

Exploring Healthcare Experiences and Needs of Children with ADHD, Jordanian Mothers Perspective: A Phenomenological Study Protocol

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Abstract

Background: Attention deficit hyperactivity disorder ADHD is a common behavioral problem among children in the world as in Jordan. However, Children with ADHD were significantly less likely to have appropriate health care services when they need health care. Thus, phenomenological study is important and needed as a gap exists in the literature concerning the health care experiences and needs of children with ADHD from the parents' perspective. Accordingly, this study will conduct to gain an in-depth understanding of the healthcare experiences and needs of children with ADHD. **Aim:** The aim of the current qualitative study is to explore and describe the health care experiences and health care needs of children with ADHD from their mothers' perspectives within the context of the phenomenological approach. **Study Method:** Descriptive phenomenological research design. Semi-structured interview will be conducted with the mothers of children with ADHD who will be recruited purposefully from special Attention Deficit and Hyperactivity Disorders Medical Clinics in order to ensure and to confirm the diagnosis from the specialist there. Data will be transcribed, managed and analyzed using descriptive, phenomenological analysis. The Jordan University Ethics Committee approved the study. **Discussion:** The findings of this study will make an original contribution to our knowledge about the health care experiences and health care needs of children with ADHD from their mothers' perspectives within the context of the phenomenological approach, in order to help health care providers in general, and nurses, in particular, to provide optimal health care services for children with ADHD that address the children physical and mental health care needs of the highest priority from mothers' perspectives.

Keywords

ADHD, Phenomenology, Jordan, Qualitative Research

1. Introduction

Attention Deficit Hyperactivity Disorder ADHD is a neurodevelopmental disorder characterized by a pattern of hyperactivity, inattention, and impulsivity [1]. ADHD is a multifactorial disorder caused by multiple factors, including psychosocial, genetic, and environmental factors [2]. ADHD affects the physical and psychological health of children profoundly [3]. These physical comorbidities might increase medical care utilization and costs [4]. Worldwide, the prevalence of ADHD varies from 0.2% - 28%, the reported differences in prevalence across countries are mainly related to the differences in diagnostic criteria used [5]. However, regardless of statistics, ADHD is perceived by different countries as a disorder that has a high prevalence rate [5].

ADHD has received attention in the United States and Europe, but less attention is recognized in the Arab countries [5]. A shortage of studies that address children's mental problems in general and ADHD in specific is documented [6]. There are limited studies about the risk factors, cultural factors, and health needs of children with ADHD within the Arab countries; the majority of the studies were prevalence studies [7].

There is an increase of children with mental disorders admitted to general pediatric units [8]. They have more medical conditions and these conditions lead to more healthcare services utilization [9]. Children with ADHD were significantly less likely to have appropriate health care services when they need health care [3].

The process of access to health care among children with ADHD is complex and different across countries [10]. There are several barriers to health care services provided for children with ADHD in healthcare settings, including misconceptions, stigma, lack of education, and lack of resources [10]. There are significant unmet health care needs among children with ADHD, despite the high rate of health care utilization [9]. Caring for children with mental disorders in general health care settings provides challenges for nurses and health care providers as they are poorly prepared and incompetent [11].

Despite the high rate of physical and psychological comorbidities in ADHD children, they were significantly less likely to have appropriate health care services when they need health care [3]. Thus, there is a need to ensure that nurses have the skills to understand health care needs and provide care for children admitted to a pediatric unit with a mental health diagnosis especially children with ADHD [4].

Caring for children with ADHD in health care settings is a complicated issue for nurses and health care providers as their needs are inadequately recognized

[8] [11]. By looking at the different aspects of patient experience, nurses can assess the extent to which patients are receiving care that is respectful of individual patient preferences, needs, and values [12]. Health care experience of children with ADHD has not explored adequately in the Jordanian literature as most of the studies were prevalence studies [7]. As searched the literature using a different database, no single study was found that addresses the health care experiences and needs of children with ADHD from their mother's perspective in Jordan. According to the Centers for Disease Control and Prevention (2016), one of the main obstacles that impede the establishment of effective health care services for children with ADHD in the developing countries is the lack of research studies that can inform about the health care needs of children with ADHD. Health care experiences and needs of children with ADHD within the Middle East region are not well-defined [7]. In Jordan, Khalaf [13] highlights the importance of conducting qualitative researches as a method for investigating nursing issues.

The purpose of the current qualitative study is to explore and describe the health care experiences and health care needs of children with ADHD from their mothers' perspectives within the context of the phenomenological approach, in order to help health care providers in general, and nurses, in particular, to provide optimal health care services for children with ADHD that address the children physical and mental health care needs of the highest priority from mothers' perspectives.

The current qualitative study is expected to answer the following questions:

- What are the experiences of Jordanian mothers' related to the health care provided to their children with ADHD?
- What are the health care needs of Jordanian children with ADHD from their mothers' perspectives?

2. Methodology and Methods

2.1. Methodology

The qualitative methodology is congruent with the aim of this study, which is to explore health care experiences and needs of children with ADHD from the mothers' perspectives in order to help health care providers, especially nurses to provide physical and mental health care services for children with ADHD that address their health care needs.

Descriptive phenomenology allows the researcher to diligently explore and describe the in-depth lived experience of caring for the whole person in order to add to the unique knowledge of nursing [14]. In the current study, the descriptive phenomenology approach developed by Husserl will be used to explore the health care experiences and needs of children with ADHD from their mothers' perspectives. Since phenomenology has become an influential approach in nursing research [15]. Furthermore, utilizing descriptive phenomenology will help to provide an in-depth description of individuals' experiences, needs, and

concerns [14].

2.2. Study Design

As the purpose of this study is to explore and describe the health care experiences and health care needs of children with ADHD from their mothers' perspectives, the descriptive phenomenology approach developed by Husserl will be used. As a method, it involves studying a small number of subjects through extensive and prolonged engagement to develop patterns and relationships of meaning. In this process, the researcher sets aside his/her own experiences in order to understand those of the participants in the study.

Researcher Role

Through the research process, the researcher will be the data collectors. The researcher will analyze the data, will write the findings, will discuss the finding, and will write the recommendations. The researcher in this phenomenological study requires the identification of personal values, experiences, preconceptions, and biases at the beginning of the study.

Population, Sampling, Sample size

The study population is Jordanian mothers of children with ADHD live in Jordan. Purposeful criterion sampling will be used in the current study. Purposeful criterion sampling is commonly used in qualitative research. It involves selecting participants according to the needs of the study [14] in that researcher chooses participants who give a richness of information that are suitable for detailed research according to given criteria. In order to ensure a homogenous sample, the following inclusion and exclusion criteria will be used in selecting the participants. All participants should be:

- Jordanian mothers of children who are diagnosed with ADHD, in order to get a homogenous sample, since the mothers are more involved in the health care of children more than fathers within the Jordanian context;
- 18 years and older, mentally competent, and able to consent to participate in the study, mothers who are diagnosed with mental disorders will be excluded, because they cannot articulate their conscious experience;
- Have either a male or female child diagnosed with ADHD, in order to get different experiences, children with ADHD who had severe ADHD and other comorbidity will be excluded;
- Have children between the ages 3 - 18 years old, to cover childhood age;
- Speak and read Arabic fluently, so that facilitate interviews;
- Have access and can use the healthcare services in Jordan, in order to understand the experiences of children with ADHD who had previously accessed health care services.

In the current study, the sample size will be determined on the basis of theoretical saturation, that is when themes or essences have emerged from participants and data are repeated, the number of participants will be adjusted according to reaching data saturation.

Recruitment Plan & Settings

The eligible participants will be recruited purposefully from special Attention Deficit and Hyperactivity Disorders Medical Clinics (pediatric neurology clinic and pediatric psychiatric clinic) in order to ensure and to confirm the diagnosis from the specialist there. One clinic is in Amman, and the other in Irbid, selecting different settings in order to establish the study transferability. The study flyers will be distributed to the selected ADHD clinics. In addition, an e-mail or an SMS will be sent to list the potential participants asking them whether they would be interested in participating in a research study. The email will introduce the researcher, will state the purpose of the study, will describe the research and clarify the procedures, confidentiality, and risks and benefits. The health care providers in the selected ADHD clinics will be asked for help in the identification of the potential participants and in the invitation of the participants. Finally, the location of the participants' interviews will be determined after the participants agree to participate, according to the participant's preference and agreement of the researcher.

Ethical Considerations

In phenomenological studies, the researcher necessitates protecting the participants with respect to the participants' rights, needs, values, and desires. In the current study, ethical approval is obtained from the research ethics committee at the University of Jordan; also, approval from the special ADHD clinics. All interviews will be voluntary and based on the informed consent process, which is a dynamic process rather than a single time consent, the participants will have the right to withdraw from the study at any time.

Confidentiality of interviewees will be assured; the mothers will be informed verbally that they will be given a pseudonym and an ID number from the point of data collection, permission for recording will be obtained before starting the interview, the record will be transcribed immediately after each interview and the audiotapes will be erased upon study completion. In addition, the transcription will be stored securely; no one will have access to the data except the advisor and the researcher. In addition, audio recordings will be saved in a secure password on the researcher personal computer and backed up on a secure external hard disk. The names of the participants will not be mentioned in the final research.

Furthermore, the participants will be informed that a psychological referral could be provided if they need it. If any stressful event will be memorized by the participants, or any psychological distress occurs the interview will be stopped immediately, and psychological consultation will be obtained. There will be no financial reward for participation. Since the study is descriptive qualitative, the researcher will not provide any advice to the participants; but the researcher will provide them with a list of resources for further information.

Data Collection Instruments

Data will be collected using face to face semi-structured interview, this ap-

proach will provide flexibility and will allow for open discussion to take place while having the interview stay focused on specific questions for all participants, the semi-structured interview for each participant will start with the main guide open question “What are the healthcare experiences of Jordanian children with ADHD from your perspectives as a mother?”. Further questions are listed for probing in the interview guide. The audio recording will be used to record participants’ responses, for each participant after taking the permission to record the interview by signing a written consent, the data collection will be carried out in a single interview session, and each interview is expected to last 30 - 45 minutes. Moreover, field notes regarding the researcher observations will be documented immediately after conducting each interview.

The questions of the interview are formulated in a way that is relevant to the experience under investigation; the questions are selected to answer what and how questions related to the phenomenon of interest. In addition, they are selected based on the reviewed literature to expand the understanding of the phenomenon. In addition, the interview questions are open-ended, clear, specific, and not leading; the content of these questions will be validated by expert researchers in qualitative studies. The questions organized in an interview guide.

Initially, pilot testing of the interview with one mother will be applied, this will help the researcher to ensure that the data taken from participants as a response to the interview questions will reflect exactly what the researcher is going to know, and will help the researcher to modify the interview questions.

Data Collection Procedure

Ethical approval from the school of nursing/ the University of Jordan is obtained. In order to target the study participants, the study flyers will be distributed to the selected clinics that offer services for children with ADHD after obtaining permission from the selected clinics. A card with the name of the researcher and the phone number will be attached also to the flyer, so the targeted sample will have the chance to talk with the researcher and inquire more information about the study. Then an appointment will be scheduled for an interview for those interested in further participation. Agreeing to the interview will be considered as an agreement to participate in the study, the time and the location of the interview will be determined after the participant agrees to participate as shown in **Figure 1**.

Each participant will be informed to sign written consent to participate in the interview. The demographic characteristics will be obtained during the interviews. Only the researcher and the participant will attend the interview session; to ensure the privacy of the participants and make them more comfortable. With the participant’s permission, each interview will be recorded using a digital recording device; during the interviews, the researcher will use a semi-structured format to obtain participant data about their description and understanding. Probing questions will be asked as needed for more clarification. The expected time for the interview is 30 - 45 minutes.

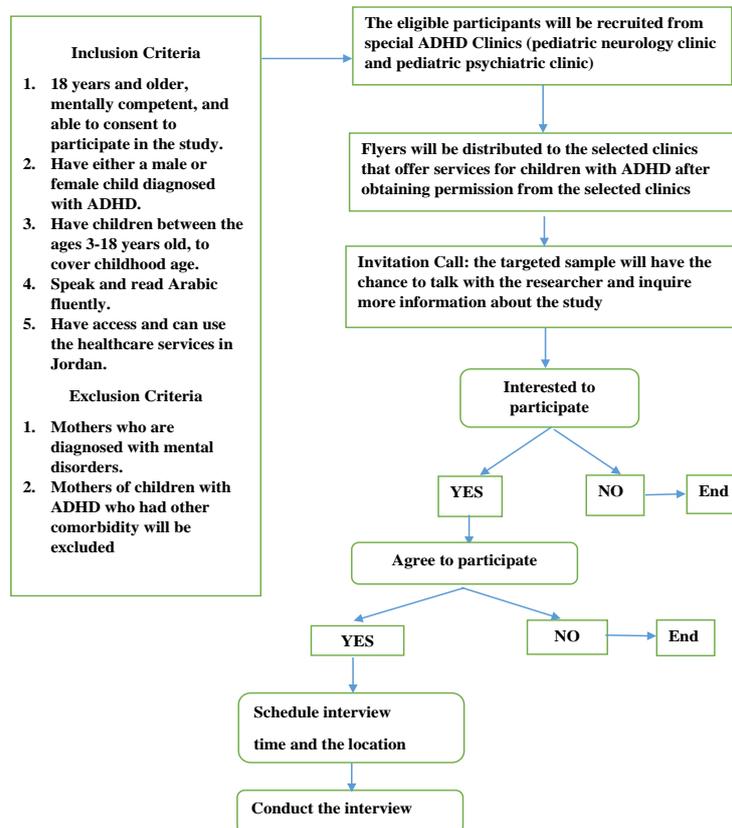


Figure 1. Illustrate the recruitment and data collection process.

Data Management

Data collection will be conducted using the researcher's and participants' official language, which is "Arabic". The data will be transcribed verbatim in the Arabic language by the researcher, then the written transcript will be verified by the researcher by listening to the recording to check the accuracy of the transcription, thus the original meaning and intention of the data will be preserved. After conducting the data analysis in Arabic, the significant statements will be translated into English using the meaning of the sentences based on the World Health Organization (WHO) guidelines of translation. Moreover, the transcription will be validated by an independent bi-linguistic expert.

Data Analysis

Colaizzi's (1978) method of data analysis will be used, beginning with reading the Arabic transcript several times to acquire general meaning and to immerse in the data, then the significant statements will be extracted and formulated into meaningful units. After that, the context will be organized into clusters of themes, the meaningful units will be described in details and an interpreted whole of the phenomenon will be formulated, finally, after data analysis will be completed, final themes will be returned to participants to validate the captured meaning of healthcare experiences and needs of children with ADHD from mothers' perspectives as shown in **Figure 2**. Descriptive statistics will be used to summarize the participants and children-related demographic information.

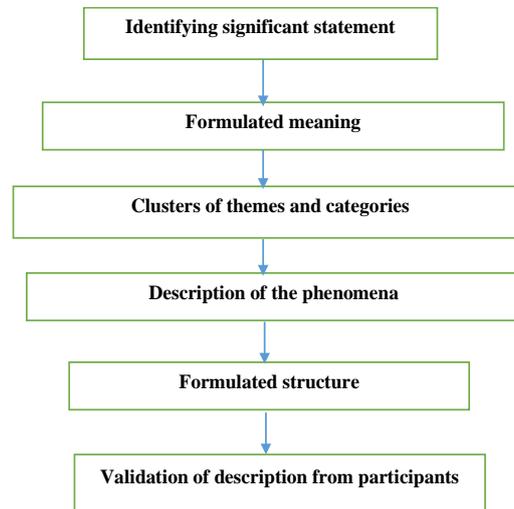


Figure 2. Illustrates the process of descriptive phenomenological data analysis created by Colaizzi (1978).

Trustworthiness and Rigor of the Study

According to Lincoln and Guba (1985), the principles of dependability, credibility, and transferability will be used to establish trustworthiness in qualitative research. These principles will be applied throughout the research process.

3. Discussion

Nurses play a crucial role in assessing the health care needs of children with ADHD and their parents, because nurses constantly interacting with children in healthcare settings [4] [16] [17]. Caring for children with mental disorders in general health care settings provides challenges for nurses and health care providers as they are poorly prepared and incompetent [4] [11]. Once the nurses have recognized the health care experiences of parents, especially mothers, effective partnerships could be developed [17]. Thus, health care providers, including nurses need to recognize the health care experiences and needs of children with ADHD from the mother's perspective. Understanding patient experience is essential for family-centered care, and for health care quality.

The findings will assist professionals, including nurses to provide health care services for children with ADHD that address concerns and needs extend from mothers' perception, and can be utilized to establish health care strategies and clinical practice guidelines for those children. This study will add new knowledge and provide information to nurses, health care providers, mental health professionals, educators, and policymakers about health care needs of Jordanian children with ADHD. Guide policy development regarding health practices for children with ADHD. This study will inform future researchers who wish to investigate issues related to children with ADHD. Since the current study will explore new areas in health care service for those populations using qualitative inquiry.

4. Conclusion

In conclusion, each child with ADHD presents challenges for all healthcare providers, including nurses, and their health care should be personalized and designed to deal with their individual circumstances. The needs and perception of the delivered health care should be well addressed and recognized while providing this care. In this spirit, this study will provide evidence in this aspect related to the physical and mental care provided for those children and will inform the health care providers about their needs from their mothers' perception.

Availability of Data and Materials

The data described in this paper are referring to this study protocol only and there are no raw data reported. The datasets will be collected and analyzed and can be available from the corresponding author on request.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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