وقت. سوف تحصل على نسخة من هذه الوثيقة.

التوقيع (الباحث)

التوقيع (المشارك)

اسم الوالد أو الوالدة ____

____

توقيع الوالد (الوالدين) أو الوصي القانوني التاريخ

____________________ ____

:التاريخ

التوقيع :

APPENDEX IV
Questions to Guide the Interview (Arabic language):

APPENDEX C: Demographical data and Questions to Guide the Interview (Arabic language):

تضمن البروتوكول الخاص بالأطفال العديد من المعلومات الديموغرافية (العمر والجنس والأداء الأكاديمي ودخل الاسرة والمستوى التعليمي للوالدين وسبب البتر ونوعه(مكتسب او خلقي) و متى حصل البتر و هل يستخدم الطفل طرف صناعي وما نوعه) و 20 سؤال:

1. هل يمكن ان تخبرني عن نفسك ؟
2. اين تعيش ومع من؟
3. من الاقرب اليك من عائلتك؟
4. متى تم اجراء عملية البتر ؟
5. ما السبب وراء عملية البتر؟
6. عندما اخبرك الطبيب بضرورة اجراء البتر، ما هي مشاعرك في ذلك الوقت؟
7. ما هي ردت الفعل التي راودتك بعد عملية البتر؟
8. ماذا كانت اكبر مخاوفك بعد العملية؟
9. ما هي التغيرات التي أضافها البتر الى حياتك من النواحي التالية: الاسرة والدراسة والمظهر الجسدي والاعتمادية وتعامل المجتمع؟
10. اخبرني المزيد عن تاثير البتر على حياتك اليومية وعلى عائلتك؟
11. هل لديك طرف صناعي؟ متى تم تركيبه؟
12. يرجى وصف تجربتك في ارتداء طرف صناعي؟
13. ما هوا شعورك نحو تجربتك الخاصة للتعايش مع البتر؟ وماذا يعني ذلك بالنسبة لك؟
14. عند وضع الطرف الصناعي هل تعاني من الم جسدي أو نفسي؟
15. سؤال للوالدين: هل يعتمد الطفل كليا على والديه؟ ام انه يؤدي اعماله وانشطته اليزمية بمفرده؟
16. سؤال للوالدين: منذ متى اصبح معتمدا على نفسه بعد البتر؟
17. هل لديك اراء بخصوص الخدمات الصحية المقدمة للاطفال الذين فقدوا اطرافهم؟
18. هل عوملت بشكل مختلف عن أفراد الأسرة الآخرين ، في المدرسة ، أو عند الذهاب إلى مكان عام؟
19. ما هي التحديات والصعوبات التي تواجهك؟
20. من الشخص الذي يساندك عادتا؟