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Exploring the lived experience of Arab patients with spinal cord injury of intermittent self-catheterization: A Phenomenological Study

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A Thesis

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Dedication

This work is dedicated to the soul of my late father, who taught me how to handle a pen and write words without regret.

My mother, who provided unconditional support, believed in me, and kept me in her prayers; I am in debt to my mother.

My beautiful wife Shrouq and our three little children's (Salah, Hamzah, and Yamen) for their continuous encouragement and support.

I also dedicate this work to my brothers and sisters, those whom I am confident I can always depend on, who understand me without even a word and are with me side by side even if they are miles away.

I would like to extend my sincere thanks to everyone who helped and contributed to the production of this work; it is not enough to mention their names.

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Anthology of Publications and Presentations

Peer-Reviewed Papers Published

- **Nurse's Experience of Caring for participants with COVID-19: A phenomenological Study**
  Published in: Frontiers in Psychiatry, section Public Mental Health, 2022

  Rasmieh Al-amer, Maram Darwish, Malakeh Malak, Amira Mohammed Ali, Kadejeh Al weldat, Abdulmajeed Alkhamees, Khaled Alshammari, **Yacoub Abuzied,** and Sue Randall

- **A practical Guide to Kaizen Approach as a Quality Improvement Tool**
  Published in: Global Journal on Quality and Safety in Healthcare, 2022

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- **Clinical Characteristics and Management of Ovarian Vein Thrombosis: A Case Series**
  Published in: Frontiers in Cardiovascular Medicine, section Thrombosis, 2022

  Mohammed AlSheef, **Yacoub Abuzied**, Amer Altamimi, Abdulrahman Mashi, Ali Alfayez, Muteb Alosaimi, Qusai Almahmood, Noura Ali AlBulushi, Jehan Almutair, Qusai Alwazna, Abdul Rehman Zia Zaidi, Amani Abu shaheen

- **Combined Oral Contraceptives and Vascular Thrombosis: A Single-Center Experience**
  Published in: Cureus, 2022

  Mohammed AlSheef, **Yacoub Abuzied**, Ghady R. Alzahrani, Nihal AlAraj, Nada AlAqeel, Hala Aljishi, Mukhtar J. Alomar, Abdul Rehman Z. Zaidi, Ohoud M. Alarfaj

- **Bullous Pemphigoid after Second Dose of mRNA-(Pfizer-BioNTech) Covid-19 Vaccine: A Case Report**
  Published in: Annals of Medicine and Surgery, 2022

  Fouad Alshammari, **Yacoub Abuzied**, Abdulrahman Korairi, Mohammed Alajlan, Mohammed Alzomia, Mohammed Alsheef

- **Impact of one-stop clinic on the clearance of COVID-19 surgical backlog**
  Published in: International Journal of Health Sciences, 2022

  Yasir AlShareef, Sami A. AlShammary, **Yacoub Abuzied**, Yahya AlAsseri, Khalid I. AlQumaizi

- **Assigning green hospitals during the COVID-19 pandemic assure continuous and safe resumption of surgical services**
  Published in: Annals of Medicine and Surgery, 2022

  Yasir AlShareef, Sami Ayed AlShammary, **Yacoub Abuzied**, Yahya AlAsseri, Khalid I. AlQumaizi

- **Enhancing palliative care occupancy and efficiency: a quality improvement thesis that uses a healthcare pathway for service integration and policy development**
  Published in: BMJ Open Quality Journal, 2021

  Sami Ayed Alshammary, **Yacoub Abuzied**, Savithiri Ratnapalan

- **Effectiveness of therapeutic heparin versus prophylactic heparin on death, mechanical ventilation, or intensive care unit admission in moderately ill participants with covid-19**
  Published in: BMJ Journal, 2021

  Michelle Sholzberg, Mohammed Alsheef, Fahad AlSumait, Abdulhadi M. Alqahtani, Emad K. Zayed, Ammar AlSughayir, **Yacoub Abuzied**, on behalf of the RAPID trial investigators

- **Heparin for Moderately Ill Participants with Covid-19**
  Published in: MedRxive, 2021

  M Sholzberg, M AlSheef, F AlSumait, **Y Abuzied**

- **Psychological Responses Among Healthcare Workers Providing Care for Participants with COVID-19: A Web-Based Cross-Sectional Survey in Riyadh, Saudi Arabia**
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  Yacoub Abuzied, Rasmieh Al-Amer, Somduth Shreemathie, Silva Gerald, Anitha Muthuraj, Saad AlEnizi, Khalid AlGhamdi

- **Satisfaction and Experience of Palliative Participants with 24/7 Hotline Service During the COVID-19 Pandemic in Saudi Arabia**
  Published in: Biomedical Journal of Scientific & Technical Research, 2021

  Sami Ayed Alshammary, Yahya Assiri, Reema Al Rasheed, **Yacoub Abuzied**, Igbal Abelati Mahgoub, Khalid Alqumizi

- **Development of a Saudi Palliative Care Essential Medication List (EML)**
  Published in: Biomedical Journal of Scientific & Technical Research, 2021

  Sami Ayed Alshammary, Igbal Abdelati Mahgoub, Waleed Alshehri, **Yacoub Abuzied**, Abdullah Al Tamimi

- **Reducing the length of stay by enhancing the patient discharge process: using quality improvement tools to optimize Hospital efficiency**
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  Yacoub Abuzied, Hassan Maymani, Basim AlMatouq, Oweida AlDosary

- **Efficacy of Point-of-Care for INR Testing Compared to Standard Laboratory Methods at a Tertiary Care Hospital in Saudi Arabia**
  Published in: Global Journal on Quality and Safety in Healthcare, 2020

  Manzoor Bhat, **Yacoub Abuzied**, Zahra Fagih, Tariq Wani, Ismael Gawan, El Mae Andalay, Mohammed AlSheef

- **Glycemic and Cardiovascular Risk Control among Participants with Type 2 Diabetes: A Saudi Tertiary Care Hospital Experience**
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Conference Paper (Accepted Paper)

- **Annual Research Symposium – King Fahad Medical City**
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- **Annual Research Symposium – King Fahad Medical City**
  Riyadh, Saudi Arabia
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Patients with spinal cord injury of intermittent self-catheterization: A literature review

Yacoub Abuzied

- **Hospice Palliative Care Ontario, HPCO**

Annual Conference, April 24–26, 2022

Satisfaction and Experience of Palliative Participants with 24/7 Hotline Service During the COVID-19 Pandemic in Saudi Arabia

Sami Ayed Alshammary, Yahya Assiri, Reema Al Rasheed, **Yacoub Abuzied**, Igbal Abelati Mahgoub, Khalid Alqumiziat

https://www.conference.hpco.ca/ **Ontario, Canada**

- **Hospice Palliative Care Ontario, HPCO**

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Enhancing palliative care occupancy and efficiency: a quality improvement thesis that uses a healthcare pathway for service integration and policy development

Sami Ayed Alshammary, **Yacoub Abuzied**, Reema AlRasheed, Savithiri Ratnapalan

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Under Review Papers

- **Creating a Palliative Care Process Blueprint in the Northern part of Saudi Arabia: A Paradigm of Experience**

Submitted to: Eastern Mediterranean Health Journal, WHO

Sami Ayed Alshammari, **Yacoub Abuzied**

- **Plasmablastic Lymphoma in Immunocompetent Patient: A Case Report and Literature Review**

Submitted to: Oman Medical Journal

Mohammed Alsheef, **Yacoub Abuzied**

Yacoub Abuzied

- **A Practical Guide to Magnet as a Quality Improvement Process**

Submitted to: Global Journal on Quality and Safety in Healthcare

Yacoub Abuzied

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ABSTRACT

Background

Intermittent catheterization (IC) is the insertion and removal of a catheter several times a day to empty the bladder. This catheterization is used to drain urine from a bladder that is not emptying adequately or from a surgically created channel that connects the bladder with the abdominal surface. IC is frequently recommended as an effective bladder management method for individuals with idiopathic or neurogenic bladder dysfunction who have incomplete bladder emptying. Although there is scant research about how individuals feel about IC and how it impacts their daily lives, significant research has been done on self-intermittent catheterization (SIC), such as infection rates and renal effects.

Purpose

To explore the lived experiences of Arab patients with spinal cord injuries (SCI) who utilize IC to empty their bladder.

Methods

Husserlian phenomenology and Colaizzi’s approach were used to seek an in-depth understanding of the lived experience of Arab adults using IC. Ten adult Arab participants from the SCI unit, rehabilitation hospital, King Fahad Medical City (KFMC) who used IC after they had SCI with the same medical condition were interviewed during the first week of April 2022 and were completed on the first week of May 2022.

Findings

Five major themes emerged from the data including The Way to IC, The frequent use of IC daily practice, cleanliness and general care, body image and sexuality, and lifestyle and self-adaptation. According to the study, SIC influences almost every aspect of a person's life, including their career and social lives, personal relationships, body esteem, and even what they drink and how they sleep.

Conclusion

The topics are investigated, and relevant literature is used to provide a credible foundation for the issues expressed by participants. The new knowledge is detailed, and there are recommendations for practice changes and calls for more advanced research.

Keywords: Intermittent, catheterization, self-intermittent, clean intermittent, experience.

Chapter 1

Introduction

Background

Spinal cord injury (SCI) is a condition characterized by damage to the spinal cord itself; this often results in a wide range of health problems (Bazzocchi et al., 2021). To illustrate, it is evident that the anatomical site and injury levels define the bladder condition. The lower the injury, the more severe the bladder problems that occur. For example, a SCI at or lower than Thoracic 12/L1 level would result in a flaccid bladder and sphincter in which they lose their tone (Ko, H. Y. et al., 2019). This region block controls the pathway of the reflex responsible for bladder emptying; however, a global injury of this region would result in areflexia, when participants cannot empty their bladders, and they suffer from a wide range of consequences, including but not limited to renal problems, incontinence, and frequent urinary tract infection (Mehnert et al., 2019), which means that no contract of the bladder's muscle would be traced.

During urination, the bladder contracts, internal and external sphincters, and the pelvic floor muscles relax, allowing urine to pass via the urethra. Usually, after the bladder empties, a small quantity of urine (less than 75 mL) may remain in the bladder, called post-void residual (PVR). (Marschalek, et al., 2021). For example, assume a person cannot urinate or empty their bladder. In that case, The PVR increases, which can lead to urinary tract infections (UTIs), urinary overflow incontinence (UI), irreversible bladder and kidney damage, and autonomic dysreflexia is present in SCI participants, which is fatal if not managed. In addition, inadequate bladder emptying or urine retention can result in developing a neurogenic bladder, a general term referring to voiding dysfunction (Ginsberg, et al., 2021). Neurogenic bladder might be caused by: 1) upper motor neuron disease; 2) SCI; 3) lower motor neuron disease. The neurogenic bladder represents one of the most common problems in individuals with various neurological impairments (Hamid et al., 2018). This study focused on clients with SCI who used intermittent catheterization (IC) to empty their bladders. Needless to say, that the most frequent urologic consequence after SCI is the neurogenic bladder, which, in the case of SCI, causes significant implications concerning the patient's wellbeing (Hamid et al., 2018). Thus, bladder programming or management is a vital step in reducing adverse health outcomes for participants with SCI.

Bladder management is critical in preserving bladder functions, controlling UTIs, and enhancing patient wellbeing. It involves inserting and removing a specific type of catheter into the bladder to empty it. SIC replicates the bladder's normal filling and emptying process, reducing the residual amount of urine and decreasing the infection rate in this cohort (Zderic & Canning, 2018). IC is the **the gold standard** method for emptying the bladder among participants with bladder dysfunction, specifically neurogenic bladder (Liao, 2022). Overall, using IC in this SCI patient has eliminated many complications associated with an indwelling urinary catheter, such as urinary tract infection (Zhang et al., 2015).

However, it has a wide range of benefits including,

1. It enables participants with SCI to achieve complete bladder emptying. It keeps the participants in a catheter free state at risk of common indwelling catheter-associated complications and infections.
2. It enhances the engagement of the participants as active partners in their self-care activities.
3. It enhances self-care and independence.
4. Reduced patient financial burdens by reducing the need for catheter-related equipment such as drainage bags (leg bags).

5. Has fewer barriers to intimacy and sexual activities.
6. It possibly reduces urinary tract symptoms (frequency, urgency, incontinence) between catheters and indwelling urinary catheters.

IC maintains renal function, improves bladder function, and lowers the risk of UTI in participants with SCI, resulting in a better prognosis and quality of life. (Cooley et al., 2019).

Self-intermittent catheterization (SIC) for men and women with SCI, this is the most successful technique of bladder emptying. (Madero-Morales, et al., 2019). In addition, in participants with UTIs, SIC promotes self-esteem and boosts the effectiveness of antimicrobial treatments (Chibnall et al., 2020).

Literature has found that participants performing SCI suffer from a wide range of emotional difficulties such as personality and behavioral changes, depression, fatigue, and anxiety in individuals with SCI (Craig et al., 2017). Also, as it is plausible that SCI influences the psychological status of the clients, and although there is little information available on how it affects people's feelings about having this therapy performed, it was suggested that this cohort experience a less optimistic outlook than their counterparts who do not use SCI. (Conti et al., 2019)

Of note, research on SCI has been minimal, particularly regarding Arab participants' lived experiences with SCI (Robert et al., 2018). Although the Arab world covers mainly Africa and Asia (Mousa et al., 2019), in which the combined area of these countries exceeds 5 million square miles, with the population of all nations combined is 423 million. This means that the Arab distribution is not limited to the middle east and Africa but also around the world. (Abi-Hashem, 2008) (American Community Survey, 2018) (United Nation, 2019)

The purpose of this study was to explore the lived experiences of Arab patients with spinal cord injuries (SCI) who utilize IC to empty their bladder.

Problem Statement

Bladder function and continence are essential to SCI participants, their families, and community support groups (Arkan et al., 2018). Individuals with SCI may lose urinary bladder function, necessitating clean intermittent self-catheterization (CISC) as the gold standard bladder emptying regimen. This is owing to indwelling catheters that can cause significant consequences such as urine infections, bladder stones, urethral upper urinary tract degeneration, and even pressure ulcers, requiring frequent and lengthy hospitalizations (Ong et al., 2020).

Understanding the experiences and feelings of Arab participants with SCI using IC helps create a straightforward approach for proper management and enhanced care delivered. Conversely, misunderstanding their expertise may result in inadequate treatment, affecting their psychological condition and losing a direct relationship to this issue if we lack such expertise. (Cohen et al., 2019) With such a range of Arab nations, and based on the history of IC and SCI, as well as literature, there is an essential need to focus on this type of study to assist Arab people all over the world in benefiting from this experience (Allen et al., 2017). However, according to the search, there was no direct researches on this subject.

Significance of Research

Researchers have yet to discover more about how patient's feelings about conducting this personal operation and their lived experience of the treatment's daily influence on their life. The principal researcher noticed this gap during his practice and based on the resources available.

Because of their frequent interactions with a large population group, SCI at Rehabilitation hospitals is crucial in promoting bowel and bladder programs because they play a significant role in screening practice. Improving the patient is lived experience with SIC minimizing co-morbidities and the number of advanced UTI cases, typically linked with poor outcomes.

The findings of this study might aid in:

(a) developing and adapting sensitive educational and other relevant treatments for SCI in Saudi Arabia to boost bowel and bladder control programs; (b) allowing the patient to be content without the need for an indwelling catheter; (c) improving participants' psychological wellbeing, resulting in a higher quality of life.

The lived experience of Arab participants with SCI would assist Arab individuals all across the world in exploring and understanding the experience of IC and its process. The communication barrier may act as a language barrier, affecting the life and psychological status of Arab SCI participants (Youssef & Deane, 2006). This thesis intends to assist in understanding SCI participants' requirements, the value of utilizing IC, and how this will aid and enhance their lives. This thesis might be used to refer to Arab participants all over the world. This thesis highlights the SCI Arab participants lived experiences and communicates this information to health care providers and those who perform the procedure, and also those with long-term SCI.

According to an assessment of the available resources, there was no clear literature or minimal details about the lived experience of Arab participants with SCI and how it affects their culture, religion, lifestyle, and other factors. Therefore, this study provides a reference which would provide benefit to the SCI rehabilitation community due to the participants' needs in Saudi Arabia and around the world. Also, it would be considered a one-of-a-kind reference in the region and the Arab world community in general, where it can also help researchers all over the world focus more on the phenomenon and the disease itself from the perspective of experience, which may lead to further findings.

Method Description

In terms of research, there is a lot to be said about going with a qualitative approach. Case studies, grounded theory, phenomenology, narrative, and ethnography are examples of qualitative research designs (Cypress et al., 2018). Although all approaches have their individual benefits, they were excluded because this study focuses on understanding the lived experience of IC among participants with SCI as a mean to addressing the research questions.

This qualitative study is explored using Husserlian phenomenology and Colaizzi's method because this study is mainly interested in describing the way participants experience SIC.
Moreover, the study used phenomenology because this approach allows scholars to explore in-depth a lived experience of the study subjects-in their natural world (Van der Zalm et al., 2000). It is believed that a study’s respondents' perceptions concerning the lived experiences of participants with SCI regarding the use of IC would add further aspects to the understanding of the mentioned phenomena. Therefore, this study used a qualitative method, which was suitable for gaining an in-depth knowledge of individuals with SCI and learning about their lived experiences through the IC.

Keep in mind that hermeneutic is a subdivision of the phenomenological approach, in which researchers try to describe and interpret a specific phenomenon (Van der Zalm et al., 2000). This research design permits the scholars to explore in-depth an understanding of the respondent's experience of a particular phenomenon in the participant's natural context (Chenail et al., 2011). Besides, it offers a framework for an understanding of the participants’ lived experiences which would take place through the interview process. It focuses on exploring the lived experience of the participants regarding what meaning they give to a particular phenomenon and how they interpret their lived experience (Vis et al., 2008). Overall, this approach echo's a human experience and provides an understanding of the essence of the person's experience with a thorough description of the experience. (Van der Zalm & Bergum, 2000)

Hence, this study's intent of using this approach was to collect data, interrogate and interpret the data concerning the lived experience of Arab adult participants using IC, and understand their perception of performing IC. Hence, it is plausible that the hermeneutic phenomenology approach used in this study was appropriate because exploring the lived experience of IC among participants with SCI allows for a personal narrative concerning IC. The narrative provided, which reflects the participant's stories of their lived experiences, was translated into a textual conversion. (Van Manen, 1997).

Hermeneutic phenomenology method was ascertained to be the most suitable approach for this study because, with this approach entailing the description and the interpretation of the IC phenomenon, it permits the scholars to explore in-depth an understanding of the participant's reality or their natural milieu (Van Manen, 1997), which in turn provides a thick and rich grasp of the meaning that could be captured throughout the persons' daily lived experience (Van Manen, 1997). This approach was this explored and captured with participants with SCI and using IC.

Aims of this Study

This study bridges a knowledge gap in the lived experiences of Arab adult participants who do SIC, which in turn could benefit others based on their experiences.

The following are the study's objectives:

1) To describe Arab participants lived experiences with SIC.

2) To outline the more significant SIC concerns, it includes what the participants consider to be successful instruction and if SCI participants are pleased with this form of bladder management.

3) Examine and identify the significance of the related experiences.

4) To contribute to the corpus of information related to SIC experiences.

5) Use the patient experience in improving the patient care.

6) To Improve and enhance the SIC techniques for inpatient and outpatient.

Research Question

The following question guided this study:

What is the lived experience of Arab participants with SCI using intermittent self-catheterization?

Scope and Delimitation

This study was conducted in rehabilitation at KFMC in Riyadh, Saudi Arabia. Hence, this study explored how participants with SIC described their own experience with IC, the researcher gathered extensive descriptions of the patient experiences concerning bladder management using SIC. This study recruited 10 participants (adults 18 years and above) using Face-to-face at the SCI unit, rehabilitation hospital, King Fahad Medical City (KFMC), Riyadh, Saudi Arabia, and the saturation guided this study.

The patient’s lived experience at KFMC could be distinct from other participants worldwide in different health care settings. However, the themes of the Arab adult’s lived experience of using IC at a rehabilitation center is sufficient to generalize among Arab participants on a larger scale. Nonetheless, we believe that the standards of care are not similar across the Arab region; hence, the same results could not be replicated.

Definition of Terms

Some of the terminologies used may confuse readers who are inexperienced with SCI as they more specific to SCI and more familiar with rehabilitation. Exploring these terminologies will help in understanding SCI and IC basic concepts. (See Appendix E).

The following definitions are used in this study; (Amirov & Bodrova, 2021)

- Self-Intermittent Catheterization (SIC): The process of a person passing a catheter into their bladder to empty urine. The catheter is removed immediately after the bladder is drained.
- Indwelling catheter (IDC): A urethral catheter inserted into the bladder that is attached to a drainage bag and remains permanently in place.
- Spinal Cord Injury (SCI): Irreversible damage to the spinal cord at any level resulting in loss of function including motor and sensory disturbances and bladder, bowel, and sexual dysfunction.
- Continence: Defined as the ability to remain dry from urine leakage between each IC.

Assumptions

Hermeneutic phenomenology is a research design that describes an individual’s life experience. The personal story, that participants shared, provided scholars with an opportunity to experience and view the respondent's lives as they portrayed their thoughts. According to Tan, Wilson, and Olver (2009), understanding the core nature of a particular experience would be achieved by describing the human experience. Given that, the participants are expected to provide a reliable and unbiased narrative during the interview. However, capturing the understanding of the participants lived experience of IC requires the researcher to employ active listening skills, understanding, and the ability to interpret without predetermined judgment or bias, with the primary researcher assuming that those who agreed to participate in the study could answer the interview questions (Luo & Chan, 2022). Further, the researcher recognized that using IC could be a very sensitive topic that could invoke anxiety. This current study aimed to explore the lived experience of participants with SCI who use IC to empty their bladders.

Structure of the Thesis

The first chapter of the research includes an introduction, objectives, and background information. Next, the study's importance is examined in light of the researcher's experience and the larger body of accessible knowledge. Finally, this chapter has defined four significant objectives that should guide the study's path and outcomes.

The second chapter offers extant literature related to the SIC experience, as well as an examination of the relevance and rigor of this research to identify potential knowledge deficiencies. Before any data was obtained, a literature study was conducted.

The third chapter describes the study's research methodology. There is an investigation and defense of the qualitative paradigm, especially Husserlian phenomenology and Colaizzi's method. This study mainly describes how participants experience SIC as part of their daily activities. The acts of research hermeneutic phenomenology are empirical (collecting of experiences) and reflective (analysis of their meanings). Personal experiences, verbal interviews, and thorough observation are described in the techniques. This chapter also examines the sampling procedure, participant demographics, the study's ethical issues, data collection as well as analysis.

Chapter Four. The data analysis was given in the form of five theme categories identified from theme clusters. In addition to the textual discussion, participant quotes from interviews provide evidence of data analysis.

Chapter Five examines the study's strengths, limits, knowledge discovered, recommendations, and conclusion.

Conclusion /Summary

This study looked at the life experiences of ten Arab male SCI participants who utilize SIC to empty the bladder. SCI is a serious health problem with grim consequences, such as neurogenic bladder; this condition is characterized by bladder muscle atony in which the participants cannot normally empty their bladders. Hence, bladder programming or management is vital in helping the participants drain their bladder and in reducing the adverse health outcomes for participants with SCI. To illustrate, bladder management is critical in preserving function and controlling UTIs. Where understanding the experiences and feelings of Arab participants with SCI using IC would help create a straightforward approach for proper management and enhancing care delivered, literature has reported that intermittent catheterization is a standard gold method among participants with SCI, for it preserves the kidneys' function.

Conversely, misunderstanding their experience may result in inadequate treatment, affecting their psychological condition and losing a direct relationship to this issue if we lack such experience. Hence, this study utilized a qualitative approach, particularly hermeneutic phenomenology, to explore the lived experience of using IC among adult Arab participants with SCI. This approach is suitable for exploring the lived experience of a particular phenomenon.

Chapter 2

Literature Review

Review of the literature “A study of the literature is crucial because without it you will not develop a grasp of your topic, of what has already been done on it, how it has been investigated, and what the significant concerns are” (Leite, 2018). Overall, the study used Husserlian phenomenology and Colaizzi's method to investigate the lived experience of Arab participants utilizing SIC since this study primarily discusses how participants experience SIC. This study used a descriptive phenomenological approach, considered appropriate for this research as the researchers were interested in telling the lived experiences of the study participants (Jackson, 2018). Specifically, the researcher employed this approach to explore the experiences of SIC. This approach values the individualistic expertise of a particular phenomenon as perceived by human awareness, which forms an entity of a scientific inquiry (Jackson, 2018).

This chapter discusses the previous literature relevant to patient’s experience of Arab participants with SCI of IC. Hence, first, it presents the search strategy related to the experience of participants with IC; second, it provides an overview of sources that the primary researcher explored while researching the background of SIC among SIC participants. In addition, it demonstrates how this current research fits within a larger field of study.

Search Strategy

A search was run in the databases CINAHL, Medline, and PubMed using one or more of the following keywords: (intermittent" OR "intermittence OR "intermittent" OR "intermittently "OR "intermittent)) AND ("self-catheterization" OR "clean intermittent) OR (**clean IC OR intermittent self-catheterization)**) AND (**experience OR** experiences)) **AND (Arab OR Arabs)) AND**

(phenomenology's "OR " phenomenology OR lived experience OR qualitative OR narrative "))). Filters: **In the past ten years.** This search syntax was used at the MESH levels and sometimes at all field levels; in other words, the key terms were tailored according to each searched database.

In this chapter, the material discussed was based on studies which were published within the ten years between 2012 and 2022. There were certain exceptions, such as when used research published before 2012, such as those relating to phenomenological philosophy, or where there was no recent literature to cover some missing data that was not obtained within the indicated time constraints.

Summary of Literature Searched by Categories

Previous evidence

This section discusses the literature reviewed to support the study by examining the lived experience of participants on SIC, evaluated the participants' experiences with IC concerned with the learning experience, the procedures, adherence to CISC, and the quality of life. These studies explored the use of IC for a variety of diagnoses. However, the studies investigating participants' experience with spinal cord injuries who lived with intermittent self-catheterization are limited, and studies conducted to explore the Arabic participants' experiences are lacking.

Several studies explored the experiences, practices, facilitators, barriers, and quality of life of CISC among participants with various diagnoses (Goldstine et al., 2019) (Balhi, S., & Arfaoui, R. B. (2021) (Orlandin et al., 2020). For example, a qualitative study explored individuals with SCI experiences of learning to carry out CISC and interviewed 15 participants with self-catheterization for different indications (Logan et al., 2008). The study identified various themes related to psychological issues, physical problems, and service interaction themes. For example, participants reported shock and embarrassment emotions when introduced to intermittent self-catheterization.

However, effective communication by nurses helps to alleviate these negative emotions. Thus, the study emphasized the importance of therapeutic communication skills in facilitating information exchange and retention and reducing embarrassment and anxiety among participants using IC (Logan et al., 2008). The results of the mentioned study confirm that effective communication and providing instructions to empower self-management support of participants living with conditions that have physical, psychological, and emotional impacts are vital. Although this study yielded important results, it did not include participants with SCI, who are the most affected cohort (Logan et al., 2008).

Another qualitative study interviewed 30 older and younger participants with a physical impairment (e.g., spinal cord injury) to explore the barriers and facilitators of long-term and short-term adherence to CISC in the Netherlands (van Achterberg et al., 2008). The availability of the material of this study, with also physical impairment, and resistance to sickness, can further compromise the commitment of younger participants, with the study, in addition, highlighting the difficulties of integrating clean intermittent self-catheterization into daily activities and reporting that knowledge, process complexity, misunderstandings, fear, shame, motivation, and quality of care influenced adherence to CISC methods. The outcomes of this study further highlight the need to address these variables when introducing CISC to participants (van Achterberg et al., 2008). It is important to establish a daily routine regarding using IC, as it is plausible that using IC is a turning point that carries a wide range of implications.

Further, a current phenomenological study explored the views of 39 participants who used IC regarding the benefits and the drawback of a single use or reuse of IC over three months’ period (Avery et al., 2018). This study indicated that the patient’s narrative revealed that participants had concerns in relation to UTIs, hygiene, preparation phase, social roles, and practicalities. However, participants in this study were anxious about their safety specifically with urinary tract infection events while reusing the same catheter. Not to mention that, there has not been adequate evidence-based research to support a high risk of the incidence of urinary tract infection when comparing reuse of catheters with single use catheters (Hooton et al., 2009). On the other hand, participants considered that a single use of the IC is satisfactory, safe and free of fear of infection risks. However, this highlights the need for more robust studies that utilize different designs to conclude valid evidence-based results.

More in-depth studies are needed to generate a valid estimate of determinants to adherence to clean IC and their frequency. A more recent qualitative multicenter study interviewed 11 participants in the Netherlands who use IC to determine the barriers and facilitators of using the Netherlands who use IC in their life activity (Cobussen-Boekhorst, Hermeling, et al., 2016). All participants described instruction and follow-up care as facilitators while describing the preparation before the handling of IC as a barrier (Cobussen-Boekhorst, Hermeling, et al., 2016). Unlike the previous older studies, participants in this study showed more positive outcomes and revealed that IC caused no problem with their privacy, including sexual intimacy (Cobussen-Boekhorst, Hermeling, et al., 2016). Although this study indicates that the preparation phase is a critical stage that needs more attention while shifting participants on IC, emphasized is the fact that participants were satisfied with instruction and did not encounter major difficulties in performing IC, and most of them felt using IC was a relief of their complaints. This could be related to the reliance on bathroom access and privacy (2013) and Wilde et al. (2011) (Cobussen-Boekhorst, Hermeling, et al., 2016). The same researchers led a one-year quantitative follow-up prospective study to identify the associated factors of successful IC (Cobussen-Boekhorst, Beekman, et al., 2016).

The study included 129 adult participants with different diagnoses referred to an outpatient clinic and performed catheterization. The majority of participants reported that catheterization positively affected their lives. A potential explanation for this is that the procedure is linked with good quality of life and most participants considered it as a satisfactory and simple (Cravens & Zweig 2000, Kessler et al. 2009) (Kessler et al., 2009). Over time, the impact of the bladder condition on everyday life, limits in daily activities, and bad feelings diminished. In addition, the study found that adherence to successful IC was weakly associated with younger age (Cobussen-Boekhorst, Beekman, et al., 2016). This could have enhanced more independence among this cohort.

Similarly, a quantitative cross-sectional study from Switzerland by Kessler M. et al. (2009) surveyed 92 participants (91% response rate) with voiding dysfunction to assess their perception of CISC. The questionnaire was based on the short form 12 (SF-12) for health-related quality of life. Most participants in this study revealed that the procedure was easy and painless, did not interfere with their daily activities, and improved their quality of life (Kessler et al., 2009). However, while the study had several limitations, such as selection bias by including highly compliant participants, and did not measure the baseline information before using CISC, only 13 participants in the study cohort suffered SCI (Kessler et al., 2009). Therefore, further in-depth and follow-up studies addressing these limitations were recommended (Kessler et al., 2009).

A Brazilian observational longitudinal study identified the adherence rate and factors associated with adherence to CISC among participants with void dysfunction and referred them to a training program (Girotti et al., 2011). Participants were examined after two weeks, monthly for six months, and one year of CISC training. The participants are considered adherents if they achieve 80% or more of the recommendations. Half of the participants (30) had neurological conditions. The study reported that the adherence rate at 6 and 12 months was 61.7% and 58%, respectively. However, younger participants had a higher adherence rate (86%) (Girotti et al., 2011).

The adherence was higher among women and participants with neurological conditions. In addition, the study reported that participants with exemplary commitment had higher quality of life, specifically in the psychological and social relationships domains (Girotti et al., 2011).

A recent prospective observational study in France determined the time required to perform CISC daily and assessed its impact on adherence and quality of life (Leroux et al., 2021), where there was no significant association between the time of CISC and quality of life (Leroux et al., 2021), and participants recorded diaries to determine the specific duration of the CISC (insertion and removal tie). Among 25 participants, the median duration of CISC was two and four minutes.

However, the study is limited to a small sample size, and further studies are needed. The literature review reinforced my point that there is insufficient research on this population and their experience with IC. This thesis is expected to add to the little knowledge on the issue and offer a better understanding of the experience of using IC as a bladder emptying technique. In addition, the findings might potentially serve as a foundation for future research on the quality of life associated with IC use.

Conclusion / Summary

Most studies on this issue have been undertaken solely from the perspective of bladder management. Therefore, the impact of IC on daily life for SCI participants has not been thoroughly investigated. Recent research has shown that helping people with spinal cord injuries manage bladder dysfunction during regular activities enhances their independence, self-esteem, and dignity. However, while such studies would aid people worldwide in learning, managing, and coping with their daily lives, there was no research specifically looking into the lived experience of Arab participants with intermittent self-catheterization due to SCI.

Chapter 3

Methodology

This study aimed to explore the lived experience of Arab adult participants who had SCI and were using IC. Hence, this study sought in-depth understanding of the lived experience of Arab adults using IC. This chapter provides an overview and explanation of the research design, research paradigm, phenomenology, a description of the methods including research aim, questions, settings and sampling procedure, and a review of the ethical considerations related to the study. The chapter presents the data protection and collection procedures followed by the data analysis.

Qualitative research approaches entail a certain philosophical and theoretical framework that is used in a systematic inquiry of a social phenomenon within its natural world. (Creswell & Poth, 2018). Phenomenology is one of the most widely used qualitative research methodologies (Gelling, 2011; Goulding, 2005; Padgett, 2017; Strandmark, 2015). Further, phenomenology is referred to as the phenomenological approach used in this study, in which case, and depending on the inner fundamental nature and structure of participants' lived experience, the primary researcher seeks to understand in depth a phenomenon's basic aspect.

The primary arching goal of this study was to provide an in-depth understanding of Arab participants lived experience of using intermittent self-catheterization. In other words, it explored the lived experience of intermittent self-catheterization in Arab adults with SCI. Hence, this study used hermeneutic phenomenology for this methodology, allowing for the revealing of a certain phenomenon from the point of view of how individuals interpret and assign meaning to their existence (Fuster Guillen, 2019).

In this study, it was assumed that a patient is unique, and every patient would have a special experience; hence, individuals who suffer from SCI and are on intermittent self-catheterization will need to experience using IC. Exploring the patient's IC lived experience provided insight that would facilitate the education and implementation of educational strategies related to IC among participants with SIC to promote sustained self-care and management.

The philosophy of phenomenology has been widely used in the nursing practice (Urcia et al., 2021) because this practice involves humanistic philosophy and scientific precision (Knights et al., 2021). Of note, descriptive phenomenology was employed by Brentano (1838–1917), which underlined the intellectual inspiration for Husserl's development of phenomenology (Fréchette et al., 2019). Afterward, Husserl embraced Brentano's philosophy as a baseline concept to understand mindful and conscious actions, acts, and existential intellectual practices (Hanna et al., 2021); the essence of each mental process refers to some (Moran 2000), in which all kinds of perception will entail meaning (Owen 1994). For example, Van Manen (1990) believed that any “thinking, imagining, perceiving, reminiscing …etc." is at all times thinking about something (Van Manen 1990). As a result, it refers to the subjective experience of something (Brown et al., 2020).

Edmund Husserl's theory was used for this study because it highlights the importance of understanding certain phenomena in their social contexts and their natural world. He considered the experience a primary source of knowledge. (Neubauer et al., 2019)

Also, Van Manen (1984, 1990) has seen phenomenology in similar ways; the phenomenological approach described by Van Manen was utilized to craft research design; bearing in mind that Van Manen referred to other phenomenologists; it is evident from his work that Merleau-Ponty's philosophy influenced his methodological stance.

Merleau-Ponty's said, “phenomenology is the study of essences . . . [and it] also is a philosophy which puts essences back into existence” (1945/1962, p.vii). Van Manen (1990) said that “Research on phenomenology is (the study of essences . . . the description of the experiential meanings we live as we live them . . . the human scientific investigation of phenomena . . . the attentive practice of thoughtfulness . . . a search for what it means to be human).”

Concerning this study, what is the lived experience of IC among Arab SCI participants? Served as a framework for unstructured interviews to obtain participants' perspectives on this technique, as well as their sentiments and challenges.

Research Design

The qualitative method is used because this study is mainly interested in describing the way participants experience SIC. It was considered appropriate for this research as the researchers were interested in capturing the lived experiences of the study participants (Jackson et al., 2018). Specifically, the researcher employed this approach to explore the experiences of SIC among rehabilitation SCI participants at KFMC, Riyadh, Saudi Arabia. This approach values the individualistic expertise of a particular phenomenon as perceived by human awareness, which forms an entity of a scientific inquiry (Jackson et al., 2018). Our strategy in SCI participants who do not recover normal micturition is to perform long-term SIC if necessary, allowing them to be continent and catheter free. However, after an extended follow-up, we discovered that some participants modified their bladder control system without consulting a doctor or/or the program coordinator due to their needs, especially during unexpected crises such as COVID-19 and services temporarily shut down during the pandemic.

Research Paradigms

According to classical Husserlian phenomenology, human experience only depicts or “intends” things through certain concepts, thoughts, ideas, pictures, … etc. The qualitative research method is inductive in that the researcher constructs abstractions, ideas, hypotheses, and theories from details.

The quantitative paradigm is positivist in nature. The empirical study distinguishes science; all phenomena may be reduced to practical indicators indicating truth. The ontological perspective of the quantitative paradigm is that there is only one truth, an objective reality that exists irrespective of human experience. A qualitative paradigm was utilized in this study to characterize and provide meaning to life events. (Alharahsheh, H. H., & Pius, A. 2020). Qualitative research addresses questions such as, “What is this?” or “What is going on here?” (Plceg, 1 999, p.36). The study's question does not need the development of a hypothesis or data collection but instead seeks information about the human experience of self-catheterization. Accordingly, this study “was a qualitative investigation based on a hermeneutic phenomenology."

Phenomenology

A phenomenological method was employed in the study to explain the lived experience of IC/SIC in Arab participants with SCI. According to Speziale and Carpenter (2003, p.51), phenomenology is appropriate for nursing research since the profession is “enmeshed in people's lived experiences.” According to Merleau-Ponty (Oiler-Boyd, 2001, p.96), “the entire endeavor of phenomenology is to explain the experience as it is.” Phenomenology has evolved from exploring phenomena via a philosophical investigation in terms of perception and essence to being a recognized, thorough investigation approach (Neubauer et al., 2019).

The phenomenological technique is divided into two types: descriptive and interpretative (Van Marien, 1990). The work of the German philosopher Edmund Husserl influenced descriptive phenomenology significantly (1859–1938). Husserl's phenomenological method is founded on experience and attempts to characterize these experiences and the phenomena that emerge due to this process (Patton et al., 2020). Husserl, originally a mathematician, invented phenomenology to explore the substance of experiences, in contrast to the positive paradigm prevalent in the late nineteenth and early twentieth century. He thought that experience produced knowledge and that awareness provided contact to this knowledge (Patton et al., 2020).

Interpretive phenomenology is similar to descriptive phenomenology in that the investigator goes beyond just reporting the occurrences and strives to explain the facts. This strategy concentrated on philosophers such as Gadamer, Hirsch, Ricoeur, and, most importantly, Husserls' former assistant, Martin Heidegger (Van Manen, 1990). Heidegger's phenomenology was equally concerned with lived experiences, but the approach required the researcher to interpret these experiences by evaluating and connecting them with their own (Bordogna et al., 2021).

The researcher aims to characterize the person's experience by returning to the intended question, “what is the experience of doing self-intermittent catheterizations for Arab participants with SCI?” Furthermore, where for these reasons, the study collected and presented data using a descriptive phenomenology, qualitative study because it allows the researcher to explore individuals’ thoughts in relation to their experiences of using IC products and produce results using the study participants’ own narrative, the researcher strived to develop a balanced account from the subject's standpoint rather than classifying or defining the person or experience.

Research Aim

The purpose of this study was to explore the lived experiences of Arab adult participants using IC after SCI events. Understanding the perception of participants using IC is based on their views and expectations, understanding their views and their expectations would be an important objective to provide the participants with holistic individualized care. Also, this would help health care providers to be more aware of this cohort's need, hence, prioritizing their needs in their healthcare plans. It is crucial to understand and recognize the patient's perception which would in turn allow for tailoring individualized interventions. Overall, this study aimed to elicit in-depth data from participants using IC in order to provide insight and awareness regarding how participants using IC construct their own experiences.

Research Questions

Research questions in this study lend themselves to the purpose of this study, hence, the current research question guides the following process including, data collection, and data analysis. Accordingly, the following research question was used for this hermeneutic phenomenology study; RQ: What is the lived experience of Arab participants with SCI using intermittent self-catheterization? However, the interview guide had sub-questions that were asked to the participants to encourage them to share their lived experience about using IC.

Sampling and Settings

Using a purposive sampling technique, a total of 10 adult Arab participants with SCI and using IC were recruited. Purposive sampling is recognized to be a more practical way in qualitative research to select data rich case relevant to understanding a certain phenomenon which facilitates the purpose of a qualitative study (Campbell et al., 2020). It is well suited to phenomenology research with different aims, and its logic lies in choosing participants or cases that provide rich information about research problems. Hence, it is plausible that purposive sampling technique is appropriate to develop in-depth understanding of the impact of a certain phenomenon.

Indeed, when the research question lends itself to purposive sampling, the researcher would not determine the number of the study participants ahead of the study's entry (Barratt, et al., 2015). This is because the researcher should start and progress in the data collection and start the inductive analysis process, this would help in identifying the similarities and differences to understand the research phenomenon. Thus, the number of the study participants is defined by the saturation of the data, when the collection of the additional data will add to understanding the research problem. Glaser and Strauss (1967) noted that saturation means that collecting new data will not result in the facility in KFMC's new findings, hence, at this stage, the researcher should not approach other participants and the data collection process should come to an end. Keep in mind that our study reached saturation with 10 participants.

Hence, we believe that recruiting 10 participants for this study was reasonable according to the argument of using purposive sampling in qualitative research. Of note, such a sampling method allows the researcher to collect rich data, spend enough time the study participants which in turn facilitates the collection of rich data.

This study was carried out at the Rehabilitation hospital at King Fahad Medical City, Riyadh, Saudi Arabia in which all the participants were hospitalized at the SCI unit.

Even though there was no purposeful prejudice in the sampling method, all ten participants where all men could be related to the fact that SCI has always been much more significant in men. From 2004 to 2005, male and female SCI ratios were 82% and 18 %, respectively (Cripps, 2006); or related to the gender issue among Arabs.

Participants were described as anyone with SCI, male or female, who had suffered a traumatic SCI and now used IC as their primary bladder control method. Traumatic SCI was favoured since it gave experience from the perspective of someone with normal bladder function at some point in their lives. Ten male participants took part in this study. There were no female participants since they declined to participate in this study, and the sample was chosen from male SCI participants due to the limited availability of female participants. After ten interviews, it was determined that saturation had occurred since no new ideas arose in the final two interviews. (Braun, 2021)

Sample Size

A total of 10 participants were included from the SCI unit at the KFMC rehabilitation hospital, Riyadh, Saudi Arabia. This study used a purposive sample approach to recruit participants with SCI who use SIC. All the participants were from the same clinical area and had the same medical diagnosis and shared the same extent of injury. The data collection of this study was guided by saturation in which additional data would not lead to new emergent codes and be based on the Consolidated criteria for reporting qualitative research (COREQ) guidelines. (Braun, 2021)

Subjects

The inclusion and exclusion criteria are explained in detail as the following:

Inclusions

- Arab Participants attending Rehabilitation SCI units at KFMC who came for their regular admissions;
- On IC for at least six months;
- Adult participants ≥ 18 years' old;
- Willing to participate;

Exclusions

- Participants with poor cognitive functions as evident in their medical records;
- Pediatrics and adolescent's participants;
- Not able/willing to sign a consent;
- Non- Arab participants.

Ethical Consideration

This study sought ethics via Isra University and KFMC. The approval of Isra University, Amman, Jordan was obtained through the research ethics committee (institutional review board (IRB) No. SREC/22/04/040), and KFMC, Riyadh, Saudi Arabia through the IRB log number: 22-262. (Appendix D).

After the ethical approval was granted by Isra University ethics committee and KFMC rehabilitation center, the primary researcher advertised for this study by: a) placing a poster in the rehabilitation centre's walls; b) visiting the facility to talk with participants personally; c) or was provided with names of possible volunteers by the SCI program coordinator.

The participant information letter, the poster, and the direct interaction with the researcher were used to inform participants about the study. (Appendix A). Participants who wanted to take part of this study completed a permission form (Appendix B) that acknowledged their understanding of the study and accepted their rights as participants. Those who handed the consent form to the primary researcher were then asked to do a scheduled face-to-face interview at a location and time that was suitable for them. These locations included the researcher's office and accessible conference rooms within the rehabilitation unit.

Participants were informed that the interview would be kept confidential and used specifically for research purposes. Also, they were informed that the interviews are audio-recorded after their approval, this was in line with the interviews protocol developed by Pope and Mays (2006). With the researcher told how the data would be handled and what efforts would be made to keep their names and provided information confidential, he/she also recorded the interviews in order for him/her to be able to present a detailed rich and accurate description of the results.

Data Protection

The information is only visible to the principal researcher and the research supervisor. All information and interviews narrative transcriptions were kept in a closed closet, permitted only access from the researcher for data collection and analysis.

All participants were assured that they can withdraw from the study without any potential penalty. However, the participants have the right to be informed about the results and will be given full access to this thesis. Before starting the interviews, the researcher documented his thoughts, opinions, and previous information regarding SIC to grasp and prevent these beliefs from infiltrating and tainting the current studies. (Appendix C).

The linking approach allowed a more detailed comprehension of the participants' experiences, but it was not limited to the interviews. The researcher utilized this approach throughout the study; Bias may impact how certain data is seen, especially during data description and analysis.

Data Collection

Interviews

Data was gathered through face-to-face interviews, which were audiotaped after we obtained a consent form from the participants, following protocols suggested by Pope and Mays (2006). The primary goal of recording the interview was to allow the interviewers to concentrate on listening, questioning, and following up while preserving eye contact with their interviewee. In addition to that, recording the interview aided the researcher to present a precise description of the data and detailed transcription of the interviews. The ten interviews ranged between 30 and 45 minutes and the data collection process took one month as the data collection started during the first week of April and was completed on the first week of May 2022. The average time of each interview was 41 minutes per patient.

The interview was held by the researcher himself as he is trained on this type of qualitative interviews and a certificate is already obtained in this type of studies, and working at the same area in the same hospital building at the rehabilitation hospital in KFMC, where the particular room was assigned within the SCI unit and upon the participant’s request; the room was within the unit and prepared for such a type of interview where privacy was ensured, as the interview was done in the Arabic language where the interviewer was a native Arabic speaker and within the same culture for easy understanding as well as working with SCI participants at the same unit. Where the interviews went smoothly and all of this motivated the discussion and response. (COREQ) guidelines were used for easy guidance and to structure the interview. (Tong et al., 2007)

Before data collection, the interview guide was piloted among three participants that satisfy the same inclusion and exclusion criteria of the study participant, this was done to ensure that methodological and practical concerns could be shaped and modified through pilots. Based on the pilot research, minor adjustments were made to the question guide.

Of note, the feedback and comments of the pilot study participants were incorporated and the guide was amended accordingly. The interview was informal, and prior to each interview, the primary researcher provided the interviewee with the study guide in order to present a prototype of the kinds of the questions the researcher would like to explore. Dara was collected via face-to-face interview; open-ended questions were used for good measure with a few prompt questions put in for good measure (see Appendix D). Informal interviews are appropriate data collection strategies because they allow the researcher to ask questions and concentrate on wider discussions. (Melia, 1997, p.34). Anecdotally, it has been discovered that because SIC is such an essential part of everyday life for persons with SCI, most are eager to communicate how it affects them. As a result, the interviewer's intervened minimally to the beginning and led the dialog. Following each interview, in the same book that was used for initial bracketing, the researcher had taken handwritten field notes regarding the participant and the conversation, providing a distinct viewpoint to refer to later when reviewing the transcriptions.

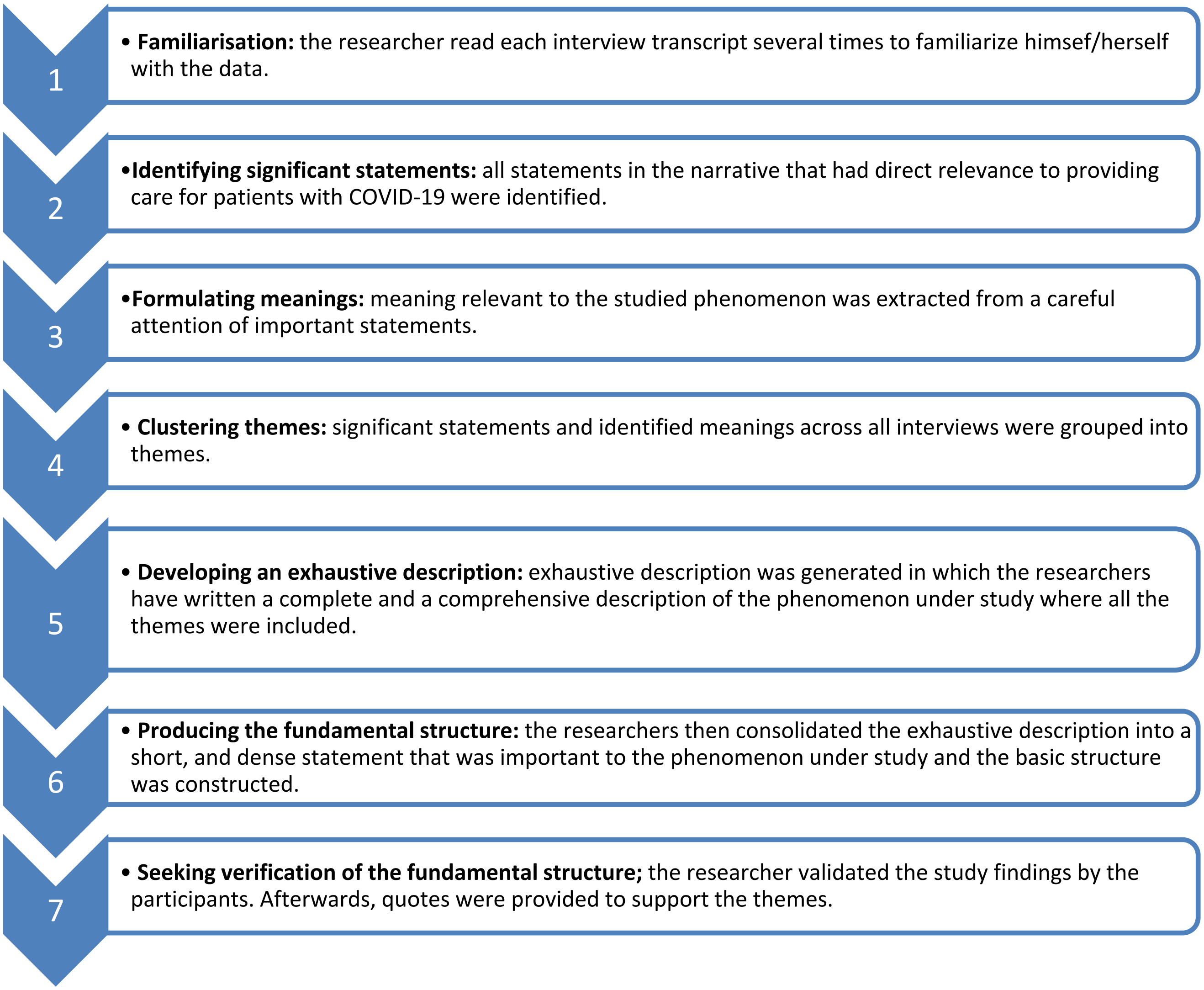
Interviews were transcribed following each interview. The authentic names of the study participants were replaced by pseudonyms. Then, the researcher transcribed the interviews himself. Following transcription, each participant was assigned a pseudonym. To maintain participant anonymity, all additional identifying information, such as names and personal or professional addresses, was removed from the transcript.

Data Analysis

The most challenging and complex aspect of qualitative research is data analysis. Many phenomenologists have worked to formalize data analysis by building data analysis processes. Van Kaam, Giorgi, Parse, and Husserl were among those who developed a reasonable method for examining data (Giorgi, 2020). The Colaizzi approach (Fig. 1), which was utilized in this study, is the most often used data analysis method with Husserlian phenomenology (1978).

Colaizzi created seven processes for assessing data from recorded interviews (Wirihana, 2018); which is a rigorous and strong qualitative technique to identify, comprehend, explain, and illustrate the experiences from different studies.

Figure 1: The Colaizzi approach for the data analysis



1. **Familiarisation:** the researcher read each interview transcript several times to familiarize himsef/herself with the data.
2. **Identifying significant statements:** all statements in the narrative that had direct relevance to providing care for patients with COVID-19 were identified.
3. **Formulating meanings:** meaning relevant to the studied phenomenon was extracted from a careful attention of important statements.
4. **Clustering themes:** significant statements and identified meanings across all interviews were grouped into themes.
5. **Developing an exhaustive description:** exhaustive description was generated in which the researchers have written a complete and a comprehensive description of the phenomenon under study where all the themes were included.
6. **Producing the fundamental structure:** the researchers then consolidated the exhaustive description into a short, and dense statement that was important to the phenomenon under study and the basic structure was constructed.
7. **Seeking verification of the fundamental structure;** the researcher validated the study findings by the participants. Afterwards, quotes were provided to support the themes.

After the researcher familiarized himself with the data through reading the transcript, the researcher identified the significant statement using the color-coding approach to formulate meanings, then progressed to step four in which the researcher groped the identified meaning theme cluster. As the data analysis was done by the primary researcher and supervised by the thesis supervisor.

Theme Clusters

The fourth step was to group the formed meanings into topic clusters to begin the data summary process. Eighteen subject groups were established to incorporate the 380 developed meanings. Chapter Four contains a thorough examination of the theme clusters. The 18 topic clusters were examined for similar meanings and divided into five theme categories to compress the data further.

Validating the Findings

The information was extracted and reallocated to its initial interview to validate participant participation after being organized into theme clusters and reduced into theme categories. For example, all of the ideas that emerged during Interview 01 were compiled into a single document and delivered to the participant for evaluation and comment. In this validation procedure, participants double-check the established meanings and structure of their terms to verify that they accurately reflect their intentions. All participants were contacted and agreed to review their findings to ensure the accuracy of the data analysis.

Following an assessment of the data, everyone agreed that the interview reflected their views about SIC. Validating remarks included everything that read correctly to me.

Conclusion/ Summary

This chapter defines the research methodology, goal, and significance of producing a research methodology section step by step, which describes a straightforward approach to this type of qualitative thesis. It goes through what the researcher should and should not include in a research methodology part, the various methods to research methodology that may be employed, and the phases involved in the methodology section.

Chapter 4

Findings

This chapter presents the qualitative findings of the study. The analysis of this study revealed that participants with SCI had different inherent challenges with IC. Some participants experience SIC daily by-product of living with a catastrophic SCI. Still, others are obsessed with the process of SIC in practically every area of their life. The interview findings examining the living experience of IC in Arab persons with SCI will be presented in this chapter. The findings are summarized under topic categories, reducing the original theme clusters found in initial statements and creating earnings. These findings are well addressed in the five themes per each cluster to summarize it in a well-organized way. Through the stories of the study participants, it became apparent that they have struggled before they have reached a settlement in their life. Five major themes were generated from the data, then were translated form the source language (Arabic language) to the target language (English language) for the purpose of dissemination (Al-Amer et al., 2016).

During the translation process we considered content equivalence while maintain semantic equivalence to produce informative themes (R Al‐Amer et al., 2015) (Al-Amer et al., 2021). The five major themes were, Theme 1: "*The Way to IC"*; with two subthemes *"The frequent use of IC daily practice"*; Theme 2: *The frequent use of IC daily practice*" with four subthemes "*Frequency of the practice"; Environmental and health issues "; Privacy and Performing IC"; and Intake and Output"'.* Theme 3*: "Cleanliness and general care" with two subthemes "Cleaning the catheter" and "Incontinence": Theme 4: "Body image and sexuality"* Theme 5*: Lifestyle and self-adaptation with four subthemes "Flexibility and freedom" "Physical access to the community" "Traveling" "Work and Social life balance".*

In the following paragraph, the demographic data of the study participants are presented and each theme was presented and described, also supporting verbatim quotes will be drawn from the participants' narratives. Needless to say, the confidentiality and anonymity of the study interviewee were ensured by using a number. Participant profiles are shown in (Table 1).

Demographic Data

The ten male participants varied in age from 23 to 61 years, with a mean of 33.5 years. The time since injury ranged from one to five years, with a mean of 3 years. All the subjects were paraplegics, and all of the case's injuries were due to a motor vehicle accident. The demographic collected including nationality, duration of IC, education level, marital status, occupation, history of AD or/and UTI … etc. Data showed the variety of patients education, life style, experience of SCI and IC and to see how this could be reflected on their experience of IC. (Appendix F)

Table 1: Demographic characteristics

Demographic characteristics	**N = 10**
Age (years) mean (range)	33.5 (23 – 63)
Marital status	
○ Single	4
○ Married	6
Year of IC practice, mean (M)	3
levels of Education	
○ Not educated	1
○ Secondary school	4
○ Bachelor degree	4
○ Master's degree	1
SCI condition:	
○ Paraplegic	10
○ Quadriplegic	0
History of:	
○ Autonomic Dysreflexia	10
○ Urinary Tract Infection	10

Themes

Theme 1: The Way to IC

The first theme area is called "The Way to IC" and has two subthemes including *"Service provided and acceptance"* and *"The experience,"* in which participants remarked that they had struggled to reach the point where they were interviewed. Participants discussed their journeys to IC, and their lived experiences were evocative of a process from their initial exposure to catheterizing to acceptance of the approach in their life as a routine lifestyle, where it is a must and mandatory. Clusters in this category relate to the options offered to participants, the educational process, as well as the assistance offered. It also examines the members in the adverse reaction cluster.

Subtheme 1.1: Service provided and Acceptance

Patient's narratives showed that there are numerous bladder management alternatives that participants were provided or were exposed to during their SCI lifetimes since their day one of hospitalization. To the study participants, the term of IC reflects that most interviewees were never given a choice in bladder control or a proper explanation of the available resources and their usage. In addition, participants remarked that in the early stages of their post-injury bladder management, and as a result of not being given the option of IC, they have tried many approaches for many years before settling on IC/SIC as their preferred technique: Most of their experiences reflected that participant had few choices, as stated by participant 01:

> *"It's either a leg bag or a urine bag, according to what I've been informed. Participant*" [01]

In addition to that, all participants remarked that the healthcare team informed them that IC is the best choice for them and did not give them other choices, and they narrated that they did accept it because they felt that this was the only choice to drain urine at a regular time and help them live their life during a day. This was reflected by the account of participant [03],

> "*I was informed it was the superior option, so I chose it. Participants* [03]

However, they all confirmed that as long as that was the only choice for them, they willingly wanted to use it; Participants [02,05] said,

> "*It's the only choice offered I will do it because I am satisfied with it."* [05]

Further, by time, four of the study participants remarked that they researched alternate possibilities to IC, either practically or conceptually, with the majority having a reasonable awareness of available options or resources. They felt that, although they had thought of other options, they found the use of IC was a practical option to empty their bladder, as stated by Participants [02 and 03],

> "*I haven't found a better choice than a catheter, even after searching numerous websites; everything else sounds quite irritating to me*" [02].
>
> "*Surgical solutions were frequently examined, but they were unattractive and uncomfortable to IC"* [03]

In addition, all of the participants came to the term and found that the IC became their only solution to manage their bladder, and they felt that as long as they can control their bladder with this catheter, their lives will move on. All of the participants interviewed were satisfied with their current bladder management and how they got there.

> *"I am delighted with how our life goes as far as that goes, especially with the availability of catheters accessible by the government*" [07]

Subtheme 1.2: The educational experience

The manner in which participants are educated and learn about IC, as well as the quality of medical, nursing, therapist, and social worker they got, are key milestones in their journey to IC. The majority of participants, in a form of education in which it may not be accessible to give follow-up teaching or guidance due to time restrictions and language barriers, were assisted by a nurse. In addition, most individuals who undertake IC do not receive any advice or comments from others, which may give additional support during the process, where each case has a different diagnosis and levels of injury and treatment plan.

Seven of the study participants remarked that the IC, like any technique, must be taught well for the learner to deliver the most benefits from the approach. They narrated that they did not receive a thorough education concerning the IC insertion and removal. They said that they shared their personal learning experiences and discussed the advantages and disadvantages through the patient club, which was conducted by the rehabilitation hospital at KFMC, to share their knowledge and encourage them. Many were trained by nursing staff in the hospital and mastered the method by practicing IC as stated by participants [02,03 & 05]

> *“Nurse taught me how to insert and remove the catheter, and then I got to where I am today by relying on the expertise of others with the same injury or situation and YouTube.”* [02]
>
> ” *They showed me how to use the catheter to drain the urine, they explained it to me, and I was reasonably comfortable with it*” [03].

Although the majority of the participants were satisfied with the health education they received in terms of the IC, six of the study participants remarked that they believed that they should have paid more attention when the healthcare providers explained to them how to use the IC.

This is because some of them suffered from complications related to IC usage. Participants [07] and [08] stated,

> "*One thing I should have done, is to listen to what the nurses told me about the IC.*" As stated by Participant's number [07].
>
> *"I think about it; if I had taken what they told me in the hospital seriously, where I did not, it would have been better*." [08]

Five of the study participants also sought some education from their friends those who had the same case and now are using the IC. Participant [07] stated that,

> "*I had to talk to my friend about it because he does them and has the same story and knows it very well." Participant* [07]

Without sufficient knowledge and assistance, participants may get overwhelmed by the drawbacks of IC and be inclined to attempt alternative solutions. Nevertheless, participants were generally tolerant of the idea that they had to conduct IC, while six reported that there were certain things that they considered unpleasant, such as being alone in this situation, lack of support especially during critical time, as remarked by the following quotes,

> "*Doing catheterization is OK; it is simply usual, I'm accustomed to it, and that is fine. However, when you compare that to everyday life before, I needed catheters, as it is suddenly transformed into a trial, on the dot, has to think about it, have to plan it, have to pay for it in such cases for example during COVID-19 pandemic were no one around, have to clean up after yourself. Participant. [06]*

Also, seven of the study participants remarked that the health education about the IC was positive features of IC, and they felt without the education, it was difficult to familiarize themselves with using this device, as narrated by Participant number [08] and [06],

> "*It is a requirement of existence, nobody can abstain from going to the bathroom, and that is it.*" [08]

> "*Bladder control in whatever form is a serious issue and requires attention.*" [06]

Theme 2: The frequent use of IC daily Practice

This them has four subthemes including, *"Frequency of the practice"; Environmental and health issues "Privacy and Performing IC"; and "Intake and Output."*

Individuals who practice IC build a routine daily sequence of actions related to this procedure. The daily grind, the second theme category, features clusters that involve the tedious, yet necessary tasks required to get through the day executing IC. The expression daily lifestyle is frequently used to characterize the monotony of a working day with its related restrictions, time constraints, and deadlines, and privacy was an important issue. Participants described IC as a job that needed specific time intervals between each catheter, the formation of a routine, and monitoring the fluids intake.

Subtheme 2.1: Frequency of the practice

Participants appeared to take a ritualistic approach to the regularity with which they practice IC, typically two to four hours as a frequency, but much more frequently if there is an illness, problems, or fluid consumption. They got regulated to execute catheters at specific times and leaving this routine caused considerable discomfort. This regime differs greatly among persons.: Four of the study participants felt that the time needed to drain urine for the bladder should be held at least every two to three hours per day, and felt it is a burden," Participants number [03] and [09] remarked, "*I usually do it two hourlies regardless of the situation as a routine*." [03]

"*I was proposed to do it every two to three hours and you know this is a huge work*." [09]

However, three of the study interviewees remarked that draining the bladder should be done every four hours, which means that they had to empty their bladder at least eight times a day, which varies according to fluid intake, as well as in the semester," as Participant number [06] said,

> "*We found doing it six times a day is excellent, so we tend to catheterize every four hours." Participants* [06]

Also, three of the study participants found it more overwhelming and they felt they were doing it around the clock, and it varies according to fluid intake, the semesters, and the weather; Participants number [04] remarked,

> "*I do it early morning, after each meal, before each prayer, and before going to sleep over the night and you know in winter it is more often, and when I drink water, it could be more."* [04]

Subtheme 2.2: Environmental and health issues

All of the study participants said that they observed that the frequency of using the IC is bound by seasons, weather, and the participant's health status; for example, they narrated that winter is a time where they use the catheter very often, however, summer is the time were using this catheter was less frequent. Hence, using the IC varies by several factors, as stated by [04].

> "*I used the catheter very often; however, I might do it more frequently, it depends on many factors, for example, in summertime I use this catheter less than in the wintertime, as I might do more and more even hourly*." [04]

According to the health status, seven of the study participants said that when they got sick, they use the catheter very often, and they believed that during sickness, they drank plenty of water. The following accounts represent the health status; participants [03] and [09] said,

> "*With UTI, we might do it every hour, just drinking water and trying to flush it to have fewer symptoms and treat the UTI." Participant* [03]. "If *there is leakage, we do it very often." Participant* [09]

Subtheme 2.3: Privacy and Performing IC

Participants remarked that privacy is a great deal when it comes to frequency of using the IC; participants strive to ensure privacy by using appropriate bathrooms or hiding from discovery by people they are with. Participants remarked that it is difficult to do this practice very often during a day and maintain privacy. It is challenging to talk about the need for SIC, and others may have preconceived notions about how the person with SCI maintains their bladder, keeping in mind that SIC is a personal, intimate procedure, and most participants prefer to always keep the specifics as secret as possible. The study participants remarked that this catheter has to be used many times each day and privacy is also a burden because of the frequent use of this device.

> *"Nowadays, it is difficult to use such catheter every day and keep it at lowkey"* [05]
>
> *"It is challenging to obtain privacy for SCI because when I need catheterization, I can't find specific areas to do it there." [09]*
>
> *"Maintaining privacy in public is a big challenge in particular I need to find a suitable bathroom that enables me to draw my bladder, I can't wait until I reach home.*" [10]

Subtheme 2.4: Intake and output

Eight of the study interviewees believed that the frequency of IC is determined by the amount of fluids consumed. Although health professionals encouraging participants who used IC to drink water for this practice entails a wide range of advantages, the participants experience some drawbacks because of this practice. For example, drinking fluid based on the health team's recommendation made the participants obliged to use the IC more often which became an issue when the study participants went out to a social gathering. The account of the respondent reflects this issue,

> "*I am not consuming too much fluids based on what my doctor advised me to avoid infections, and always I feel that my bladder is full and when I go out with my family, I feel it is uncomfortable for me to do it many times, I had to drain the urine*." [03]

Participants were intensely aware of their fluid consumption throughout the day and the risks of drinking too much or too little. They said that sometimes they did not consume fluid even if they felt they were in need for fluid because they feel this is a mirror of frequent drainage of their bladders; these thoughts are echoed by Participant's number, [07]

> *"Sometimes, even if I feel thirsty, I do not drink, because I am aware the more, I drink, the more I need to drain my bladder*." [03]

Theme 3: Cleanliness and general care

The narrative of the study participants showed that hygiene is critical to keeping a healthy bladder. Therefore, the third theme area is cleanliness and catheterization technique, which shows participants' active actions to maintain clean equipment and reduce the risk of infection before, during, and after discharge. An intelligent strategy minimizes the risk of infection by utilizing clean hands and uncontaminated surroundings and not contacting or touching the sterile catheter before use.

Subtheme 3.1: Cleaning the catheter

The study' participants remarked that they know that personal hygiene and cleaning the catheter are the source of effective IC. They understand that any catheters or equipment must be clean before use to reduce overall infection risks, and they said, at the hospital, using the IC was limited to a single use albeit they all knew that this catheter can be reused up discharge for a maximum of 24 hrs per the hospital policy. All participants remarked that they reused the catheters at home as per the medical advice strictly. They cleaned it after each use, varying from washing with soap and water to deep drying the catheter and using it for one day.

Participants number remarked,

> "*I have a group of catheters as supplied by the hospital; we wash out with soap and water once peruse for a maximum of 24 hrs.* [04, 06]

Two of the study participants said that washing the reused tube is not practical especially during traveling and in summer and using it for more than one time is not in favor of their health. They said the storage of a reused tube is not optimum during traveling and in the summertime, Participants number [05] said,

> "*Storing the reused catheter affects the tubes, especially during traveling and in the summertime with hot sunlight, this would jeopardize my health*" [05]
>
> "*Not sure if the cleaning was perfect and prevented infection, reused catheter is a tricky issue*." [05].

Subtheme 3.2: Incontinence

Cleanliness, or the lack of it, was viewed by our participants as reasons for contamination and illness. For example, participants believed that UTI’s and kidney problems could cause urine incontinence between catheters.

All of the study participants commented that the worst aspect of IC, according to participants, was incontinence between catheters, either actual or anticipated, and they used medications to assist prevention of leaking between catheters. However, the ten participants were all aware of the problem. Hence, all of them used draw sheets or pads when practicing IC;

Participants number [01] and [09] said,

“I *always use pads to prevent any urine leakage.*” [01]

“*I feel wit if I did not use sheets before draining my bladder, I know it takes time, but this how I do it.”* [09]

Theme 4: Body image and sexuality

Alternatives to SIC involve permanent catheters with an attached leg bag, which contributes to a negative body image. The participants narrated that the main benefit of SIC is that no fixed drainage device is required. It helps the study interviewees to see and feel reasonably normal in between catheters, which is critical for those who are self-conscious about their appearance. All the study participants felt that using intermittent catheters improved their body image and remained active in comparison with using a Foley catheter attached to them. They narrated that IC does not alter their body image, which helped them to simulate as closely as possible their normal lifestyle, and simulate as closely as possible their daily lifestyle. These views are reflected by the following quotes, “*Never be happy with the leg bag* *and Foley's catheter having something attached to the legs, with the folly's catheter, which makes attention, everyone looks to me."* [06]

> "*You know, IC helped me feel normal and I felt that my body image is very close to my body before this accident, I feel I can live a normal life image." Participant.* [01]

Also, three of the study participants remarked that body image is a very important aspect of their life and once the integrity of their body image was maintained, they had the chance to focus more on adapting and familiarizing themselves with the daily and frequent use of this catheter, as Participant number [08] said,

> "*Listen who do not care about body image, but I ok with this catheter, as what it is now; I am focusing more on how to adapt"* [08]

All of the study participants viewed their sexuality as part of their body image, and they were satisfied by using the IC because this catheter is not attached to them on a regular basis. They said, when they need to interact and perform their sexual role with their partners, they did not experience a physical barrier while using the permanent IC. Also, participants were all satisfied in choosing IC, as they were able to maintain a normal body image that was close to their previous body image and were able to continue in their intimacy life by removing obvious drainage devices and urine bags, remarking that at the beginning of their accident, they had to use a fixed drainage device and that was deemed unhygienic, and they have viewed the fixed catheter as a physical barrier in dealing with their partners. Participant number 06 said,

"IC enhanced my intimate life, and it is the best in this matter, I feel I'm the same person, even my partner accepts that" [06]

Theme 5: Lifestyle and self-adaptation

Participants narrated that although adapting to a new lifestyle when using IC is a lifelong process of bladder management in SCI, which means that they believe that any strategy of using IC must allow for an acceptable degree of social participation and freedom. Participants discussed the positive and negative elements of IC in their daily lives. Lifestyle Factors in IC, the fifth theme category, incorporates these remarks into theme clusters that examine topics like freedom and control. Other clusters deal with physically accessing bathrooms and public facilities, long-distance travel issues, and the numerous strategies used to manage continence overnight. Finally, topic category five addressed the diverse perspectives on the impact of IC on social and, to a lesser extent, work-life.

Subtheme 5.1: Flexibility and freedom

Nine of the study participants remarked that using IC has many positive aspects such as, it gave them flexibility and freedom; they said they were able to socialize, feel normal, and move around without any restrictions. In addition, they said that the IC freed them up for a more engaging lifestyle. Participants number [08] & [09] said,

> *"IC allows me to walk around freely without having to worry about connected drainage bags and devices*" [08]
>
> "*This allowed me to feel normal in between catheterizations and get back to my life"* [09]

Three of the study participants viewed using IC as having complete freedom to access their life, and changed their lives to a better state; the following are quotes by Participants [02] & [06]

"*I had been using these drainage bags for a long time and now catheterizes, felt it provided him with full freedom*." [06]

Subtheme 5.2: Physical access to the community

Physical access in the community was a huge concern for the study participants because they perform IC, this because the participants said that it is very difficult to access many kinds of bathrooms and it is difficult to use the bathrooms while using a wheelchair, even though there are accessible toilets.

Lack of access to residences also complicated the relationships with family and friends and made it difficult. Seven of the study participants said that practicing IC they feel comfortable enough to undertake it, although they had certain restrictions. As Participants [05] said,

"*When I need to go to a restaurant with my family or my friends, the first thing I asked if restrooms at that restaurant is accustomed for people like me*." [05]

"*I always have worries about the restrooms and if I can reach them, and you know, people like me, who are on the wheelchairs are unprepared to use regular restrooms, except for some places that invest in people like me*" [05]

Subtheme 5.3: Traveling

The narrative of this study revealed that long distance traveling in a wheelchair to physically access other places is extremely difficult and requires a through and hard planning. While all of the participants were very aware of the possibility of embarrassment if incontinence occurred during the trip and planned to avoid such embarrassing accidents by having a wide range of preparations such having all the items that could be needed and reducing drinking water, five of the study participants agreed that they had serious concerns in terms of their life, for example, they said traveling is extremely difficult, especial if they needed the use of aviation routes. Participants number [03] and [02] have commented,

> "*Using IC is considerably more difficult for me, emptying my bladder during a flight is a huge burden, particularly airline restrooms, are famously cramped and do not fit as it is small and not suited for the wheelchair*" [03]
>
> *"I never had travelled by a plane before I had the accident in my back, as I was traveling by car, where it is much easier for me to control myself, whereas became almost very difficult to me to travel by a car, and I am obliged to travel by plan and bare on all the hassles, it is not easy*" [02]

Four of the study participants said they were able to manage traveling by using temporary catheter, in which they used to insert an indwelling catheter for the length of the flight. They said although it was not the best solution, it is the most practical one until they reached their destinations, and after that they used to shift back to using the IC as this would involve less complication and have more positive advantages. The study participants adopt temporary solutions such as indwelling catheters and leg bags to prevent the need for IC while traveling. For shorter flights, it is usual practice to dehydrate before take-off and limit fluids intake during the flight to avoid needing to catheterize.

Participants number [01, 03 and 09] said:

> "*Before the flight, I am putting an IDC in before I go to avoid the travel risk*" [01]
>
> "*Flying with indwelling catheter provided me with feelings of control, satisfaction and I had less stress."* [03]
>
> "*I used to limit fluids to enable me control fluids intake and had also using IDC.*" [09]

Subtheme 5.4: Work and Social life balance

The narrative in this study showed three of the study participants revealing that even though, and if, the participants with SCI were able to come back to their work, they would experience a wide range of difficulties such as an accessing their offices, using the restrooms which are either inaccessible or unsuitable for SIC, and the need to catheterize at work, although work is an important dimension in their lives, remarking that, doing SIC at work might be more of a problematic issue, since many workplaces are not wheelchair accessible, or the employee has difficulties getting away for the needed time and most of companies did not accept those cohorts to get back to their work. Participants number [07] and [10] stated,

> *"It was not designed for toilets in rural regions, as it is in major cities such as Riyadh, and no one think of us, and the work, its rarely we get the chance to get back to our work."* [07 & 10]

Summary

This study aimed to explore the lived experience of participants who used IC as a result of SCI accident. The outcomes of interviews to establish the lived experience of IC in Arab persons with SCI were highlighted in Chapter Four. Five major themes related to their way to IC, the frequent use of IC daily practice, cleanliness and general care, body image and sexuality, and lifestyle and self-adaptation. Participants reported having encountered a wide range of consequences, however, they all had a consensus that the IC was the best solution for their situation and granted them more freedom in their life.

CHAPTER 5

Discussion

This study's results describe the many complex challenges people with SCI using IC encounter when doing IC to empty their bladder. These findings were described in Chapter Four, giving significant insight into these people's lives and the daily obstacles as a routine every 2–4 hours. Chapter five incorporates results from previous research relevant to the concepts and phenomena addressed in discussion of the study findings in light of the lived experience of Arab persons using IC.

This study aimed to examine the lived experience of Arab adult participants with SCI and using IC.

The participants of this study were all males albeit the primary researcher was aiming for males and females' participants.

Nationality, duration of IC, education level, marital status, employment, history of AD or/and UTI, etc. Were all gathered. Data demonstrated a range of patients' education, lifestyle, experience with SCI and IC, and how this reflected on their IC experience. Where all of this reflected on each participant's response and maturity level, as well as how much they were oriented to the issue.

The study could not recruit any females; hence this study only echoed the male's experience of Arab participants using IC. However, this kind of participation reflects gender inequality which is deep issue in the Arabic communities. To illustrate, men enjoy a higher level of freedom, and they can express their health problems more than women (Heise et al., 2019). In particular, when it comes to a sensitive topic such as the self-catheterization, the narrative analysis of the Arab participants who suffered from SCI and using IC revealed five emergent themes including "The Way to IC," "The frequent use of IC daily practice," "Cleanliness and general care," "Body image and sexuality," "Lifestyle and self-adaptation."

All of the mentioned themes are echoed in previous literature. (Balhi, S., & Arfaoui, R. B. (2021) (Orlandin et al., 2020) (Velaer et al., 2021)

The Way to IC

The data analysis showed that Arab participants needed time to figure out what kind of medical therapy would be beneficial for their situations, and they tried different kinds of catheters before they settle for the IC. Also, it was evident from the narrative that participants with IC viewed their experiences as a journey that holds positive and negative dimensions. Hence, this study would increase the awareness among healthcare providers, especially the nurses, when teaching participants about their options. In findings in line with previous literature which reported that participants with neurogenic bladder needed the primary healthcare team to teach them about their options and to show them how to practice it (Balhi, S., & Arfaoui, R. B. (2021) (Orlandin et al., 2020) (Velaer et al., 2021), we see that, according to Peplau’s model, nurses serve as educators, counsellors, and surrogates (Senn, J. F. (2013). Accordingly, they could use the current study findings to fulfill the mentioned role when dealing with participants with bladder control problems.

However, it is evident from the participant’s narrative that Arab participants who suffered from SCI viewed the bladder control as the biggest obstacle that prevented them from leading a meaningful active functioning life after they had SIC. It is clear that IC evolved with them to become an effective bladder emptying method. In some cases, this method had evolved over many years in various ways, while in others, they had always done IC, but the approach had changed to match their lifestyle and continence needs. These findings are in line with lifestyle and accommodation which revealed that the barriers and facilitators. (Cobussen-Boekhorst, Hermeling, et al., 2016)

The frequent use of IC daily Practice

Participants with IC spend a large portion of their time managing their bladder, and they reported that they had spent more than three hours at a minimum each day, and some of them needed more than three hours to manage their bladder. In findings that are consistent with previous studies, which reported that the management of neurogenic bladder after SCI, particularly in those undertaking CIC, takes time, this study reflects that those participants are practicing time-consuming self-care activities, hence, healthcare providers should focus their education on helping participants to perform such self-care activities efficiently. This time commitment may influence long-term bladder management options. (Goldstine et al., 2019) (Balhi, S., & Arfaoui, R. B. (2021) (Orlandin et al., 2020) (Velaer et al., 2021).

Also, the findings of this study added to the body of literature the dimension of seasonal effect, to illustrate, the study participants reported that during winter they practiced some self-restriction activities in terms of drinking water. They reduced fluid intake, keeping in mind that this is not a healthy practice, but they chose to limit their fluid intake to reduce the frequency of using IC. This reflects that patient with IC feel burdened with this daily practice and they were jeopardizing catching infection as a result of low fluid intake in favour of lower the frequency of using this. Bearing in mind that the international guidelines emphasize the fact that participants who are on catheter are advised to drink plenty of water (Ko, H. Y. 2022), and low levels of adherence to the mentioned guidelines would expose the participants to a wide range of health difficulties such as urinary tract infection which in turn could impose grim consequences on kidneys (Ko, H. Y. 2022), a previous study about climate change and disability reported that the seasonality and the weather are both important factors that influenced participants' views in terms of IC. (Alexander et al., 2019)

Further, this study revealed that participants who were on IC considered that using such device made their lives more exposed and they were having difficulties maintaining their privacy. Needless to say, it is worth mentioning that all participants have the right to privacy (Gutierrez et al., 2020), and that self-catheterization is a sensitive procedure and it is reasonable that participants experience lack of privacy specifically when they move out their homes. This privacy is a basic need for everyone, and once the privacy of a person is breached, a person would feel uncomfortable and may feel low self-worth (Gutierrez et al., 2020). The current study findings agree with previous literature which reported that participants who used IC experienced constraints related to their privacy (Gutierrez et al., 2020).

Cleanliness and general care

The participants in this study had varying levels of experience with other bladder management options, but the majority reported that the options were limited and did not fit their lives. In general, reviews of the literature reveal that there are few options for bladder care in SCI, where participants were only provided with one method of bladder management in the post-acute period of their injury, and they felt this decision could not be challenged. These findings are consistent with previous literature which reported that limited options are available for bladder management with SCI. (Goldstine et al., 2019) (Balhi, S., & Arfaoui, R. B. (2021) (Orlandin et al., 2020)

The open-ended questions provided crucial qualitative information (Agarwal et al, 2020). Individual comments made it clearly evident that IC had a significant physical, psychological, and emotional impact on them, as well as their partners, caregivers, and entire families in many cases.

In females and high tetraplegics, indwelling or suprapubic catheters are routine, but problems are common (Pannek & Pannek-Rademacher, 2021). These are often linked with fast bacterial colonization of an inside catheter and the widespread effect such an infection can have, such as sepsis, pyelonephritis, and renal calculi. This conclusion is consistent with Hammell's (2010) research findings, which indicate that bladder management is the top research priority for participants with neurogenic bladder following SCI.

This significant IC time utilization adds to the number of issues that SCI persons encounter (including concerns such as difficulties finding accessible bathrooms, feeling of embarrassment and lack of privacy). In addition to impeding productive work hours, the temporal stress may worsen challenges with IC adherence, as previously described in the SCI population. As a result, and in findings lending support to previous literature which is reported, persons with SCI continue to prioritize catheterization speed and efficiency. On the other hand, the findings of this current study were inconsistent with a previous study which reported that the participants did not complain from any problem regarding their own privacy (Cobussen-Boekhorst, Hermeling, et al., 2016). A potential explanation for that is that among Arabs, it is not allowed to discuss a sensitive topic or to talk to people about it because they are collectivist communities in which an individual should work in favour of the family, hence, if an Arabic person has a sensitive health issue, the culture demands that this person should keep it low key because this could put the whole family under stress of explanations and justifications. (Zakhour et al., 2022)

The majority of the participants understood the technique and the product used, although a few were uncertain about personal cleanliness, constipation, and the usage of catheters when traveling. Bladder management education can be improved by adjusting it to each individual’s settings and continuing after discharge. While this study lends support to a study published in 2016, which explored the experience of participants with IC in which it was reported that all the study participants needed thorough preparation before they were put on IC (Cobussen-Boekhorst, Hermeling, et al., 2016), emphasizing important habits such as IC frequency, and supporting timely urology evaluations may help to avoid possibly harmful self-care changes post-discharge.

Body image and sexuality

Further, intermittent catheter users in this study experienced body image difficulties and this was part of their perception of themselves which was established by their own minds to illustrate, the study participants construct how they viewed themselves and how others would think and perceive themselves. In this study, the interviewee manifested some dissatisfaction about their body image. Keep in mind that studies have reported that body image is one of the main constructs of the self-concept which is very important in terms of how an individual would see her/himself (Boyington et al., 2015). In addition, body image is an important fact in determining how a person identified him/herself with their culture and social world (Dotse, J. E., & Asumeng, M., 2015). Accordingly, body image dissatisfaction could affect participants' wellbeing and maximize the negative consequences effecting their health issues, with health care providers therefore spending more time monitoring the physical, the psychological, the emotional and the social dimensions of participants' lives, and this study's findings being used by policy makers in planning a thorough education program that is evidenced-based and focused on real need of participants who use IC.

Also, although the majority of the study participants saw their sexuality as part of their body image, they reported that this part was intact and reported that IC did not interfere with their sexual life. Of note that the guidelines concerning IC usage required participants before any sexual activity to: a) empty their bladder because a full bladder would increase the risk for infection; b) maintain good hygiene of their genital areas (Naber et al., 2001). Further, during sexual activity, the participants are advised to: a) use water-soluble (lubricant) which reduces the friction which in turn reduces the UTI; b) consider birth control pills rather than diaphragms and spermicides because they could irritate the genital area which in turn could lead to UTI. Also, after sexual activity participants should: a) empty their bladder immediately; b) drink around 2–3 glasses of fluid which would provide a good stream of urine and prevent infection. Maintaining good hygiene levels would enhance the positive self-image, hence, participants feel that their body image is intact, hence they will be able to practice their sexuality even if their bodies are changed (García & Álvarez, 2014).

Lifestyle and self-adaptation

The study findings also revealed that participants felt that their lifestyle has changed, however, they had to adapt. Studies have reported that participants with chronic health issues could hinder their daily life activities (Maresova et al., 2020), however, the majority of them adapt and cope with their health difficulties (Maresova et al., 2020). Further, we emphasize in here that the healthcare team should focus on the holistic care for the patient, their families, and their communities, hence the findings of this study casted a light on the adaptation levels of those participants. However, using IC restricted the participant’s freedom and they experienced some difficulties in terms of gathering. All the study participants recognized that IC are necessary to them and a vital part of their health, and they should take it on the plane they were having concerns regarding their limited options in terms of accessing the bathrooms, besides, the study participants found that traveling by planes for long physical distances was very complicated. A study held in the Netherlands was consistent with our study findings, IC are necessary to them and a vital part of the health (Cobussen-Boekhorst, Hermeling, et al., 2016).

Also, this study invites policymakers to use its findings and consider institutions managers and operators to work toward higher levels of accessibility for this cohort, where the study participants reported that they struggled in their work environment as it is not well prepared for people who had physical disabilities, and services offered for those people who suffer from SIC and use IC are very limited. In line with our study findings, literature has reported that people with SCI and using IC experience low levels of accessibility, Wilde et al. (2011) (Cobussen-Boekhorst, Hermeling, et al., 2016).

This study was intended to evaluate the living experience of Arab participants with SCI of intermittent self-catheterization. However, further studies are needed. The literature review reinforced my point that there is insufficient research on this population and their experience with IC. This thesis is expected to add to the little knowledge on the issue and offer a better understanding of the experience of using IC as a bladder emptying technique. In addition, the findings might potentially serve as a foundation for future research on the quality of life associated with IC use.

Overall, a review of the literature on the findings revealed that data from the interviews mirrored prior studies in certain areas, such as the frequency of SIC, catheter cleaning, and the prevalence of UTIs. Participants presented questions that were not supported by current literature in other areas. Some of these encounters add to the corpus of knowledge in this field, while others present newly uncovered difficulties.

Implications

The current study findings, to improve the practice in relation to using IC among participants with SCI, specifically, in the Arabic region, have important implications for healthcare practice and for establishing healthcare related polices. The following paragraph casts a light on the study-related implications.

Implications for clinical practice

The current study is important for it explored in-depth a crucial aspect related to IC practices among Arab adult participants with SCI. Using a phenomenology for this study has been a fruitful design in providing directions for how to educate the participants about IC considering the frequency, environmental issues, privacy, hygiene and general care, body image and adaptations. Nurses in the Arab region need to develop expertise in IC care. This is highly important as developing specialized experience in this area would help participants to achieve more precise information about the above mentioned in relation to participants' education. Hence, healthcare institutions could enhance their healthcare providers by providing them with specialized courses and developing curriculum related to IC care. To illustrate, in the western communities, particularly in Canada, nurses established a sub-speciality that is called "continence advisors"; in which nurses achieve more expertise and become specialized in teaching, caring for and providing health education regarding continence care (Brockelhurst, 1990). This kind of specialization would equip nurses with the knowledge about intervention related to incontinence and foleys catheter care and they would be able to provide forms of consultations for home care nurses.

Implications for health policy and practice

The Saudi health policymakers would ideally IC general care and body image counselling-enhancing interventions in programs promoting for self-catheterization care. Participants in this study reported that they had difficulties in relation to IC practice, needless to say that successful intermittent self-catheterization requisites thorough education; hence, health policy makers are invited to incorporate these study findings when planning for health-related issues among participants with SCI and using IC. For example, as mentioned earlier, they could establish a curriculum related to IC care and also provide certificates to enhance nurses' expertise in this area. Preparing knowledgeable and experiences healthcare providers, particularly nurses, is a vital issue for successful and effective self IC teaching.

Hence, it is crucial to establish health education programs that are led by trained nurses who can practice and counsel participants with IC, and those nurses should be made aware of the body image and privacy issue that participants practicing IC encounter. Therefore, such health education programs should focus on fostering a sense of good self-concept, and engaging participants with their social communities.

Participants in this study had concerns regarding their body image and adaptation to a new lifestyle. Thus, health policy makers could invest in this study findings by establishing funds for establishing counselling programs that are led by expert counsellors, because psychological support should be an integral part of participants with an IC health plan which in turn would help participants to navigate their situations and adapt to their new lifestyle.

Moreover, the participants in this study declared that not all the areas in the rural area's like the restaurants or buildings are disabled friendly, particularly in that they do not have water cycles that are designed to consider the needs of participants using IC, and this had limited their mobility and their access to their communities, where they mentioned its well presented in most of the areas except very limited areas but still this consider as a gap affecting their life. Despite its well presented in the big cites, malls, airports, hospitals, …etc. For example, the plains water cycle is not fit for the wheelchair and its very small Further, people with physical disabilities such those who had SCI could found a curb of a few stairs is difficult to be climbed. Hence, the policy makers can establish a construction rule that obliges all building contractors to consider the needs of this cohort when designing building, restrooms and other utilities.

Implications for health care providers

Health care providers specially nurses could use the findings of this study to provide individualized clear explanation about how to use IC, the care for IC and its physical and psychological implications.

The study participants lived experience showed that that those participants struggled to reach to a final decision in terms of using IC because they did not have health literacy in relation to IC, they did have clues about their options. Hence, and based on the lived experience of the study participants, participants should know about the equipment's needed for the IC, the sizes (as there are many different sizes), the care of IC, advantages and disadvantages and any other options.

Also, the study findings could be used to raise the awareness among the nurses about the psychological impact of using IC as the participants would experience major changes in their lifestyle, specifically in the way they empty their bladder, keeping in mind that IC is not what they intended to practice. Also, the study shed a light on the lifelong changes in which embodied changes disruption and altering one's perception of their own selves within their world. For example, the study participants suffer from difficulties when moving around, during sexual activities, traveling; hence, nurses should understand their participants' needs to be able to provide support and individualized care to their participants.

Also, as participants experienced psychological difficulties in relation to their body image, and this shift in the urination routine-imposed vulnerability among those participants, hence, health education implications from this piece of information could be to plan ahead for a structured and thorough health education session that is culturally sensitive in nature. For example, nurses can think of what kind of instrumental and emotional support they could offer before starting an educational session. Also, as participants found it difficult to move out and access their communities and pursue their interests. Nurses can provide support and help them plan for outings activities, such as thinking of what kind of restroom they expected that would fulfil their needs. As such, planning would make outings feasible for those participants with IC.

These study findings also revealed that, and where nurses can use this finding in helping their participants in coping with vulnerability, that there are some times in the year that make them feel more vulnerable, for example, during winter in which they restrict their fluid intake to avoid frequent use of IC. This is because people feel inadequate during vulnerable time for chronic illness mirror moral overtones that sometimes are difficult to be spotted or traced.

Implications for Future studies

Although this study provided an important insight in the lived experience of participants with SCI and using IC, it is important to that research investigating clinical strategies in relation of how to manage a long-life self-care activity. Also, it is important that a study based on the grounded theory to produce a theory about how to manage this daily practice is highly important. In addition, as some of the sensitive topic such as sexuality, body image, incontinence, and privacy were raised by the participants because nobody has talked about them, hence, it is vital that further studies about the extent of psychological and instrumental support are needed. These studies could establish a protocol related to IC care. This is because catheter-related health issues were not exactly the same those which were found in the literature.

Also, there are not clear recommendations about the period that participants can use and reuse a catheter, however, reusing the same IC for multiple catheterizations is not recommended, besides, the cleaning of the IC and using it more than once has no basis in literature, this is because scholars did not invest for a randomized control trial in relation to cleaning the used IC. Hence, it is important to broaden the research in this field in terms of studies, design, and the topic matters.

Strengths and Limitations

The major goal of this thesis was to explore SCI participants' lived experiences with the bladder management approach they employed in rehabilitation, especially intermittent self-catheterization, among Arab participants. The findings revealed significant points based on the participants' experiences with the IC during their hospital stay and sickness, which can enhance the service offered and help others.

Qualitative research can enhance quantitative data by adding depth and insight. The source of qualitative research data is the human experience. It can provide a more profound, comprehensive image of customer behaviour by providing a window into audiences' brains that quantitative data cannot. While quantitative research can reveal broad patterns in product attitudes, qualitative data can explain why such trends exist and how to adapt to fit the target audience better.

Because qualitative data is intrinsically more collaborative, researchers from diverse backgrounds may contribute multiple perspectives on the same data set, qualitative research can change on the fly due to participant reactions and replies.

Like all studies, this study has some limitations that need to be addressed. The sample size of the study while considered small, was determined by achievement of theoretical data saturation and pragmatic considerations of the nature of this sensitive topic among Arab participants. However, the sample size was adequate to answer the questions as the study reached the saturation.

For qualitative research, many people's ideas, viewpoints, and experiences must be gathered. As a result, collecting sufficient data from participants takes time, and synthesizing the data is more complicated than just putting it on a graph. Researchers must go through each response to gain a more comprehensive picture of why participants felt or reacted in a particular manner, because of the nature of qualitative data. Because the replies are frequently descriptive rather than numerical, analyzing the results took longer than processing quantitative data.

Also, this study included only male participants due to there being no female participants since they declined to participate in this study, and the sample was chosen from male SCI participants due to the limited availability of female participants. Hence, we recommend that further studies to be held by a female researcher as they could succeed in recruiting female participants, as the above limitation prevented the study from echoing the females’ voices in such Arabic communities in terms of using IC.

Another limitation of this study was the extent to which emotional experiences were documented. As a response to varied stimuli, participants reported annoyance, some tension, shame, and lost confidence. Because the study is descriptive in nature, the findings can’t be generalized to the larger population. Keep in mind that the researcher is a clinical nurse’s specialist and was able to counsel them and offered immediate support no serious issue was reported.

Regarding the strength points, regardless of the sensitivity of the topic, the participants' positive reaction and active engagement in this section resulted in primary five themes with subthemes, as all of this was viewed as guidance and pure experience gained and may be used as a reference in the future. Despite the fact that the sample only included male participants, it created a healthy and stress-free environment for the participants to express their thoughts and discuss their experiences. Because the researcher conducted the interviews personally as an Arabic speaker with a good relationship and response with the participants, the information gathered from them was more effective and passed more easily. Having this thesis with all of its features regarded a rare issue and not conducted anywhere else in this manner considered a valid point and provides it more strength and power.

The findings of this study might serve as the foundation for future research that includes more participants and expands on the findings. Further researches are recommended in order to collect a large amount of evidence-based experience and compile it into applicable experiences as lessons learned. Due to the significant outcomes, sharing the outcomes will help measure, validate and improve the experience of IC among SCI participants.

Conclusion

IC is the best-preferred method for emptying the bladder in participants with SCI. Even though it is the most widely used strategy by participants with SCI, there have been few studies on best practices for catheterization, and long-term catheter usage and care as a reference may help them, even though standards have been created. The frequency or schedule of catheterization should therefore be decided by frequency-volume records, urodynamic data, and functional bladder capacity, where clinicians must be informed of current proposed practices and engage in evidence-based research to educate participants about long-term IC usage, complications, and catheter management.

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Appendix

Appendix A: Consent Form

Explanatory message to the participants in the study – English Version

Dear participant,

I would like to request your participation in my thesis on “Exploring the lived experience of Arab participants with SCI of intermittent self-catheterization: A Phenomenological Study." I am asking you to take part because you met the criteria required in this study. Please read this form carefully and ask questions you may have before agreeing to take part in the survey.

Information Sheet

Introduction

I am doing qualitative research about “**Exploring the lived experience of Arab participants with SCI of intermittent self-catheterization: A Phenomenological Study.”**

I want to invite you as a participant in this study. I am providing information about the research, which you can read. If you have any questions, please do not hesitate to ask me. You do not have to decide today whether or not you will participate in the research. Before you choose, you can talk to anyone you feel comfortable with about the study.

Purpose of the Research

The purpose of the study will be to discover how you experienced **“Exploring the lived experience of Arab participants with SCI of intermittent self-catheterization: A Phenomenological Study."** The researcher is interested in your perception and understanding of this period. Your personal story and interpretation of this time are essential to us and will help us improve the care of current and future studies.

Type of Research Intervention

The research will involve personal interviews and completing surveys.

Participant Selection

You are invited to participate in this research because you are willing to share your experience with "**Exploring the lived experience of Arab patients with SCI of intermittent self-catheterization: A Phenomenological Study enrolled in an."**

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. You can withdraw at any time if you feel uncomfortable.

Procedures

If you agree to participate in this study, you will be asked to enroll in an interview at your convenient time. No one else but the researcher will be present unless you would like someone else to be available with you.

Duration

The research study will be completed by 2022. The interview will be conducted within 30–45 minutes.

Risks

There are no physical risks involved at any time from the start to the completion of the study. I will respect if there are any religious or socio-cultural limitations or inhabitations from the participants. The participant will decide to what extent they will provide information.

Benefits

The information we will gain from this study may help to foster empathy and understanding of the "**Exploring the lived experience of Arab patients with SCI of intermittent self-catheterization: A phenomenological study**." This would benefit the SCI participants and could build a strategy for SCI society.

Reimbursements

You will not be given an incentive to participate in the research.

Confidentiality

Your name or any other information directly identifying you will not be obtained. A code will be assigned to your questionnaire. Only the researcher will know who is behind the given code to identify whom I can go back to for further clarification or confirmation of the information you have shared.

All information gathered will be used only for this research.

Sharing the Results

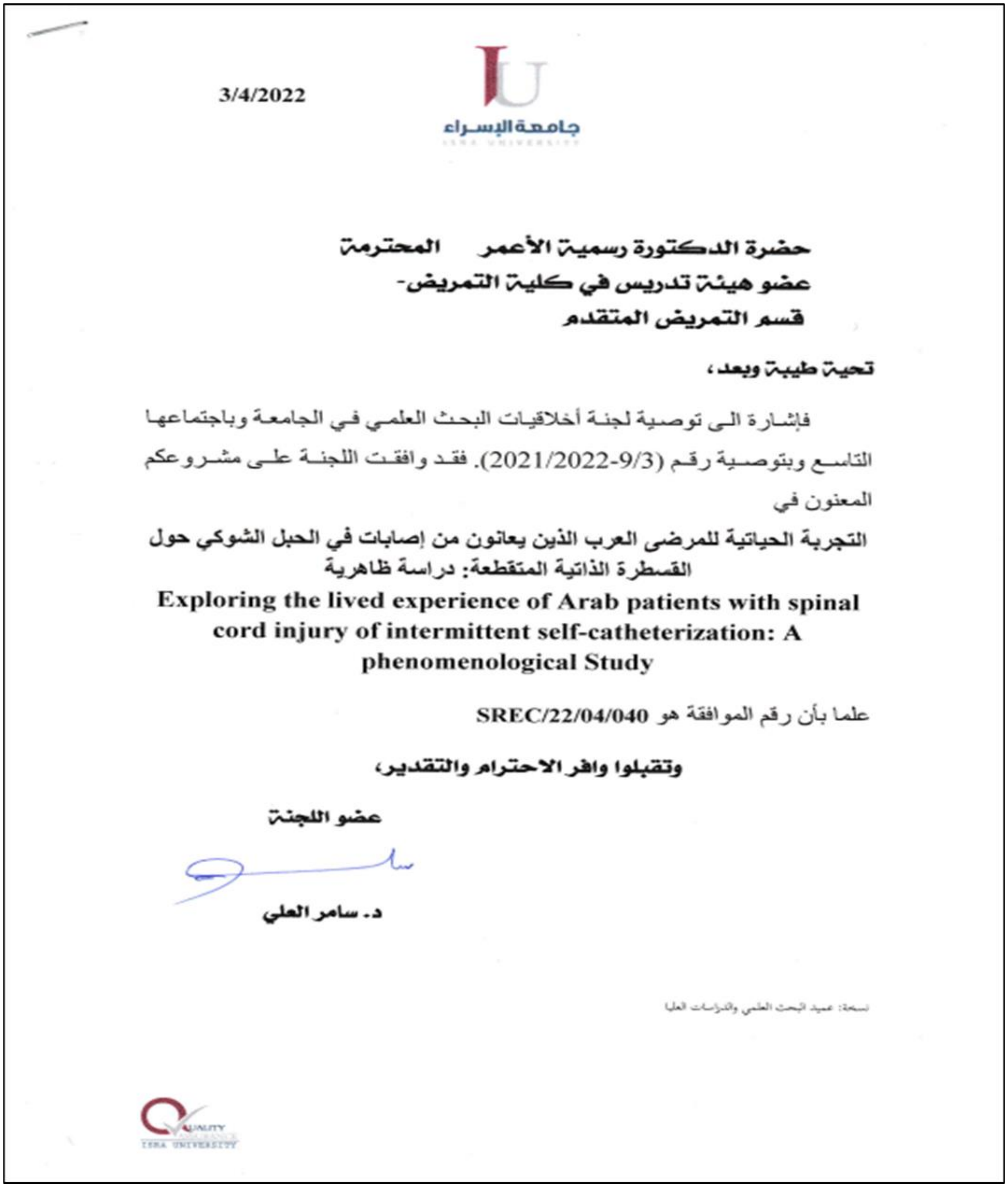
Nothing you tell us today will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge we get from this research will be shared with you before it is widely available to the public. Later on, the finding of this research will be published in an international journal and presented at an international conference.

Right to Refuse or Withdraw

You do not have to participate in this research if you do not wish to; you may stop participating in the interview anytime you want to without being affected. I will give you an opportunity at the end of the study to review your remarks, and you can ask to modify or remove portions of those if you do not agree with any notes or if I did not understand you correctly.

Appendix B: Ethics Certificate

IRB – Isra University



3/4/2022

جامعة الإسراء

ISRA UNIVERSITY

حضرة الدكتورة رسمية الأعمر المحترمة
عضو هيئة تدريس في كلية التمريض-
قسم التمريض المتقدم

تحية طيبة وبعد،

فإشارة الى توصية لجنة أخلاقيات البحث العلمي في الجامعة وباجتماعها التاسع وبتوصية رقم (3/9-2021/2022). فقد وافقت اللجنة على مشروعكم المعنون في

التجربة الحياتية للمرضى العرب الذين يعانون من إصابات في الحبل الشوكي حول القسطرة الذاتية المتقطعة: دراسة ظاهرية

Exploring the lived experience of Arab patients with spinal cord injury of intermittent self-catheterization: A phenomenological Study

علما بأن رقم الموافقة هو SREC/22/04/040

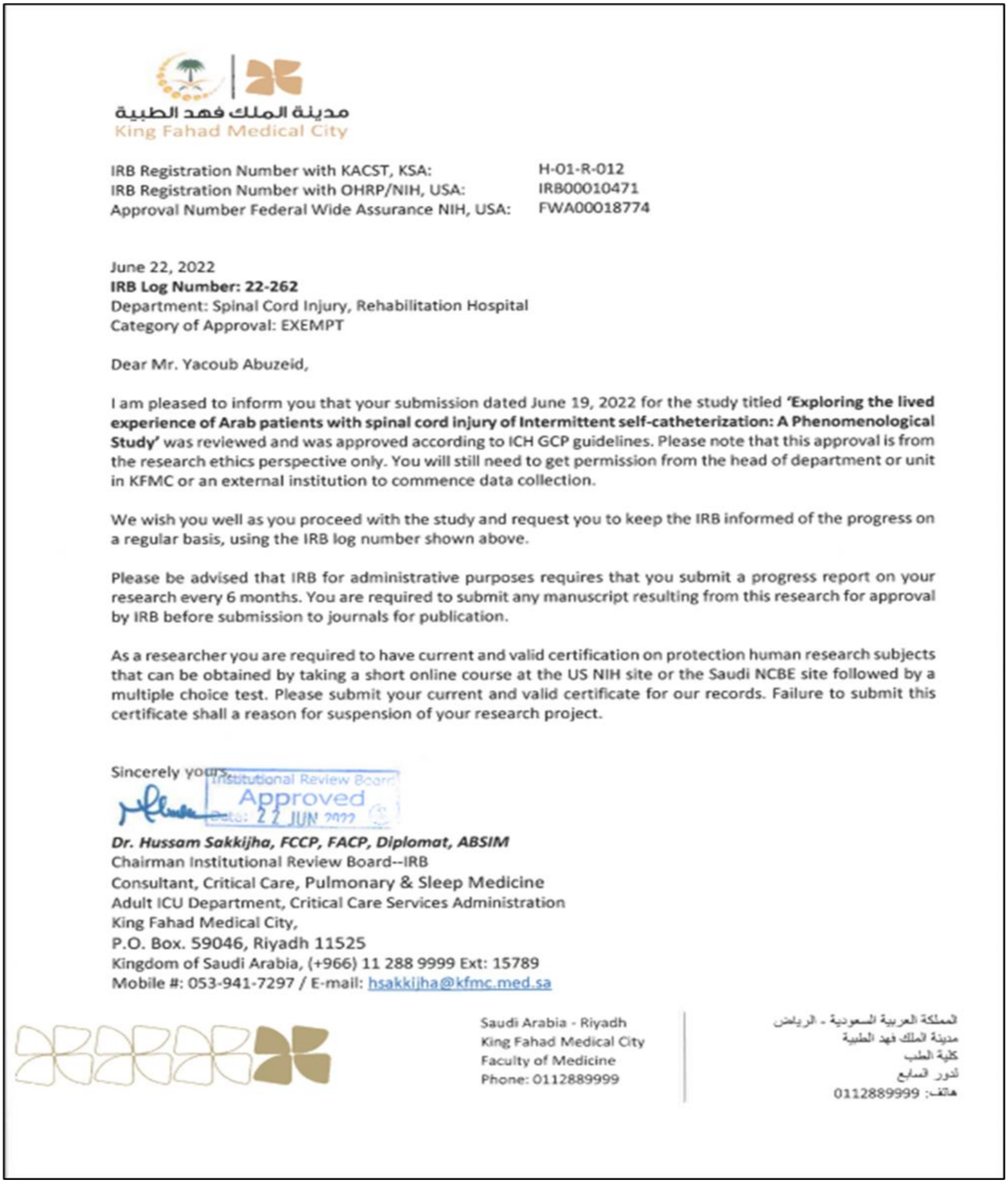
وتقبلوا وافر الاحترام والتقدير،

عضو اللجنة

د. سامر العلي

نسخة: عميد البحث العلمي والدراسات العليا

IRB – King Fahad Medical City



مدينة الملك فهد الطبية
King Fahad Medical City

IRB Registration Number with KACST, KSA: H-01-R-012
IRB Registration Number with OHRP/NIH, USA: IRB00010471
Approval Number Federal Wide Assurance NIH, USA: FWA00018774

June 22, 2022
IRB Log Number: 22-262
Department: Spinal Cord Injury, Rehabilitation Hospital
Category of Approval: EXEMPT

Dear Mr. Yacoub Abuzeid,

I am pleased to inform you that your submission dated June 19, 2022 for the study titled **'Exploring the lived experience of Arab patients with spinal cord injury of Intermittent self-catheterization: A Phenomenological Study'** was reviewed and was approved according to ICH GCP guidelines. Please note that this approval is from the research ethics perspective only. You will still need to get permission from the head of department or unit in KFMC or an external institution to commence data collection.

We wish you well as you proceed with the study and request you to keep the IRB informed of the progress on a regular basis, using the IRB log number shown above.

Please be advised that IRB for administrative purposes requires that you submit a progress report on your research every 6 months. You are required to submit any manuscript resulting from this research for approval by IRB before submission to journals for publication.

As a researcher you are required to have current and valid certification on protection human research subjects that can be obtained by taking a short online course at the US NIH site or the Saudi NCBE site followed by a multiple choice test. Please submit your current and valid certificate for our records. Failure to submit this certificate shall a reason for suspension of your research project.

Sincerely yours,

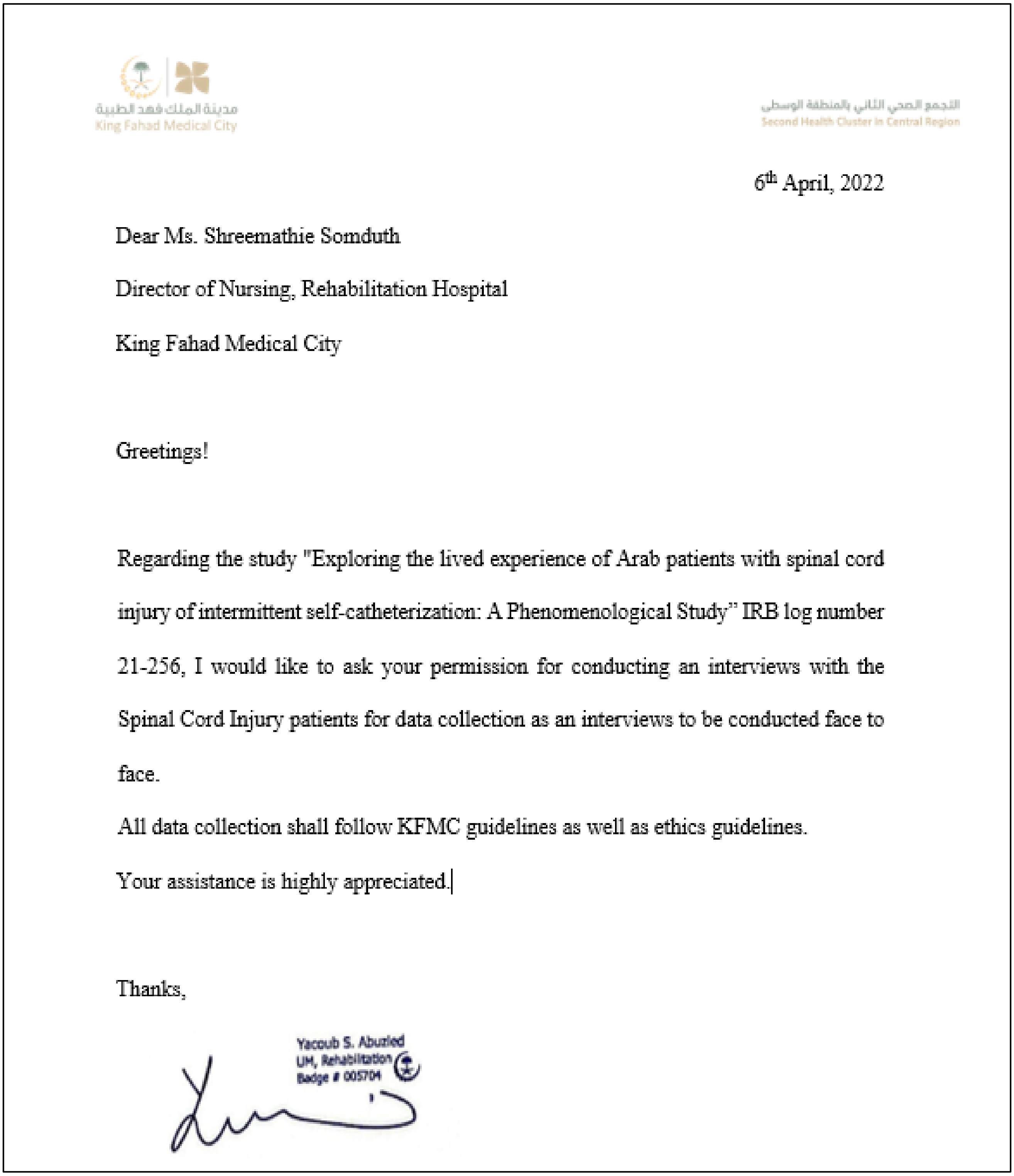
Institutional Review Board
Approved
Date: 22 JUN 2022

Dr. Hussam Sakkijha, FCCP, FACP, Diplomat, ABSIM
Chairman Institutional Review Board--IRB
Consultant, Critical Care, Pulmonary & Sleep Medicine
Adult ICU Department, Critical Care Services Administration
King Fahad Medical City,
P.O. Box. 59046, Riyadh 11525
Kingdom of Saudi Arabia, (+966) 11 288 9999 Ext: 15789
Mobile #: 053-941-7297 / E-mail: hsakkijha@kfmc.med.sa

Saudi Arabia - Riyadh
King Fahad Medical City
Faculty of Medicine
Phone: 0112889999

المملكة العربية السعودية - الرياض
مدينة الملك فهد الطبية
كلية الطب
الدور السابع
هاتف: 0112889999

Data Collection Permission



مدينة الملك فهد الطبية
King Fahad Medical City

التجمع الصحي الثاني بالمنطقة الوسطى
Second Health Cluster in Central Region

6th April, 2022

Dear Ms. Shreemathie Somduth

Director of Nursing, Rehabilitation Hospital

King Fahad Medical City

Greetings!

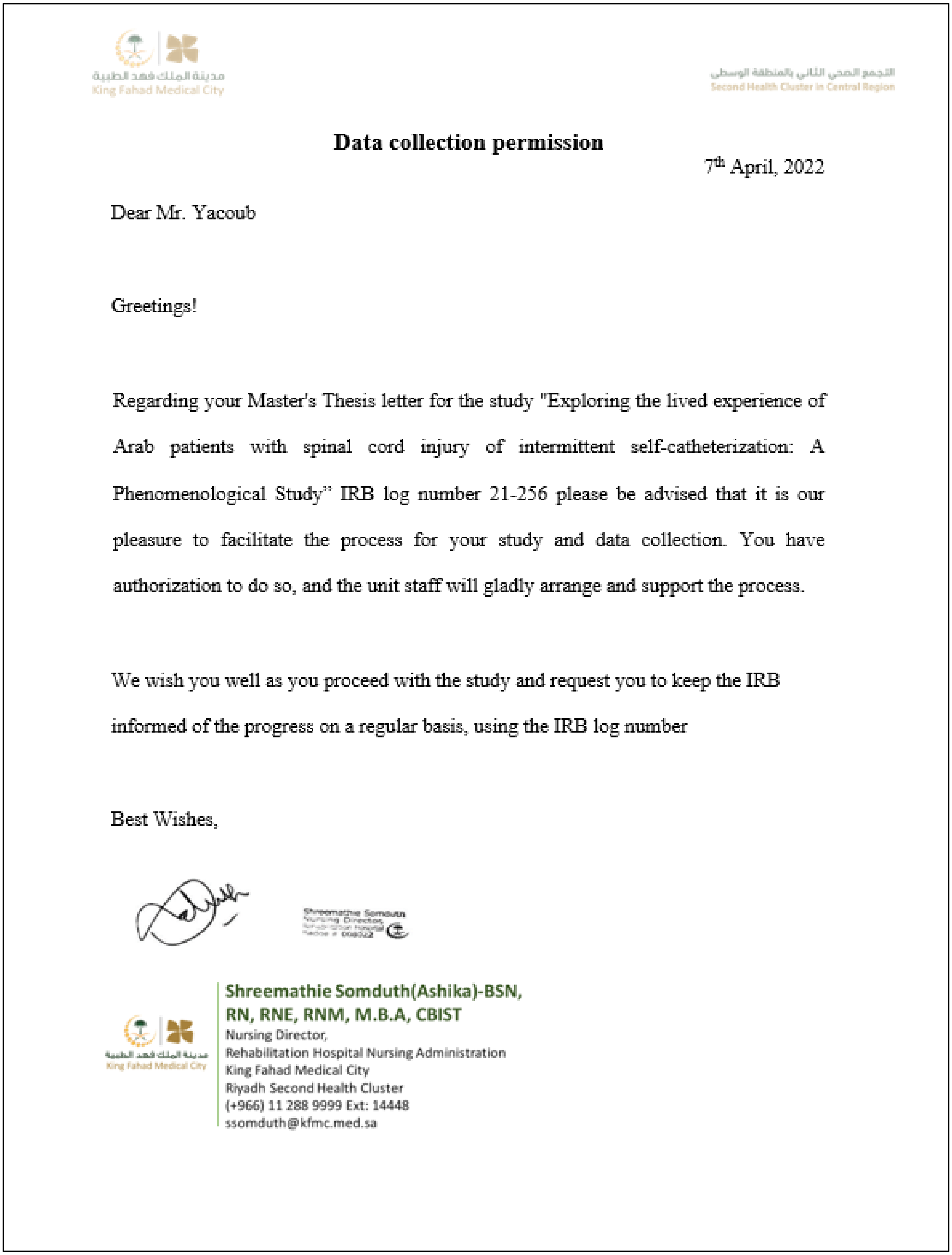
Regarding the study "Exploring the lived experience of Arab patients with spinal cord injury of intermittent self-catheterization: A Phenomenological Study" IRB log number 21-256, I would like to ask your permission for conducting an interviews with the Spinal Cord Injury patients for data collection as an interviews to be conducted face to face.

All data collection shall follow KFMC guidelines as well as ethics guidelines.

Your assistance is highly appreciated.

Thanks,

Yacoub S. Abuzied
UM, Rehabilitation
Badge # 005704



مدينة الملك فهد الطبية
King Fahad Medical City

التجمع الصحي الثاني بالمنطقة الوسطى
Second Health Cluster in Central Region

Data collection permission

7th April, 2022

Dear Mr. Yacoub

Greetings!

Regarding your Master's Thesis letter for the study "Exploring the lived experience of Arab patients with spinal cord injury of intermittent self-catheterization: A Phenomenological Study" IRB log number 21-256 please be advised that it is our pleasure to facilitate the process for your study and data collection. You have authorization to do so, and the unit staff will gladly arrange and support the process.

We wish you well as you proceed with the study and request you to keep the IRB informed of the progress on a regular basis, using the IRB log number

Best Wishes,

Shreemathie Somduth
Nursing Director,

Shreemathie Somduth(Ashika)-BSN, RN, RNE, RNM, M.B.A, CBIST
Nursing Director,
Rehabilitation Hospital Nursing Administration
King Fahad Medical City
Riyadh Second Health Cluster
(+966) 11 288 9999 Ext: 14448
ssomduth@kfmc.med.sa

مدينة الملك فهد الطبية
King Fahad Medical City

Appendix C: Glossary

CISC	Clean Intermittent Self Catheterization
SCI	Spinal Cord Injury
SIMC	Self-Intermittent Catheterization
IC	Intermittent Catheter
UI	Urinary Incontinence
UTI	Urinary Tract Infection
PVR	Post-Void Residual
IRB	Institutional Review Board
ID	Identity Document
FM	Formulated Meaning
SS	Significant Statement

Appendix D: Participant Information Sheet

What is the purpose of the current study?

To explore the lived experience of using SIC among RH SCI participants

Who is the researcher responsible for this study?

Mr. Yacoub Abuzied. You can reach him on his mobile at 0502508769

How much time am I required to spend on this study?

You are expected for 30 to 45 minutes of your time to taken to answer the questions and have a conversation after signing a consent form to join the study.

Do I have to give any blood or other specimens?

No

Does the study require another visit or future collection of information?

Maybe

Am I allowed to withdraw from the study after participation?

Yes, you have the right to withdraw at any time without any commitment to the study team.

Do I get money or any other benefits from participating?

Your will receive no financial benefit, but the research will help us understand the lived experience that could be fixed for the sake of SIC.

Am I in any harm if I participate in this study?

There is no expected harm.

Does it affect the service I should get here if I refuse to participate?

No, acceptance of participation is entirely voluntary, without any impact on the service provided at RH SCI.

If I participate, will my identity information have to be shared with any third party?

Your identity information, including name, national ID, date of birth, and contacts, will not be collected or shared with any third party.

Can I get the results of the current thesis?

Yes, you can. Contact the researcher in approximately six months to get the main results of the current research.

Appendix E: Study Guide

Study guide

1. Can you tell me how life has been since you started using IC?
2. Can you share with me an experience that was of significance to you during the time when you were performing IC?
3. Please share with me a day of your experience of using intermittent catheter.
4. Can you tell me a story when you started to perform SIC?

Appendix F: Demographics

1. **Date:** ------/-------/-----------
2. **Age:** -----------–years
3. **Marital status**
    - ○ Single
    - ○ Married
    - ○ Divorced/separated
    - ○ Widow
4. **Education**
    - ○ Illiterate
    - ○ Primary
    - ○ Middle School
    - ○ High School
    - ○ College
    - ○ Post-graduate
    - ○ Other

5. **Current or previous history of UTI?**
    - ○ No
    - ○ Yes
6. **Current or previous history of Autonomic Dysreflexia?**
    - ○ No
    - ○ Yes
7. **Did you ever use IC during the past year by yourself?**
    - ○ No
    - ○ Yes

إستكشاف التجربة الحياتية للمرضى العرب الذين يعانون من إصابات في الحبل الشوكي حول القسطرة الذاتية المتقطعة: دراسة ظاهرية

أُعدت من قبل

يعقوب صلاح أبوزيد

أشرف عليها

د. رسمية مصطفى الأعمر

الملخص

المقدمة

القسطرة المتقطعة هي إدخال وإخراج قسطرة بولية عدة مرات في اليوم لتفريغ المثانة. تستخدم هذه القسطرة لتصريف البول من المثانة التي لا يتم إفراغها بشكل كافٍ أو من قناة تم إنشاؤها جراحيًا تصل المثانة بسطح البطن. كثيرا ما يوصى بـها كطريقة فعالة لإدارة المثانة للأشخاص الذين يعانون من خلل وظيفي في المثانة مجهول السبب أو عصبي المنشأ والذين لديهم إفراغ غير كامل للمثانة. على الرغم من قلة الأبحاث حول شعور الأشخاص تجاه إلتهاب المثانة الخلالي وكيف يؤثر ذلك على حياتهم اليومية، فقد تم إجراء أبحاث مهمة على القسطرة الذاتية المتقطعة، مثل معدلات العدوى والتأثيرات الكلوية.

الغاية

إستكشاف التجارب الحياتية للمرضى العرب المصابين بإصابات في الحبل الشوكي الذين يستخدمون القسطرة الذاتية المتقطعة لتفريغ المثانة.

المنهج

تم استخدام ظاهرة هوسرليان وطريقة كولايزي للبحث عن فهم متعمق للتجربة المعيشية للبالغين العرب باستخدام القسطرة المتقطعة. تمت مقابلة عشرة مشاركين عرب بالغين من وحدة إصابات الحبل الشوكي، مستشفى التأهيل بمدينة الملك فهد الطبية، الذين استخدموا القسطرة المتقطعة بعد تعرضهم لإصابة في الحبل الشوكي ضمن نفس الحالة الطبية، خلال الأسبوع الأول من أبريل 2022، وتم الانتهاء منها في الأسبوع الأول من مايو 2022.

النتائج

ظهرت خمسة مواضيع رئيسية من البيانات بما في ذلك الطريق إلى القسطرة المتقطعة، والاستخدام المتكرر للقسطرة اليومية، والنظافة والعناية العامة، وصورة الجسم والجنس، ونمط الحياة والتكيف مع الذات. وفقًا للدراسة، تؤثر إصابة الحبل الشوكي على كل جانب من جوانب حياة الشخص تقريبًا، بما في ذلك حياته المهنية والاجتماعية، والعلاقات الشخصية، وشكل الجسد، وحتى ما يشربه وكيف ينام.

الإستنتاج

تم التحقيق في الموضوعات، وتم استخدام الأدبيات ذات الصلة لتوفير أساس موثوق للقضايا التي عبر عنها المشاركون. تم تفصيل المعرفة الجديدة، وهناك توصيات لتغييرات الممارسة ودعوات لمزيد من البحث المتقدم لدعم الفرضيات.

الكلمات المؤثرة: متقطع، قسطرة، متقطع ذاتي، نظيف متقطع، تجربة