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Evaluation of Management of Primary Hypothyroidism among Children in the Gaza Strip

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Dedication

Every challenging task needs self-effort as well as the guidance of those who are very close to my heart.

To my loving parents, who have taught me to put in a lot of effort to achieve the goals I set for myself and who are a constant source of inspiration and motivation.

To my lovely wife for her endless support during the challenges of study and life.

To my faithful brothers and sisters, thank you for always being with me and supporting me.

To my sons, and daughters.

To all teachers who taught me in the school, in the faculty of nursing, and to the academic staff at Al Quds University.

To everyone who supported me in completing this research.

Haytham Mahmoud Foaad Mansour

Declaration

I certify that this thesis submitted for the degree of a master's is the result of my own research, except where otherwise known, and that this thesis or any of its parts has not been submitted for a higher degree to any university or institution.

Signed:

Haytham Mahmoud Foaad Mansour

Date: 13/8/2022

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Haytham Mahmoud Foaad Mansour

Abstract

***Background**:*

Primary hypothyroidism is one of the most critical endocrine disorders that affects human beings at birth. It is a leading cause of mental and physical growth retardation disorders.

***Justification**:*

This study will be carried out to assess the management process of PH that involves the availability of services to early diagnose cases of PH and the provision of prescribed medication.

Purpose and objectives:

This study aims to evaluate the services provided to children with primary hypothyroidism at governmental clinics in the Gaza Strip. To assess the services, and quality of life among children diagnosed with PH, to identify areas of weaknesses and strengths, of the provided services, to assess the perspectives of caregivers, and to suggest recommendations to improve the quality of services.

Methods:

The design of this study is a mixed method that entailed triangulation of quantitative and qualitative data collection methods. The quantitative study utilized three instruments: the first tool is structured questionnaires to collect the quantitative data from caregivers of children diagnosed with primary hypothyroidism; the second tool is the Quality-of-life Questionnaire, and the third tool was the Strengths and Difficulties Questionnaire. In total, the quantitative data collected from 212 caregivers. The qualitative study utilized two instruments, the first is the in-depth interviews and the second tool is the abstraction sheet that was developed to collect data from medical records. The qualitative data included in-depth interviews with 10 key informants. The Statistical Package for Social Sciences version 25 for quantitative data analysis was used to analyze the quantitative data and the open coding thematic method was used to analyze the qualitative data.

Results:

The study revealed that the mean age of children diagnosed with primary hypothyroidism was 6.47 years and that 60.4% of them were females. Almost one-third of children had delayed in diagnosis, at age two month and more. Near two-thirds (65.3%) of children aged when the diagnosis was one month and less according to what was documented in medical files.

The majority (88.1%) of children with primary hypothyroidism received medications from the governmental primary health care centers, mainly from the Al Remal clinic, and 14.9% reported that they received medications from UNRWA clinics. Unexpectedly, only 2.5% received systematic psychological support. For service utilization, 81.9% of participants caregivers reported that there are shortages in laboratory tests and 89.9% reported that there are shortages in certain medications in government clinics.

The caregivers of children diagnosed with primary hypothyroidism reported that the main challenges and barriers to services utilization are the lack of appointments system (71.8%); the lack of specialized services (51.5%); the lack of medications (48.5%); and financial barriers (95.3%). Additionally, the results of the study have shown that there are gaps in service provision, including shortages of many specialists, such as pediatrician, family medicine physicians, nurses, psychologists, and nutritionists. The findings of the qualitative data revealed existing of protocols

for primary hypothyroidism management, however, those protocols are not up to data and not comprehensive. The infrastructure of the child health department within Al-Remal clinic is appropriate; the waiting time at this department is appropriate, and the physical building of the place is comfortable and suitable for children. The mean time generally taken to receive services from entry to exit of the Al Remal clinic was 12.40 minutes.

The medical file documentation completeness average was 60.62%. The user-provider interaction means percentage score is 76.3%, and the satisfaction means percentage score for provided services is 73.94%. However, the strengths and difficulties questionnaire revealed that 90.3% of children were rated as having peer problems, and 58.7% had emotional problems. Using the KIDSCREEN questionnaire, the findings revealed that the total mean of children well-being score is 62.11%. Participants with a good income had controlled primary hypothyroidism, and the differences between them were statistically significant.

Conclusion and recommendations.

To improve the quality of services provided to children with hypothyroidism, it is important to update the national protocols for primary hypothyroidism, ensure timely availability of laboratory tests, and medications. It is also important to improve the health information system with the primary health care centers to properly document and follow up the services received. Finally, it is highly important to reactivate the early child development services for children with primary hypothyroidism, and to broaden the scale of provided services to include systematic psychological support and nutritional support.

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List of Abbreviation

CBR	Crude Birth Rate
CDC	Centers for Disease Control and Prevention
CDR	Crude Death Rate
CHD	Child Health Department
ECD	Early Chid Development
EMR	Electronic Medical Record
GS	Gaza Strip
HCS	Health Care System
HIS	health Information System
MoH	Ministry of Health
NGOs	Non-Governmental Organizations
OECD	Organization for Economic Co-operation and Development
PCBS	Palestinian Central Bureau of Statistics
PH	Primary Hypothyroidism
PHC	Primary Health Care
QoL	Quality of Life
SDQ	Strengths and Difficulties Questionnaire
T3	Triiodothyronine
T4	Thyroxine
TSH	Thyroid Stimulating Hormone
UNRWA	United Nations Relief and Works Agency for Palestine Refugees in the Near East
WB	The World Bank
WHO	World Health Organization

Chapter One

Introduction

1.1 Background

Primary Hypothyroidism (PH) is one of the most critical endocrine disorders that affects human beings at birth. It is a leading cause of mental and physical growth retardation disorders, if undiscovered early and untreated properly (Segni, 2017). Thyroid hormone plays a crucial role in the function and development of the different body organs, along with its role in the metabolic process. The deficiency or absence of Thyroid Hormone leads to irreversible physical and mental problems. Therefore, prompt treatment of hypothyroidism is necessary to maintain normal physical and neurological development (Tokuda et al., 2014). Luckily, early detection and proper treatment of PH prevent the short-term and long-term consequences of PH (Leung & Leung, 2019).

The definition of biochemical deficit in PH is a lack of Thyroxine (T4) and increase Thyroid Stimulating Hormone (TSH) hormones, which can be caused by either a lack of thyroid hormone synthesis or a malfunction in its receptor (Croker et al., 2021). The disorder may be manifested from birth when symptoms appear, it may only appear so as a result of one of a variety of congenital abnormalities such as phenylketonuria without presenting hypothyroidism in which the manifestations of the deficiency are delayed. PH is sometimes difficult to identify in newborns since the signs and symptoms are usually not sufficiently developed (Agrawal et al., 2015). PH has an impact on the cardiovascular, digestive, neurological, and reproductive systems, as well as the endocrine and metabolic systems (Yamakawa et al., 2021), resulting in an increased economic burden characterized by both direct and indirect costs (Hepp et al., 2021), as well as a psychosocial burden that affects the lives of children and their families (Brown et al., 2015).

A screening program for newborns is available and applies to early identify children who have a congenital abnormality. Even though the effectiveness of screening programs is very high, the health providers must be aware of the signs and symptoms of PH and must be capable of providing proper PH management (Mehran et al., 2017). Delays in diagnosis and treatment beyond the first three months of life are likely to result in irreversible neurophysiologic abnormalities, according to a retrospective study of patients with PH (LaFranchi, 2011). Prospective studies show that screening programs for newborns, early

diagnosis, and treatment of infants within the first week of life result in normal or near-normal intellectual performance and growth by the age of 5-12 years (Rahmani et al., 2016).

Many countries have reported a significant increase in the incidence of PH, mainly due to the implementation of the screening program immediately after live birth (Mehran et al., 2017). Globally, the incidence of PH ranges from 1 in 3,000 live births to 1 in 4,000 live births (Kollati et al., 2017). The incidence rate of PH is higher among female infants compared to male infants, with a ratio of almost 2 to 1 (Weiner, Oberfield & Vuguin, 2020). In the Arab countries, the incidence rates vary from country to another, for instance, in Saudi Arabia, the rate is 1 per 1,931 live births compared to 1 per 2,967 live births in Bahrain, and 1 per 1,823 live births in Lebanon (Saoud, Al-Fahoum & Kabalan, 2019). Additionally, in Egypt, the rate is 1 per 3,587 live births, compared to 1 per 2,133 live births in Palestine (Saoud, Al-Fahoum, Kabalan et al., 2019).

1.2 Statement of problem

Globally, there are more than 30,000 infants with PH who are undiagnosed or who have not received proper prompt treatment, which puts infants at risk for mental retardation (Courbage, Abu Hamad & Zagha, 2016). In general, screening for PH is typically conducted within the first week of life (Jones et al., 2018). Consistent with international standards, in the Gaza Strip, the screening program for PH is part of the Ministry of Health (MoH) interventions to detect metabolic diseases among early neonates. According to MoH records, there are 313 cases of PH, of which 202 are for children aged 12 years or less. After years of implementing the screening program for PH and providing health services to children diagnosed with PH, there is limited availability of information about PH management in the Gaza Strip. To the Researcher's best knowledge, no studies have been conducted to evaluate the management of PH in the Gaza Strip. Thus, the status of caring for PH among children and how related services are being managed is not fully clear. This study will fill the gap by focusing on the existing services provided for children diagnosed with PH and evaluating them from the time of diagnosis. The study will critically examine the availability of competent healthcare workers to deal with PH; the availability of guidelines; the affordability of appropriate treatment; the long-term follow-up process, and the referral pathways across different providers as needed. Finally, the study will fill the gap related to the availability of data among health care providers.

1.3 Aim of the study

This study aims to assess the PH management of paediatrics patients in order to provide service providers and policymakers with evidence-based information and recommendations that may, if implemented, contribute to the improvement in the quality of provided services to paediatrics clients with PH and, thus, optimize the physical development and the neurocognitive outcomes for a patient that has been diagnosed with PH.

1.4 Specific objectives

The study has the following objectives:

- To assess the services for PH among children diagnosed with PH.
- To assess the quality of life among children diagnosed with PH
- To identify areas of weaknesses and strengths, of the provided services to children diagnosed with PH.
- To assess the perspectives of caregivers of children and service providers concerning the provided services to children diagnosed with PH.

1.5 Justification

Early detection and proper management of PH among children can effectively prevent mental problems and physical growth retardation. This study will be carried out to assess the management process of PH that involves the availability of services to early diagnose cases of PH and the provision of prescribed medication. The process will include but is not limited to the availability of competent staff and guidelines, the staff's compliance with the guidelines, and the clients' adherence to treatment. The study will provide policymakers with the evidence needed to improve the quality of services provided and to support them in developing future programs concerning the delivery of services to children with PH.

In this study, the Researcher conducted a review of the available services, protocols, and policies for managing children with PH in the Gaza Strip in order to identify strong and weak points. This benefits the healthcare system by raising awareness of any weaknesses in PH management services and policies. In addition, improving the quality of life for

children diagnosed with PH. The findings of this study will be used to advise and guide policymakers and healthcare providers in developing strategies and improving the quality of care given, thereby improving the quality of life for children with PH and lowering morbidity and mortality rates. Moreover, this study will be useful to the service providers, mainly working in Primary Health Care Centres (PHCs) as it will increase their knowledge of the current status of the service provision for PH paediatric cases and identify the main areas that need improvement. Finally, this study was of particular interest to the Researcher himself, as he is a service provider working in the PHC centre.

1.6 Context of the study

1.6.1 Geographical and demographical context

According to the Palestinian Centre Bureau of Statistics (PCBS), the Gaza Strip area is 365 km^2, with a coastline of 40 km (PCBS, 2020). In the year 2021, the overall Palestinian population in the West Bank and Gaza was estimated to be at 5.3 million, distributed as 3.2 million in the West Bank and 2.1 million live in the Gaza Strip (PCBS, 2021a). In 2021, the percentage of people aged 0-14 years was 38% of the overall population (36% in the West Bank and 41% in the Gaza Strip). On the other hand, the percentage of the Palestinian population aged 65 and more was 3% of the overall population (4% in the West Bank and 3% in the Gaza Strip) (PCBS, 2021a), with one of the highest population density, with 5,835 persons per km^2 (PCBS, 2019a).

The Gaza Strip (GS) is divided into five governorates, which are Rafah, Khanuins, Deir Al-Balah, Gaza, and Gaza North Governorates. The Crude Birth Rate (CBR) is 33.4 births per 1,000 population, while the Crude Death Rate (CDR) is 3.7 deaths per 1,000 population (PCBS, 2020). Individuals' life expectancy has increased to 74.1 years in 2020, (73 years for males and 75.3 years for females). However, the West Bank and Gaza Strip have a different life expectancy at birth. In the West Bank, it was (74.4 years for males and 75.6 years for females). In the Gaza Strip, life expectancy was 73.7 years (72.6 years for males and 74.8 years for females) (PCBS, 2021b). Improvements in healthcare and a progressive decline in infant and child mortality rates are among the reasons for this increase in life expectancy at birth (PCBS, 2021b).

The distribution of the population by age group shows that 47% of the population is under the age of 17, and 24.3% of the population is aged between 18 to 29, and 23.5% of the

population is aged between 30 to 60. Finally, a total of 5.2% of the population is aged over 60 years (PCBS, 2020). The Palestinian population is one of the highest fertility rates in the region, may be because of the influence of religion and culture that encourage fertility, some people believe if they have many children there will protect the family against any treble and many children provide social support and security (Courbage, Abu Hamad & Zagha, 2016).

1.6.2 Socio-economic context

The social and economic structure is affected by important variables in the Gaza Strip, the blockade has been ongoing since 2007 by the Israel Occupation, along with the internal division. The occupation and the blockade have negatively impacted the economic and social condition of the Gaza Strip, and lead to several changes in society structure (Al-ajaleh, 2020). The GS has the highest unemployment rate in Palestine. The unemployment rate in the GS is 52% (43.5 % for males vs. 74.5 % for females, while the unemployment rate among youth aged (19-29) years is 69% (65.3% for males vs. 92.2% for females), the youth graduates are the most subcategory suffering from unemployment with a rate 78% in Gaza Strip (PCBS, 2019b).

1.6.3 Health care system

There are four main providers providing health care services in Palestine, MoH, United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA), NGOs (Non-Governmental Organizations), and private for-profit providers. MoH provides a wide range of primary, secondary, and tertiary services. UNRWA provides primary health care services only for refugees and purchases secondary care service for refugees, as well. NGOs and the private sector provide primary, secondary, and tertiary services (Glance, 2018). The health sector in the GS is confronted with three disease burdens (communicable diseases, non-communicable diseases, and injury burdens), as well as deteriorating political, security, and economic conditions. All of these factors combine to produce multiple challenges affecting service delivery, health outcomes, and delaying efficient planning and health sector management (Abdulkadri et al., 2021). The health care system in the GS suffers from a severe deficiency of essential resources. This leads to the referral of patients outdoor the GS. The main causes of this deficiency are the inadequate budget allocated for this purpose and the current blockade on the GS, which is obligatory on the GS according to the health authority in the GS (Reinicke & Donald, 2016).

MoH and UNRWA implement the PH screening program. The screening program's purpose is early detection of neonates with PH, which allows for early treatment or intervention can be offered. Neonatal screening gives policymakers information about an increased risk or condition that helps them to make a decision. The PH screening program aims to reduce mortality and morbidity through early detection and diagnosis (Hemmati, Moghtaderi & Hasanshahi, 2019). According to neonatal screening at PHCs in the Gaza Strip for PH, any child with an elevated level of TSH is potentially considered as PH and referred to the Child Health Department in Al Remal Clinic for further investigation.

1.6.4 Ministry of health facilities

In the GS, the MoH operates 51 primary health care centers and 14 hospitals. MoH facilities supply 2,616 beds and intensive care units of 156 beds (out of a total of 2,943 beds in the GS). Bed capacity was 76% (MOH, 2021). The MoH oversees all aspects of the health-care system, including financing, coordination, accreditation, regulation, and service delivery (WHO, 2020b). Regarding the shortage of some specialties, treatments, drugs, equipment, and infrastructure inside the public system, a considerable proportion of patients are referred to not-for-profit or commercial providers for tertiary care. Access to referral medical centers in Jerusalem, the West Bank, Israel, or Egypt is only available with the approval of Israeli authorities, which is a lengthy process that might cause delays and refusal of care (WHO, 2020a)

1.7 Operational definition

1.7.1 Primary Hypothyroidism

Within the context of this study, PH among children will be defined as cases that are medically diagnosed as PH and aged less than 12 years old.

Chapter Two

Conceptual framework & Literature review

2.1 Conceptual framework

The below conceptual framework was developed by the Researcher based on the Donabedian's model (1988) that focuses on the quality of care. The framework links input, process, output, and outcome (Rublee, 1989). Variables included are based on available literature and the expertise of the Researcher. The included variables will address and answer the study objectives and questions.

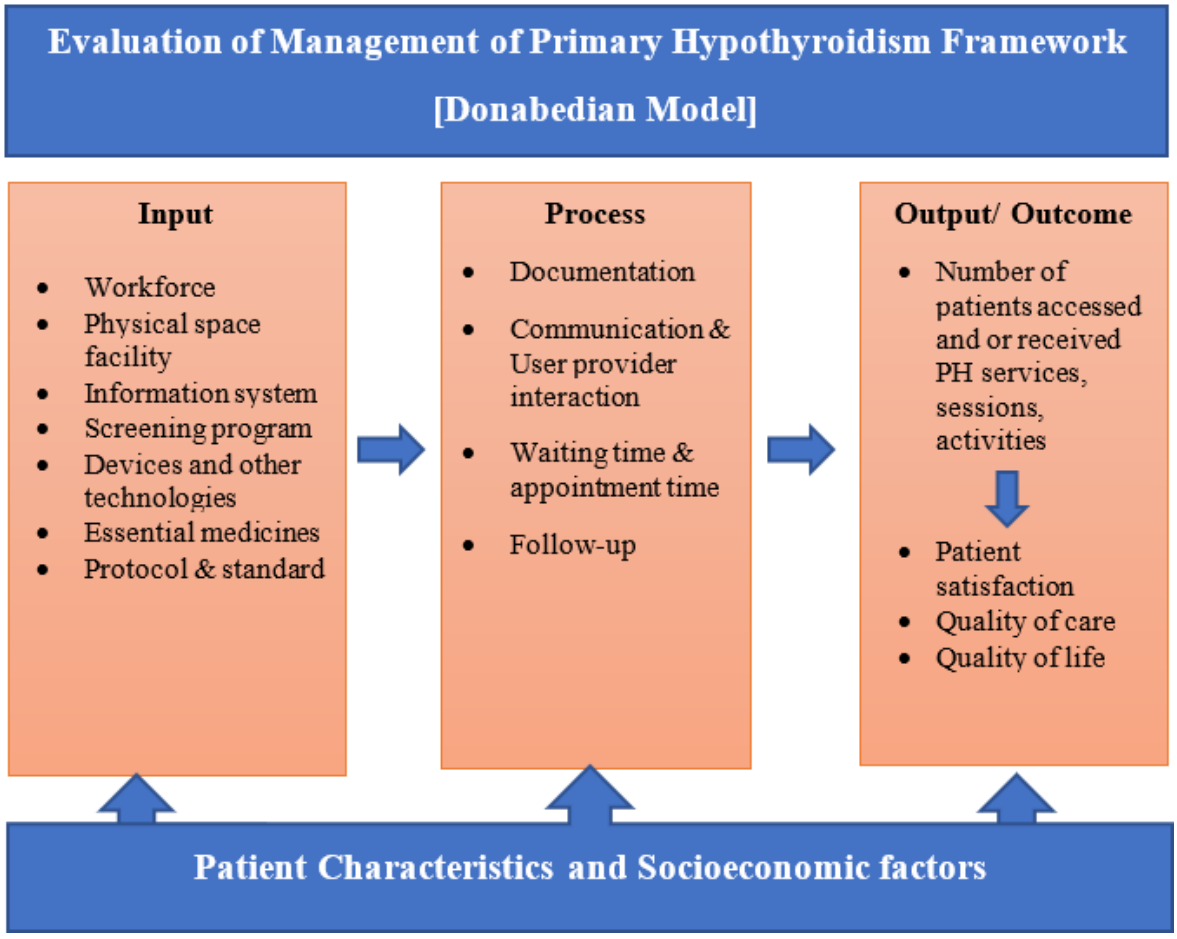

Figure (2.1): Conceptual framework of the study

2.1.1 Inputs/structures

Input includes the main requirement to review the performance of Health Care System (HCS) for PH management by focusing on (Workforce, Physical space facility, Information system, Screening program, Material & Equipment, Essential medicines and Protocol & Slandered).

2.1.1.1 Workforce

The health workforce is all individuals involved in activities with the primary goal of improving health (WHO, 2006). The Researcher looked at the availability of an adequate number of health care providers, their distribution, their capabilities. A sufficient number of highly qualified workers is necessary for efficient processes and high-quality results.

2.1.1.2 Physical space of facilities

The Researcher determined the availability, accessibility, affordability, and distribution of facilities. If there is a suitable place for the provision of services, and whether there is enough room for the delivery of services. Facilities should have areas for applying for screening programs, waiting, diagnosis, Early Chid Development (ECD) room, counselling, activities, and medication dispensing. The Researcher also evaluated the furniture, cleanliness, and if privacy and confidentiality are respected and maintained, as well as whether the environment is appropriate for children.

2.1.1.3 Information system

The Researcher assessed the availability of a database, the infrastructure (hardware or software), the validity, reliability, and timeliness of the information produced, the capability of information analysis, dissemination, and use, and the availability of data on the number of children that received services from the child health department, their specific needs, and their geographic locations.

2.1.1.4 Screening program

The Researcher assessed that the screening program is available all the time and accurate for the diagnosis of PH. The time of sampling, the methods of sending samples to the central laboratory, the mechanism for reporting positive results of the examination, the system for referring children to the Child Health Department, and the Staff trained, and qualified to apply the screening.

2.1.1.5 Material & Equipment

The Researcher explored the availability of diagnostic equipment and materials or solvents that are used to perform a diagnostic test to confirm PH, and whether its materials are accepted, have quality, safety, efficacy, and are cost-effective.

2.1.1.6 Essential medicines

Essential medications have the power to prolong life, ease suffering, and enhance health. But they must be accessible, reasonably priced, of high quality, and utilized correctly in order to do this (Simmons, 2021). The Researcher evaluated whether there are standardized protocols for drugs, whether insurance covers the costs of essential medicines to reduce out-of-pocket expenses, particularly for the poor, and whether the selection of medicines is appropriate based on patients' and the population's actual needs. The Researcher specifically evaluated the availability, affordability, and accessibility of essential medicines, particularly levothyroxine for children diagnosed with PH. Access to necessary medications is associated with successful outcomes.

2.1.1.7 Protocol/ Standers

All steps in the service delivery process should be supported by and based on evidence and be compliant with regional, and international standards. The Researcher evaluated if there are available national or international protocols or guidelines, also if they are available and access by the staff, as well as their applicability and efficacy.

2.1.2 Process

Process refers to the actual action that applies in health care to achieve an outcome, and how the process of treatment is delivered. The process includes documentation, communication, waiting & appointment time, user & provider interaction, and follow-up. All of these variables will be assessed in this study.

2.1.2.1 Documentation

Documentation is important to continue mentoring and follow-up of the health services that are delivered. The Researcher also assessed the availability of documentation; it is a continuing process, if documented and written clearly; also, check if clinical documentation is kept secure, and if there are electronic medical files.

2.1.2.2 Communication & User provider interaction

It is the manner in which patients and providers communicate, and the Researcher evaluated whether there is a positive relationship between the health care provider and the child's caregiver, if providers introduce themselves to the caregiver, if the plan of treatment and follow-up are shared between providers and caregivers, whether children and their caregivers are respected by health care providers, whether staff members are committed to treatments, whether the necessary information is properly transferred to caregivers through awareness of how their children live with their disease and how to take medications, and whether children dignity, privacy, and confidentiality are respected and secured.

2.1.2.3 Waiting & appointment time

The Researcher evaluated the appointment system to assure attendance and compliance with the planned appointment to assure all children diagnosed with PH are delivered services. Waiting times for child health services can be monitored during diagnosis, children follow-up, and medication dispensing from the pharmacy. Timely compliance for children diagnosed with PH is crucial to prevent or decrease complications of PH and improve outcomes.

2.1.2.4 Follow-up

Follow-up is necessary to review the results of provision of services. Regular physical examination, laboratory investigation, and taking medication can be considered a follow-up. Follow-up is a crucial component of service delivery between providers and caregivers to ensure continuous monitoring of children, ensure no deterioration in children's situations, and enhance outcomes.

2.1.3 Output & Outcome

Output and outcome are influenced by inputs and processes. Outcome refers to the impact of service delivered on children diagnosed with PH and satisfaction among caregivers of children. Output includes the number of patients who accessed or received PH services, sessions, and activities. In addition, the outcome includes the caregiver's satisfaction, quality of care, and quality of life for children.

Output

1. Number of patients accessed or received PH services

The number of children diagnosed with PH who accessed or received services at the child health department in Al Remal clinic reflects the capacity of the system.

2. Sessions

The Researcher checked the number of sessions provided to the children diagnosed with PH, they included diagnostic, treatment, psychological, follow-up, and ECD sessions.

3. Activates

The Researcher assessed the frequency of children diagnosed with PH visiting the Al Remal clinic, how many children arrive daily at the clinic, and how many children physicians see in a day.

Outcome

1. Patient satisfaction

The Researcher evaluated the satisfaction of caregivers of children diagnosed with PH for services delivery, quality of this service, diagnosis, pathways, waiting times, user-provider interactions, staff interactions, the responsiveness of the service and quality of care, child's health status, follow-up, medication dispensing, and patient involvement, which give feedback about services to expected how the care has been done.

2. Quality of care

The Researcher looked into how much children's care helped them achieve their intended health outcomes. The accessibility and availability of the services provided were evaluated. Processes and inputs have an impact on the quality of care.

3. Quality of life

The Researcher evaluated how caregivers' perceptions of their children's health, how they felt about life, and their social interactions affected how the services affected their

children's quality of life by using Strengths and Difficulties Questionnaire (SDQ), and KIDSCREEN.

2.1.4 Influencing factors

2.1.4.1 Patients' characteristics

Other factors that might have an influence on the service include demographic characteristics of children diagnosed with PH and caregivers, sex, age, genetic history, and any disease that is related to a medical or health problem for children or mothers of children.

2.1.4.2 Socioeconomic status

These are the factors related to the economic condition of the family, such as mother age, education level for mother and father, income, poverty, and parent occupations.

2.2 Literature Review

2.2.1 Overview of thyroid gland

Thyroid gland produces thyroid hormones, then the hormones enter the bloodstream, which circulates them to the body organs and tissues. These hormones are called Thyroxine (T4) and Triiodothyronine (T3). The brain also produces another hormone that stimulates the thyroid gland, which is called Thyroid Stimulating Hormone (Diaz & Lipman Diaz, 2015). When the elevated levels of TSH hormone are produced in the brain after birth, it is a serious indicator of the thyroid gland's problem in producing hormones (Beynon, & Pinneri, 2016). The Thyroid Hormone is needed for normal growth and development during the intrauterine life to after three years of age (Fan et al., 2020). The main functions of the thyroid hormone are to prompt, develop the brain, produce heat that keeps the body warm, and ensure that the heart, muscles, and other organs function well (Bekhit & Yousef, 2013).

2.2.2 Primary Hypothyroidism (PH)

PH in young children, especially neonates, is an actually urgent condition because it is a curable thyroid hormone shortage. It can be easily discovered after birth by newborn screening. It can also be simply, affordably, effectively, and inexpensively treated, and if identified and treated early, can be completely managed so that there are few mental or physical problems. It causes severe mental retardation, causes growth deficits, and clinically, manifestation occurs too late for treatment to completely eliminate the mental and growth retardation that results in unnecessary health, economic, and social burdens for the family and society (LaFranchi, 2021). There is strong clinical and financial support for a countrywide screening program due to the devastating consequences of undiagnosed thyroid insufficiency in the age range. PH is an uncommon anomaly that affects one in every 3,000 to 4,000 live newborns that are examined, with a 2:1 female to male ratio and a greater than 5:1 ratio between whites and blacks (Uthayaseelan et al., 2022).

2.2.3 Epidemiology of PH

Worldwide, the frequency of PH has gradually increased as new-borns screening programs have spread due to improved case detection techniques and greater disease awareness among experienced populations. The frequency of PH is ranging from 1 in 3,000 live births to 1 in 4,000 live births worldwide, and it can even exceed 1 to 900 in certain places with

iodine deficiency (Hettiarachchi et al., 2009). Different populations have varying levels of ethnic disparities in PH prevalence. For instance, the incidence among Japanese people is about 1 to 7,600, but it is roughly three times greater in Israel. Additionally, different populations have reported different prevalence rates (Mehran et al., 2017).

In the USA, for instance, the frequency of PH appears to be around half that of Caucasians among African-Americans, while the prevalence is roughly 40% higher in Hispanics and may be even greater in Native Americans. Studies in the United Kingdom and South Africa discovered that PH seems to be many times more common in Asian youngsters, while a more recent study in India reported a frequency of about 1 to 2,630 among residents of that country. According to studies, females have a higher prevalence of PH (around 2:1). Recent studies have revealed that this discrepancy may be largely explained by gender-related changes in thyroid ectopy, which may account for a significant portion of this variance (Hettiarachchi et al., 2009).

East Asia, since 1999, when the International Atomic Energy Agency (IAEA) started its regional technical cooperation project for a screening network for neonatal hypothyroidism, the IAEA has been actively involved in the regional development of PH screening. According to reports, the frequency of PH ranges from 1 in 1,000 live births to 1 in 7,336 live births in East Asia. Reports restricted to regions with low iodine levels, however, indicate incidences as high as 1 to 600. As a result, the estimated 40,000 kids who are born with PH each year in the area present a serious public health issue (Hettiarachchi et al., 2009).

2.2.4 Definition of PH

PH is a serious disease and is one of the most preventable common causes of mental retardation among children. PH is defined as the absence or decrease of Thyroid Hormone level in the bloodstream due to congenital problem in the thyroid gland either abnormal development of the gland called (Dysgenesis) or decrease secretion of thyroid Hormone called (Hormonogenesis) (Mondal, Mukhopadhyay & Ghosh, 2017). PH is caused by insufficiency in the production of or absence of thyroid hormones due to pathological causes or surgical removal of the thyroid gland (Baumgartner-Parzer, 2019). The cause of PH could be due to pathological cases related to cases to Hypothalamus and the Pituitary gland eventually led to a decrease in the production of TSH, and it appears directly after

birth. but if the causes appear after six months of birth, that is called acquired hypothyroidism, not PH (Imam & Shamim, 2016).

2.2.5 Affect thyroid hormone in growth and development

The main role of the thyroid hormone is to promote normal growth and development of children. It also has effects on oxygen consumption and metabolism (Mondal, Mukhopadhyay & Ghosh, 2017). Any disturbance in the production of the thyroid gland leads to either hypothyroidism or hyperthyroidism. Hypothyroidism among children leads to growth retardation. While hyperthyroidism leads to abnormal growth that involves excessive skeletal growth, which is manifested in an increase in children's height. In addition, the main role of the thyroid hormone is to maintain brain development during pregnancy and after birth. while any disfunction of the Thyroid gland undiscovered early and apply a plan for management and follow-up will be lead to mental retardation (Cohen, 2016).

2.2.6 Type of PH

PH can be divided into three main categories.

2.2.6.1 Thyroid Dysgenesis:

That means abnormal growth, development, or formation of the thyroid gland. This type appears in most children that have PH. Regarding this type, the thyroid gland is either absent, in an abnormal position, or not formed (Kollati et al., 2017).

2.2.6.2 Thyroid Dyshormonogenesis:

Abnormal in the production or release of thyroid hormone. In this type, the children have a normal thyroid gland, but it can't produce T3, T4 hormones (Rather, Khan, Masoodi & Alai, 2014).

2.2.6.3 Central Hypothyroidism:

In this condition, the thyroid gland in position and shape is normal, but the problem in the pituitary gland can't produce TSH, which leads to the thyroid gland not producing or releasing enough amounts of T3 and T4 that the body needs (Persani, Cangiano & Bonomi, 2019).

2.2.7 Causes of PH

The prevalence of sporadic occurrences is about 85%, and hereditary occurrences are about 15%. A thyroid gland issue accounts for about 95% of cases of hypothyroidism. This disorder is known as primary hypothyroidism. Thyroid dysgenesis, which affects 1 in every 3,000 to 4,000 live births globally, is the most frequent sporadic cause. The pituitary gland is a source of secondary hypothyroidism. 1 every 60,000 to 140,000 neonates worldwide experience tertiary hypothyroidism, which is caused by abnormalities of the hypothalamus (Weiner et al., 2020b). Several factors may lead to PH:

2.2.7.1 Anatomical defects (thyroid dysgenesis)

Responsible for 75% of all occurrences. Thyroid agenesis (total absence of the thyroid gland in 22–42% of cases) or ectopic thyroid tissue are also possible (lingual or sublingual thyroid gland 35-42%) (Kırmızıbekmez et al., 2012).

2.2.7.2 Metabolism of the thyroid hormones problems (Thyroid dyshormonogenesis)

It is possible for mutations to occur in any of the known steps in the thyroid hormone biosynthesis pathway, making PH due to thyroid dyshormonogenesis a heterogeneous disease. Around (15 to 20%) of causes of PH are genetically based worldwide, and related to (TSH unresponsiveness, impaired ability to uptake iodine, peroxidase or organification). There is a chance that other children could be impacted because this is typically passed through autosomal recessive gene mutations (Grasberger & Refetoff, 2011).

2.2.7.3 Hypothalamic or pituitary dysfunction

About 5% of PH patients are caused by hypothalamic-pituitary abnormalities. Pituitary hypothyroidism typically interacts with other conditions that cause pituitary dysfunction, such as a deficiency in growth hormone (Shanholtz, 2013).

2.2.7.4 Transient hypothyroidism

IgG auto-antibodies can cross the placenta and inhibit thyroid function when a woman is pregnant, but this is enhanced after birth. This accounts for 10% of instances and is determined to be caused by either maternal medicines, such as carbimazole, or maternal antibodies caused by maternal thyroid dysfunction (Shanholtz, 2013).

2.2.8 Prognosis of PH

The most severe consequence of untreated PH is profound mental impairment. Additionally, there is a serious reduction in bone maturation and linear development. Infants with PH who receive delayed therapy may develop neurologic disorders such as stiffness and abnormal gait patterns, slurred speech or mood changes, and autistic behavior (Agrawal et al., 2015). In a study, the intelligence quotient (IQ) of 65% of children with PH was less than 85. (Borderline intellectual functioning or lower), moreover, in 19%, it fell under 15 (profound mental retardation). Regarding estimates, infants with delayed diagnoses would need hospitalization (Saeidinejat et al., 2020).

The most serious condition associated with untreated PH are mental retardation, growth retardation, and cardiac problems. Not receiving appropriate regular treatment for PH could lead to anemia, a low body temperature, verbal and visual abilities, and language difficulties. The most serious complication for the patient with PH is impairment in growth and bone maturation (Kishore & Khan, 2018). The purpose of treatment is to get the thyroid gland back to generating thyroid hormones normally and functioning normally (Madhusoodanan, 2019).

2.2.9 Management of PH

2.2.9.1 Early diagnosis of PH

Early detection of patients suffer from PH by neonatal screening program plays a crucial role for early treatment and follow up. In addition, early diagnosis prevents neurological dysfunction, thus decreasing morbidity, mortality, disabilities, and prevent consequences of PH such as mental retardation (Rodríguez Sánchez et al., 2019c). After the positive result of the screening program, further investigation such as blood test done to confirm diagnosis. Also, other investigations like ultrasound for the thyroid gland to see the position and shape, in addition, to identify the type of PH according to thyroid absence or wrong place (ectopic), or stay in the normal position but the problem is something else (Saran et al., 2015). Since it is recommended to detect PH in the first month of life to prevent any deterioration in mental development, 22.7% of children with PH are considered late in terms of diagnosis time, which could cause irreversible damage to the brain (Rodríguez Sánchez et al., 2019b).

2.2.9.2 Criteria of diagnosis

1. History

Included the mother's history of goitrogen exposure, thyroid illness, thyroid insufficiency, and exposure to antithyroid medications. The common obstetric practice of using povidone-iodine to sterilize skin leads to transitory PH in the baby and iodine excess in the mother. Infants with PH may display a number of symptoms, such as an extended gestation period, a large birth weight, difficulties feeding, constipation, lethargy, persistent neonatal hyperbilirubinemia, umbilical hernia, big tongue, and horse crying (Nishiyama et al., 2004).

2. Physical examination

Because so little maternal thyroxine (T4) penetrates the placenta, more than 95% of newborn children have no clinical symptoms of PH (Moog et al., 2017). A puffy face and a large, projecting tongue, constipation, increased sleep, decreased activity, lack of muscular tone, poor eating, choking episodes, and jaundice are possible symptoms. As the condition progresses, this appearance typically appears (Rastogi & LaFranchi, 2010). Physical examinations reveal the following symptoms: abnormally large fontanelles; a flat nose; broad hands with short fingers; decreased muscle tone; growth failure; hoarse crying; short arms and legs; poor feeding; prolonged neonatal jaundice; protuberant abdomen; umbilical hernia; decreased stool frequency; and others (Vaidya et al., 2011).

3. Biochemical thyroid function tests

Blood should be collected to assess triiodothyronine (T3), free T4, and thyroglobulin levels as well as to confirm measurements of TSH and T4 levels. Those with suspected thyroid dysfunction have their TSH, free T4, and total T3 levels measured. TSH is high in primary hypothyroidism, although secondary causes of hypothyroidism might cause it to be normal or low. T4 levels are also lowered, and T3 levels are raised. The normal TSH values are 0.5 to 5.0 mlu/dl, T4 8.0 to 21.8 mcg/dl, and free T4 0.9 to 3.4 ng/dl (Shui-Boon & Tar-Choon, 2019).

2.2.9.3 Treatment of PH

Essential medications should be available all times in acceptable amounts, in suitable dosage forms, with confident quality and adequate information, and at a price, the individual and the community can afford without any financial burden (Mounika, 2017). Once confirm diagnosis as children have PH should be ongoing in management and follow up program. The greatest medication used in the PH is levothyroxine, which is the drug of choice. It should be begun in treatment without any delay to protect the brain from any damage or destruction caused by a deficiency of thyroid hormone. To get the extreme benefit from treatment must be started before the age of one month of the infant. On the other hand, the adjustment dose according to age is the most important (Etemad et al., 2018).

Also, when an incorrect dose of medication leads to adverse effects on brain development. The treatment includes replacing the amount of thyroid hormone that is missing to restore this hormone to the normal level. This medication description by a physician is based on medical history, age of the child, overall health, and extent of disease (Leung &Leung 2019). According to Levothyroxine in PH, this medication is the best medication for treatment for PH, and is only available in tablet form. In addition, thyroid hormone is absorbable in the digestive system, then rapidly enters the bloodstream because there is no injection available for this medication. Also, early intervention may improve cardiac function that may be a complication of PH, the levothyroxine is significantly improved the weakness in the right and left ventricular (Zeni et al., 2019).

2.2.10 Prevention of PH

The WHO describes a control program as an integrated approach combining the highest quality of care with protection regarding community education, early diagnosis, and providing counseling. Or, by other means, the control program includes both treatment and prevention. It suggests that control and prevention activities can be focused on three levels, especially primary, secondary, and tertiary (Maki, 2021).

2.2.10.1 Primary prevention

The goal of this level of prevention is to avoid having a child born with PH. There are many ways to avoid environmental elements thought to contribute to diseases. These environmental influences include the diet of the mother, infections, other diseases, or

contact with mutagenic or poisonous substances. This method has been very effective in the initial prevention of various congenital abnormalities. The thyroid gland may be destroyed in the growing fetus if a pregnant woman receives radioactive iodine for thyroid cancer. After birth, newborns of mothers who used such medications should be closely monitored for hypothyroidism symptoms (Azizi et al., 2017).

2.2.10.2 Secondary prevention

An approach that includes early diagnosis of a genetic condition and early management to decrease its negative effects. Neonatal screening is crucial because it allows for the early detection of abnormalities in children, allowing for optimal nutrition, medical care, or surgical treatment. Where the diagnosed condition is frequent, easily observable, and treatable, it is certainly useful. Congenital hypothyroidism in infants can now be identified during the first three weeks of life because of properly implemented newborn screening programs. The consequences can be reduced or eliminated in most cases with immediate and appropriate treatment (Kelly et al., 2016).

2.2.10.3 Tertiary prevention

The final preventive measure targets the patient who has been given a disease diagnosis by using effective management, treatment, and rehabilitation programs to decrease the effects of diseases, so further deterioration can be avoided. According to Centers for Disease Control and Prevention (CDC), tertiary prevention strategies include the immediate intervention of thyroid hormone replacement to treat PH and the prevention of mental retardation (CDC, 2017).

2.2.11 Previous studies of evaluation PH

Successful management of PH patients depends on early diagnosis and monitoring of disease progress, standardization of screening national program, quality improvement, and management of treatment of patients with PH. All of these points are important for policymakers and decision-making to enhance the quality of service and prevent or reduce the consequences of complications if disease is undetected or treated early (Shahmoradi, 2019). PH is one of the most critical thyroid dysfunctions. It affects people all over the world of every race, sex, age, level of life, and education (Wassner, 2017). The risk of PH increases during pregnancy, after delivery, and around menopause. The biggest risk factor is having a relative with thyroid disease due to the risk increasing with close relatives like

parents or grandparents having an autoimmune disease, having down syndrome, and with some medications such as Lithium, Amiodarone (Zdraveska et al., 2018).

Several studies have shown subnormal cognitive and motor development during childhood for children who didn't discover or receive medication early. Also, the abnormal development in motor and cognitive functions continues into adulthood (Vander, 2013). Because of that, treatment plays a crucial role in normal neurocognitive and motor development for children with PH, especially in the first 3 years of life. In addition, the monitoring and follow-up continuously enhance the quality of care and quality of life for these children (Shahmoradi, 2019). On the other hand, the significant effect of therapeutic intervention by monitoring height, weight, and head circumference along with the age of treatment beginning less than 30 days from birth plays an important role in promoting height and weight growth as normal for a patient with PH (Etemad et al., 2018).

2.2.12 Health Workforce

A competent health workforce capable of performing the entire range of crucial public health responsibilities is necessary for achieving and maintaining progress towards global health goals like universal health coverage and health security. Only health care providers and professionals can run healthcare systems, and their accessibility, acceptability, and quality are key factors in expanding access to healthcare services and ensuring that everyone has the right to the best attainable standard of health. Also, it is insufficient to simply have health professionals available. So, only when they are fairly distributed throughout the population and easily accessible, when they have the necessary competence, when they are inspired and empowered to provide high-quality care that is appropriate and acceptable to the population's sociocultural expectations, and when the health system is sufficiently supporting them (WHO, 2016).

By analysing policies pertaining to education and training, ongoing professional development, and regional distribution, the Organization for Economic Co-operation and Development (OECD) provides advice to nations on how to fulfil future demand for health professionals and how to control the supply of health workers. The OECD also evaluates changes in the range of services offered by healthcare professionals and the potential effects these changes may have on patient access, service quality, and delivery efficiency (OECD, 2016).

In some nations, the public sector's inability to absorb the supply of health professionals because of financial restrictions may also contribute to problems with universal access to health workers. As a result, several nations experience the paradoxical situation of both significant unmet medical demands and a shortage of health workers (Douglas, 2012). According to the WHO and OECD (2014), when discussing the workforce, many factors should be taken into account, such as the availability of sufficient numbers of health workers, the patient's ability to communicate with health care providers with the appropriate skills that refer to their respect, and the fact that their opinions are taken into account when decisions are related to their health. The organizational, economic, political, and cultural situations of countries allow high-quality care for populations within established norms. In addition, access to healthcare in rural areas is impacted by a lack of healthcare workers (Vahdat et al., 2014).

2.2.13 Physical space facility

Healthcare professionals have recently focused on the actual architectural design of hospitals and clinic facilities, such as their technology and equipment, and how that has an impact on patient safety. Fundamental adjustments to the way healthcare are delivered, as well as the culture and the built environment, are required to solve the problems of medical errors and serious safety concerns. These adjustments are made so that healthcare providers and the resources that support them are prepared to provide safe care (Reiling et al., 2008). According to (WHO, OECD, and WB, 2018), achieving a high standard of care that is accessible depends on the availability of facilities with the necessary equipment, and the density of both hospitals and clinics. Access to services is adversely affected by transportation costs. The primary obstacles that could cause patients to skip or be late for appointments with healthcare providers are mainly the location of service providers and the cost of transportation (Jeklin, 2017).

2.2.14 Health information system

Regarding Ohio University, information is life-saving. mainly in the medical condition. That is true for access to patient and population health data to allow medical teams, including administrators, physicians, nurses, pharmacists, lab technicians, and others, to make critical decisions regarding patient care that may have a life-changing impact (Ohio, 2019). A health Information System (HIS) makes it simple to retrieve patient data, improve recordkeeping, and decrease mistakes and data loss (WHO, 2021). There are many

obstacles to the integration and use of health information systems. One is technical, reflected by insufficient preparation for implementation and use of HIS; the other one is organizational, reflected by a lack of resources for quick and easy network connectivity; and the last one is personal, represented by a lack of awareness among healthcare providers of the benefits of HIS. Also, some obstacles are legal and ethical, as demonstrated by a lack of resources for implementing and using HIS (Tummers et al., 2021).

2.2.15 Screening program for PH

A screening program for PH to all new-borns is as a routine screening in most developed and developing countries. The main objective of the screening program is to detect any defect in the thyroid glands early enough to prevent physical and mental disability by early diagnosis and provision of proper drugs (Mehran et al, 2017). If the result of TSH level is high this indicates that a problem in the Thyroid gland that diagnosed as PH (Bekhit & Yousef, 2013). The confidence of the community, policymakers, and health professionals in an agenda for the screening of new-borns is dependent on a fast and accurate process. According to the method of the screening program in the Gaza Strip, MoH implements a program for PH screening since 1994. This screening is done for both Phenylketonuria PUK and TSH (Abed & Abu Shahla, 2004). The test is done for free of charge for all livebirths in both MoH and UNRWA clinics. The people allocated to gather the blood samples are doctors, nurses, and midwives, who play a crucial role in the screening system. In order for newborn screening to be effective, the sample must be collected within the first few days after birth, and the diagnosis must be finished in time to make a significant change in health outcomes for PH children. This means that the patient should start treatment one month after birth (Hemmati, Moghtaderi & Hasanshahi, 2019).

2.2.15.1 Early Child Development (ECD)

Early child development (ECD) means the period from birth to age six, and it involves all aspects of a child's growth throughout the first six years of life, including their physical, emotional, social, cognitive, and motor development. The brain begins to mature in all areas at this time, including the cognitive, socioemotional, and physical ones (Khatib et al., 2020). For children between the ages of birth and six, ECD is an essential program. It concentrates on the growth of the physical, social, emotional, spiritual, moral, and cognitive components of development (Tadesse, 2016). Children with PH should benefit

from the comprehensive ECD services to ensure that their growth and development is normal.

2.2.16 Devices and other technologies

Healthcare technology plays a more important role in patient diagnosis and treatment and has evolved into a necessary component of the services delivered. The volume and diversity of technological assets present in healthcare institutions reflect the difficulty of technology management, which should be efficient so that the equipment may always be used securely and appropriately (Iadanza et al., 2019). A medical device is any instrument, machine, material, solution, software system, or other similar item utilized for one or more of the following medical purposes: research, adjustment, protecting life, investigation, disinfection, and information provision through laboratory analysis of human body samples (WHO, 2019). In addition to an inadequate number of diagnostic devices, health systems face barriers to executing diagnostic mechanisms, including lack of specialists' services; lack of funding for further diagnostic procedures; shortages of laboratory material; restricted access to technology; and lack of organizational support (Huaynate et al., 2015). Children with PH are diagnosed through laboratory investigations and ultrasound imaging. Within the context of Gaza, ensuring availability of screening kits is highly important due to the current financial crisis that the MoH faces.

2.2.16.1 Ultrasound device

The cause of PH, whether carried on by dyshormonogenesis or dysgenesis, has been identified using thyroid ultrasound and thyroid scintigraphy. The thyroid gland could be missing, undersized, or in an incorrect location. In dysgenesis, the thyroid gland may be absent, reduced, or not in the right place. In dyshormonogenesis, the gland is typically normal or bigger in the absence of thyroid hormone. Making an accurate diagnosis of this issue is crucial because thyroid dyshormonogenesis may run in a family and affect 25% of the children. The outcomes of PH depend on beginning treatment as soon as possible after confirming the diagnosis. Ultrasound has a critical role in the early diagnosis of PH and any delay in ultrasound could identify the wrong treatment (Borges et al., 2017).

2.2.17 Essential medicines

Essential medicines play a crucial role in life-saving when they are accessible, acceptable, affordable, available, and appropriately used. When public and private health systems are

combined, roughly two-thirds of the world's population have good access to medications, leaving one-third without regular access. Despite this, the lack of access to important medicines continues to be one of the most serious public health issues in the world. The following are the main barriers to accessing necessary medications: medicine Funding, medical costs, and globalization (Wirtz et al., 2017). Essential medications can successfully treat the main causes of deaths and illnesses in low-income nations. The necessary essential medications are frequently unavailable, inaccessible, or incredibly expensive in many low-income nations (WHO, 2017).

Affordable costs, sustainable funding, a stable health and supply system, and the appropriate selection and use of critical medications are the four components that make up equitable access to essential medicines. Equitable pricing and the minimization or elimination of regulations and taxes are examples of affordable costs. Increasing public support for important medications and decreasing patient out-of-pocket expenses, mainly for low-income people, are two main components of sustainable funding. Stable health and supply systems include regulatory authority, manpower, purchasing, availability of medication, and strengthening of the healthcare system. Appropriate selection and use of critical medications Because no healthcare system in the world provides access to all medications, it is crucial to define national treatment guidelines and national lists of necessary medications. Consumers should choose and use essential medications wisely (WHO, 2004). As PH clients require a lifelong medical care, ensuring availability of Levothyroxine and other drugs is critical to avoid complications resulting from thyroid dysfunction.

2.2.17.1 Levothyroxine medication

Levothyroxine is a thyroid medication that takes the place of a hormone the thyroid gland normally produces to control body energy and metabolism. Hypothyroidism (decreased thyroid hormone) is treated with levothyroxine. When the thyroid gland cannot make enough of this hormone on its own, this medication is given. Goiter, or an enlarged thyroid gland, which can result from hormonal imbalances, is another condition that levothyroxine is used to treat or prevent (Sinha, 2022).

Treatment for PH should begin as soon as the diagnosis is made, ideally before the child is 2 weeks old and right after blood is collected for confirmation of the diagnosis. After six weeks of life, there is a significant risk of delayed cognitive development if treatment is postponed. Levothyroxine 10 to 15 mcg/kg/day as a beginning dose is prescribed for PH (Léger et al., 2014). The results reveal

that 100% of children with PH used thyroxine medication to prevent the risk of hypothyroidism. All children with PH use thyroxine medication in a dose that is appropriate for their age and thyroid gland functions (Barham et al., 2014).

2.2.18 Standard & protocol for PH

Availability of protocols has an impact on the quality of services provided and patient safety to prevent, reduce, and avoid any harm to the patients (Khalifa, 2019). The standards and protocol should be available for health care providers because they help to enhance the quality of service with PH children. However, their beneficial effects depend on successful implementation. According to the MoH, they have a protocol for the treatment of pediatric patients with PH (Jain et al., 2008).

2.2.19 Documentation

Clear and accurate medical records are crucial for good collaboration between patients and healthcare providers since they serve as an ongoing record of a patient's condition. Additionally, the complete satisfaction of a patient's estimated requirements is ensured through the keeping of good medical records. However, it is common to discover misread entries and incomplete data, and there are frequently disparities between entries made by healthcare professionals (Searo, 2007).

Medical records are a key component of patient management, so it is crucial for health care practitioners, policymakers, and medical facilities to correctly keep the patient's records for two basic purposes. One is that it contributes to the proper patient evaluation and the development of management planning. Another one is that, in cases of medical malpractice, the legal system highly depends on medical records. In order to protect the interests of the treating health care practitioners and the patient. Medical records must always be properly created and maintained (Bali et al., 2011).

In Makki's study showed only 40.7% of all pages in medical records contain the patient's name, 99.3% of medical files contain the patient's date of birth, and 68.3% contain the address on all pages, 18.6% of medical files were completely documented with a medical history of parents, 82.8% complete documented plan of treatment, 100% incomplete documentation of the side effect of medication, 97.2% of medical records didn’t document the mental status examinations, and finally 98.6% of medical records incomplete

documentation ultrasounds examination according to a study about ulcerative colitis that evaluated medical files in PHC in the Gaza Strip using a medical record checklist.

2.2.20 Communication & User provider interaction

The relationship between the patient and the health care provider is crucial to healthcare and behavior modification, which has increasingly established a priority on patient-centered care. Health care providers should assess each service user's demands and determine the best way to meet them. Also, continuity is required to maintain the service user's goals and difficulties all across the services and to enhance improvements in health behavior (WHO, 2018).

A beneficial strategy to adapt care for the patient in alignment with his or her individual needs and preferences and produce positive health care outcomes is shared decision-making between healthcare workers and patients. Patients who receive knowledge, counseling, and support are able to control and manage their healthcare outcomes, which facilitates the greater integration of treatment and healthcare plans (Roodbeen et al., 2020).

2.2.21 Waiting time & appointment time

Long waiting times have an unfavourable relationship with perceptions of care quality and trust in healthcare providers. Without appropriate planning, the clinic will ultimately deteriorate into a disorganized, confusing mess. This increases tension for health care providers and clients alike (Calvin & Zhenzhen, 2017).

2.2.22 Follow-up

The follow-up and monitoring are essential and required at certain intervals to review outcomes. In addition, the follow-up to prevent or reduce severe consequences for the patient. Evaluation of treatment continually improves service delivery to the caregiver and patient. The situation of the patient in follow-up sessions will depend on the patient's response to the medication and whether the goals of treatment have been met (Rodríguez Sánchez et al., 2019c).

Children with PH are more likely to have congenital problems (10% in PH compared to 3% in the general population), the most common of which are cardiac problems, pulmonary insufficiency, atrial septal defect, and ventricular septal defect. Healthcare providers must take account of thyroid function tests at regular enough intervals to ensure

that thyroid hormone dosage is promptly adjusted in order to maintain goal levels of serum free T4 or total T4 and TSH. Laboratory examinations must be performed more frequently than clinical evaluations, which can be done less frequently. Assuring growth and neurodevelopmental outcomes that are as close to their treatment's primary purpose (Agrawal et al., 2015). In this study, for behavioral development that needs to be monitored in children with PH. showed that emotional and behavioral abnormalities were present in 29.8% of children (Chao et al., 2009).

2.2.23 Patient satisfaction

Patient satisfaction is a crucial determinant of the effectiveness of healthcare since it reveals how well the provider meets clients' expectations and is a major influence on patients' perceptions and behavioral intentions. In addition, a critical component in ensuring quality, which covers everything from medical to psychological perspective during the illness pathway, is patient and caregiver satisfaction (Xesfingi & Vozikis, 2016).

2.2.24 Quality of care

Quality health care means the probability of desired health outcomes is increased to a certain extent by the health services provided to individuals and populations. It is essential for establishing universal health coverage and is founded on professional knowledge supported by evidence. It is necessary to give careful thought to the standard of treatment and health services as nations make commitments to achieve health for all. Numerous criteria can be used to describe quality health care, such as (effectiveness, safety, people-centered, timely, equitable, integrated, and efficient). Effectiveness is the delivery of evidence-based healthcare programs for individuals in need. Safe means preventing harm to those who will get the care. People-centered care is care that takes into account each person's interests, needs, and values. Reduce waiting periods and occasionally damaging delays by being on time. Equitable care is care that does not differ in quality based on a person's gender, race, geography, or socioeconomic situation. Integrated care is care that provides the whole diversity of health services available throughout the life span. Efficiency is the process of optimizing the use of resources while minimizing waste (WHO & WB, 2020).

2.2.25 Quality of life

The term Quality of Life (QoL) refers to a multidisciplinary term that covers areas regarding social, emotional, mental, and physical functioning. It emphasizes the relationship between health status and quality of life rather than simply focusing on population health, life expectancy, and mortality causes. Well-being, which evaluates a person's positive aspects of life, such as good feelings and satisfaction with life, is a concept connected to QoL (Gil-Lacruz et al., 2020). Using the Pediatric Quality of Life Inventory, a study was conducted in Egypt at the pediatric department of the hospital to assess the QOL among children with PH. The results showed that the overall mean percentage of QOL among children with PH was 65% (El-Gamasy & Abdelmageed, 2017). Rochmah (2020) study, have shown that children with PH have a poor quality of life. In addition, this study, which included 78 patients, revealed that there are developmental disorders common in children with PH, including motor delay in 13 (40.6%) children, difficulty solving problems in 11 (34.3%) children, communication impairment in 5 (15.6%) children, fine motor impairment in 2 (6.2%), and impairment in social skills (3.1%) (Razavi et al., 2019).

2.2.26 Influencing factors

2.2.26.1 Socioeconomic characteristics

In Rezaeian's (2017) study, women who are 35 years of age or older have an increased risk of giving birth to children who have PH, primarily because of decreased iodine levels and other variables such as (missing or abnormally small thyroid gland, a genetic defect that affects producing thyroid hormone). The gender of children diagnosed with PH has shown that PH is more common among female children than male children, with a ratio of 2:1 (Saoud et al., 2019). In addition, Rezaeian's (2017) study has revealed that being female is a significant risk factor for PH.

The primary TSH screening program misses thyroxin-binding globulin (TBG) deficit and its more significant PH with delayed TSH rise (1 in 10,000 live births) due to immaturity of the hypothalamus-pituitary thyroid axis, as in preterm and very low birth weight infants, which are the causes of the delay in diagnosis of children with PH (Cherella & Wassner, 2017). Any delay in diagnosis could result in permanent brain damage, as it is recommended to diagnose PH during the first month of birth to prevent any negative effect on mental development. (Rodríguez Sánchez et al., 2019b). Also, in Zeinab (2004), a study revealed that 15% of study participants have a positive family history. Co-morbid conditions include visual impairment, hearing loss, and neurological issues that affect 88% of children with PH.

Chapter Three
Methodology

3.1 Introduction

This Chapter outlines the research methodology that was used in this study. It includes the study design, study population, study setting, study period, eligibility criteria, statistical analysis, and study instruments that were used for data collection. In addition, the Chapter includes the validity and reliability of the study instruments, data analysis, and the pilot study. Finally, this Chapter is concluded by ethical consideration and the limitation of this study.

3.2 Study Design

The design of the study was a triangulated evaluation design that entailed collecting quantitative and qualitative data. The evaluation design reflects the existing facts at the same point in time as the data collection. This study involved a methodological triangulation mixed-method design which provided a combination of the quantitative part that includes an interview questionnaire with caregivers of patients, and the qualitative part that includes an in-depth interview with policymakers and staff working with PH children. The mixed-method in data collection increases the validity and credibility of the research result and the interpretation of this result through the collection and analysis of rich data (Bekhet & Zauszniewski, 2012).

3.3 Study population

The study includes two populations:

3.3.1 Quantitative study population: census

The study population involves all caregivers of children aged 12 years and less who are registered and diagnosed as PH and who have been receiving services in the PHC centers. The number of children involved in the study is 212 patients. Thus, the caregivers of children of the 212 children are involved in this study.

3.3.2 Qualitative study population

Regarding qualitative part of this study, it included the policymakers and service providers who are involved in the PH management. In total, 10 staff are involved in the management

of PH. A purposive sample of the policy makers and service providers were selected based on their area of expertise. The selection criteria of participants depend on their roles and positions. The number of stakeholders involved in the study is 10, divided as follows: 6 policymakers and 4 service providers. The qualitative part also involves audits of health records to assess the quality of documentation, assessing adherence to clinical practice guidelines, and evaluating consistency in reporting.

3.4 Study setting

The study was conducted at the Child Health Department (CHD) in Al Remal health care center. This is the main clinic where services for PH in the Gaza Strip are provided. The CHD provides comprehensive health services that involves monitoring children's growth and development, conducting laboratory tests, provision of medicine.

3.5 Study period

This study was started in November 2020. The proposal for the research was submitted and defended in front of the School of Public Health (SPH) committee in February 2021. The Researcher began to develop the research tools after having the administrative university approve in April 2021 and after obtaining ethical approval from the Helsinki Committee in May 2021. The data collected was completed in January 2022 and the writing of the findings was completed and submitted in July 2022. **Annex (1)** describes the activities of the research and the duration of each stage.

3.6 Eligibility criteria

3.6.1 Eligibility criteria-quantitative part: census study

3.6.1.1 Inclusion criteria

- All registered cases of children diagnosed with PH through the national neonatal screening program and receive services from the CHD at AL Remal PHC center.

- Files were selected based on registered children diagnosed with PH aged 12 years or less, who received services from the Al Remal clinic.

3.6.1.2 Exclusion criteria

- Cases of PH older than 12 years old.

- Cases with secondary hypothyroidism
- Damaged files.
- File of children diagnosed with PH, who have not received any health care services.
- File of children diagnosed with PH, aged more than 12 years.

3.6.2 Eligibility criteria- qualitative part

3.6.2.1 Inclusion criteria

- Healthcare providers working with PH children's management in the study place, such as physicians, lab technicians, pharmacists, and nurses.
- Policymakers who are relevant to PH children's management, and selected them based on their positions.

3.6.2.2 Exclusion criteria

- Other health care providers who are not directly working with PH children's management include other physicians and nurses working in the clinic.

3.7 Sampling process

3.7.1 Quantitative data: census study

The study population consisted of all registered cases diagnosed with PH and aged 12 years or less at the time of data collection. The number of children who utilized health services at Al Remal clinic was 212. The data were collected from the 202 children's caregivers, with a response rate of 95%.

3.7.2 Qualitative data

A sample from policymakers and service providers was purposively selected. The purposively selected sample is a non-probability technique that aims to select people who are involved in PH management. In total, 10 interviews were conducted, six interviews with policymakers and four interviews with healthcare providers. Participants were purposefully selected based on their engagement in the management of PH. Additionally, the qualitative audit was done through reviewing 202 medical records. The findings were extracted through an abstraction sheet that was developed by the Researcher.

3.8 Study instrument: quantitative part

This quantitative study utilized three instruments: the first tool is structured questionnaires to collect the quantitative data; the second tool is the Quality of life (QoL) Questionnaire, and the third tool was the Strength and Difficulties Questionnaire (SDQ).

3.8.1 Questionnaires to collect the quantitative data:

This tool was used to collect data from the 202 caregivers of registered children diagnosed with PH. Most questions were close-ended questions. The questionnaire included:

Part I: sociodemographic variables (age, gender, residency governorate, education level, income, working status, and reason of visit) (12 questions), family history, and medical information (14 questions).

Part II: input domain includes wworkforce, Physical space facility, Information system, and essential medicines (9 questions).

Part III: process domain includes waiting time & appointment time (11 questions), user - provider interaction & communication (37 questions), follow-up (8 questions), participant's perspectives about the availability & affordability of services (10 questions).

Part IV: output & outcome domain includes satisfaction (28 questions), quality of care (3 questions).

3.8.2 Quality of life (QoL) Questionnaire: KIDSCREEN-52 and the SDQ

The Researcher used the KIDSCREEN-52 (long version) international European health survey tool to measure health-related QoL of children with PH, which covered 10 dimensions that included physical activities and health, feelings, general mood, about yourself, free time, family and home life, money matters, friends, school and learning, and bullying. The children under age 8 were used the SDQ questionnaire contains 25 items covering the following (domains: emotional, conducted, hyperactivity, peer, and finally prosocial). SDQ has 14 questions describing difficulties, 10 questions describing strengths, and one neutral question.

3.9 Study instrument: qualitative part

This qualitative study utilized two instruments, the first is the in-depth interviews guiding questions and the second tool is the abstraction sheet that was developed to collect data from medical records.

3.9.1 In-depth interview guiding questions

The interview guiding questions included questions covering different topics such as availability of information systems and reporting; standards and protocol; monitoring and evaluation; quality of care; competency of human resources working with PH children, availability of diagnostic equipment and material; challenges of management and follow-up of PH children **Annex (9)**.

3.9.2 Abstraction sheet

The Researcher has developed an abstraction sheet that was used to extract data from the patient's records. The abstraction **Annex (8)** included the accuracy of documentation; clarity of documentation; and checking all services provided to children patients with PH. In addition, the Researcher has checked the physician's and nurse's records and also checked the laboratory result records, referral records, medication records, and ECD records.

3.10 Data collection

3.10.1 Quantitative data

The Researcher collected the quantitative data from caregivers of children diagnosed with PH. During the data collection, the Researcher respected and maintained the privacy and confidentiality of the information and the caregivers of children. The data were collected over almost six months, as in **Annex (1).** The Researcher also collected the data from medical records at the same time as collecting the quantitative data by using the abstraction sheet tool. Regarding to KIDSCREEN-52 This questionnaire is for children aged 8 to 12 years, and the children have filled out this questionnaire. The Researcher has filled SDQ questionnaire with caregivers of children.

3.10.2 Qualitative data

The Researcher collected data from 6 policymakers and 4 health care providers. The data were collected from policymakers after explaining the purpose of the interview and taking verbal consent approval to participate in the interviews and to record the interviews. The interviews began with factual questions for policymakers and healthcare providers. Notes were taken through the interview and using the audio recording to allow further capturing of information. The qualitative data collection was conducted after finishing the quantitative data collection and analysis.

3.11 Scientific rigor

3.11.1 Quantitative approach (questionnaire)

3.11.1.1 Validity

Under this study, 8 experts have evaluated the instrument, and their feeback have been taken into consideration in **Annex (6)**. Also, a pilot study was conducted before the actual data collection to examine caregivers of children with PH responses to the questionnaire and how they understood it.

3.11.1.2 Reliability

The Researcher attempted to increase reliability by assuring standardization of questionnaire filling. Data entry was done on the same day as the data collection. Also, ensure the data is collected correctly before being analyzed. Table (1) shows the Cronbach Alpha for all the domaines incuded in the structured questionnaires used to collect the quantitative data from caregivers of children with PH. The reliability analysis shows high level of reliability of the tools, in which the lowest reported alpha is 0.79 which is relatively high. The overall reliability of the scale questions is 0.89.

Table (3.1) Cronbach alpha coefficient for these domains.

Items	No. of items	Cronbach alpha
User-provider interaction	32	0.804
Participant's perspectives about the availability and affordability services	10	0.867
Satisfaction	28	0.794
Medical Record	33	0.902
Total domains	**103**	**0.893**

3.11.2 Qualitative approach (in-depth interview)

Trustworthiness is a method by which Researchers can convince themselves and readers that their research results are worthy of attention. It consists of the following characteristics: confirmable, dependable, credible, and transferable (Nowell et al., 2017). The following was done to assure the trustworthiness of the qualitative part of this study. The first peer check was done through experts to revise the questions of the interviewer to assure that they cover all the required dimensions. Then a member's check was done to assure validity, accuracy, and transparency of the transcripts during the interviews. The researcher checked each research step with the supervisor. In addition, an audit trail was done to keep all records, a transcript for the policymakers' and healthcare providers' interviews, and to track the information by others. Also, in pilot form policymakers' and health care providers' interviews, the Researcher applied a pilot trial for policymakers and health care providers to assure the suitability of the questions and to measure the time needed for interviews. Finally, data entry was conducted at the same time as data collection. The Researcher analyzed policymakers' and health care providers' interviews directly to assure the quality and to help the Researcher memorize facial expressions, body language, and voice tones, enhancing the reliability of the results.

3.12 Ethical consideration

Administrative approval was obtained from the School of Public Health at Al Quds University **Annex (3).** and Ethical approval was obtained from the Helsinki Committee **Annex (4).** Also, approval was obtained from the Director-General of MoH and the

Director of PHC in the Gaza Strip. To guarantee participants' rights, a cover letter indicating that the participation is voluntary and confidentiality was assured for all of them **Annex (5).** The caregivers who were selected from the clinics were asked for their consent to participate in the study. The policymakers and healthcare providers were asked for their approval to record in-depth interviews.

3.13 Statistical analysis

3.13.1 Quantitative data analysis

The Researcher used the Statistical Package for Social Sciences (SPSS) version 25 for data coding, entry, and analysis, followed by checking collected data for errors and missing data. Throughout data collection, the Researcher has checked the filled questionnaire and completed any absent information by recalling the caregiver. A re-entry test was performed with 5% of the data. Data cleaning was performed to check illogical values. Then the processing of this data was established. Each item of the medical records of children with PH was assessed through frequency tables to show sample characteristics and plot differences between various patients' characteristics variables. Moreover, cross-tabulation for main findings and advanced statistical tests such as the Chi-square test to compare categorical variables and the T-test to compare the means between variables that have only two categories. One-way ANOVA test for comparing the means between variables having more than two categories. This was done when required to analyze questionnaire data. Analyzing descriptive statistics to analyze numerical data helped to describe or summarize data in a meaningful way and helped in the calculation of the central tendency of mean and mode. A P-value equal to or less than 0.05 was considered statistically significant, with a confidence interval (CI) of 95%.

3.13.2 Qualitative data analysis

Debriefing reports were done immediately after the interview. The open-coding thematic analysis method was used to analyze the transcripts of policymakers' and health care providers' interviews. The Researcher started by summarizing the main findings from the transcripts of health care providers' and policymakers' interviews. A deep reading of the data was extracted from the transcripts. The notes had been taken to recognize the important elements. The Researcher then started with the open coding thematic analysis method through the categorization of related ideas. Then comparisons and integration between the quantitative and qualitative findings were conducted to create rich data for discussion.

3.14 pilot study

To evaluate the suitability of the study instruments, a pilot study for 20 caregivers of children with PH was completed before starting data collection. The Researcher has adjusted the study instruments depending on the findings from the pilot study. There were no major adjustments that were introduced after the analysis of the pilot. In addition, the pilot study, pilot policymakers, and health care provider interviews were conducted to assure the suitability of the guiding questions and to assess the time needed for the interviews. The data collected throughout the pilot study were involved in the study sample as no major revisions were included.

3.15 limitation of the study

The main limitations of the study are:

- The study did not involve the children with PH who didn't register in child health department at Al Remal clinic.
- As the study did not involve assessing the management of PH within the non-governmental PHC clinics and UNRWA, the findings of the study could not be generalized to the services provided by different NGOs and UNRWA.

Chapter Four

Results and Discussion

This Chapter illustrates the results of the analysis of quantitative and qualitative data, which were conducted to evaluate the management of primary hypothyroidism among children in the Gaza Strip. The Chapter includes a descriptive analysis that presents the socio-demographic characteristics, economic, and health-related characteristics of the study sample, as well as the answers to the questions of the study for children diagnosed with PH. It also includes inferential analysis that examines the relationship between selected variables and other selected covariates.

4.1 Descriptive statistic

4.1.1 Socio-demographic characteristics of the study participants

The study has a total of 202 participants. The study participants are the caregivers of children who were diagnosed with PH who filled out the questionnaire, with a 97% response rate. As shown in Figure (4.1), the majority of cases (83 cases, 41%) were from Gaza Governorate, followed by Khanyounis Governorate (35 cases, 17.3%). The remaining cases were from the other three governorates, with 33 cases, 16.3% from Deir Al-Balah and the same from Gaza North. Finally, the lowest number of cases was from Rafah, with 18 cases, 8.9%.

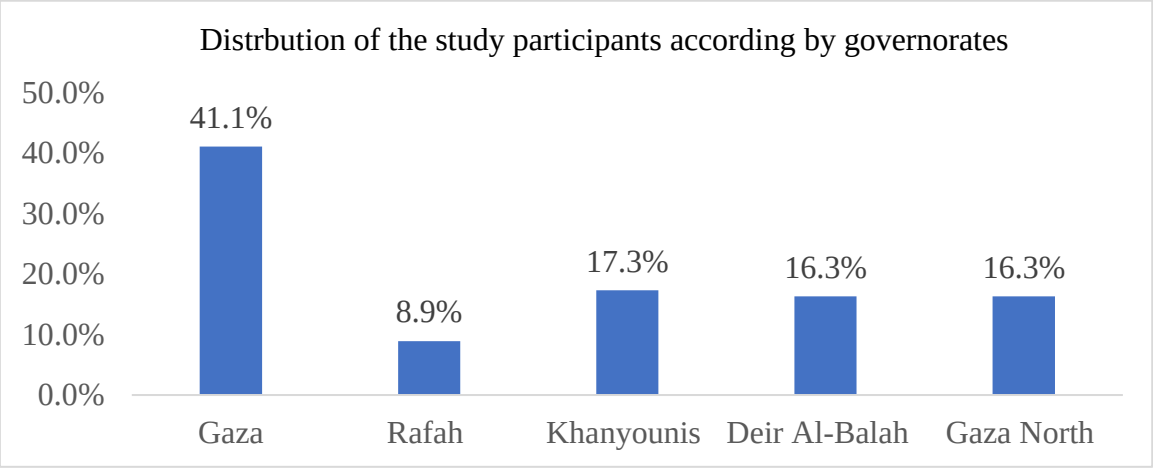

Figure (4.1): Presence of children with PH regard to governorates

4.1.2 Personal data

Table (4.1) shows that the mean age of the study participants was 6.47 years. The distribution of study participants by age group shows that 41.1% of children aged 5 years and less, 38.1% aged between 6 to 9 years, and 20.8% aged more than 9 to 12 years.

In addition, as shown in Table (4.1), the mean maternal age at delivery of the concerned child of study participants was 25.3 years. The breakdown of the age group for study participants shows that 15.3% were aged 20 years and less, 41.6% aged between 21 to 25 years, 24.3% aged between 26 to 29 years, and 18.8% aged 30 and more. This result is inconsistent with the Rezaeian (2017) study , which has revealed women aged 35 years and older have a high risk of having children with PH mainly due to decreased iodine levels and other factors such as having thyroid gland abnormalities (Rezaeian et al., 2017). The results of this study might reflect the impact of iodine deficiency on birth outcomes. However, the case impact could not be establish without conducting studies that invlvoe assessing the iodine level among women who have children with and without PH. As shown in Figure (4.2), more than half (60.4%) of the children who were diagnosed with PH were female, and 39.6% of the children were male. This finding was consistent with the findings of Saoud's (2019) study that showed that PH is more common among female children than male children, with a ratio of 2:1 (Saoud et al., 2019). In addition, the results of this study are also consistent with Rezaeian and Colleagues' (2017) study that revealed that being female is a significant risk factor for PH (Rezaeian et al., 2017).

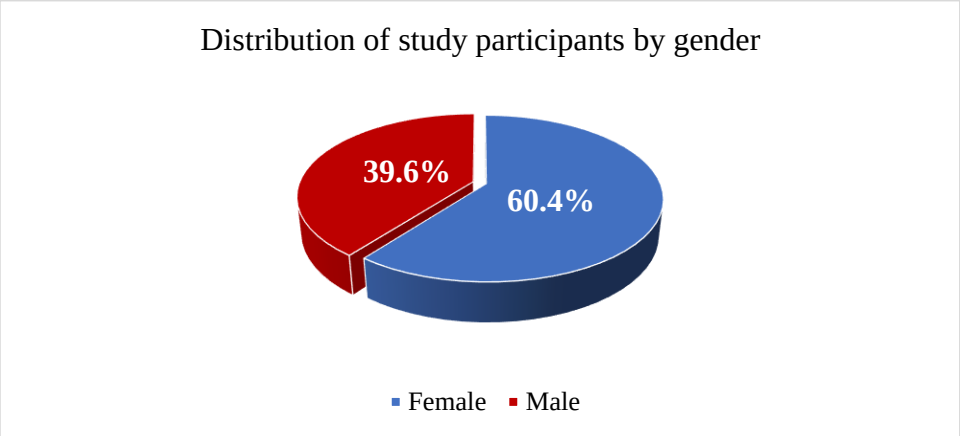

Figure (4.2): Presence of children with PH regard to gender

Table (4.1), the employment status of fathers' who have children with PH, shows that 67.8% of them are working. With regard to mothers' working status, only 6.9% of mothers

were employed at the time of data collection. The findings of the study are consistent with the findings of PCBs as the unemployment rate in the Gaza Strip in 2021 was 39.6% for males and 60.4% for females (PCBS, 2021c). Concerning the educational level, 28.2% of mothers of children who were diagnosed with PH completed their elementary school education and 71.8% completed either high school or university education. The findings of the study are consistent with the findings of PCBs as in 2021 was 75.9% of females completed high school or university education (PCBS, 2021).

With regard to family income, as shown in Table (4.1), the mean monthly income for caregivers of children who were diagnosed with PH was 744.4 New Israel Shekels (NIS), with (SD, 596.25). The breakdown of monthly income shows that 96% of caregivers live below the poverty line and 4% of caregivers live above the poverty line. The poverty line and the deep poverty line for a reference family consisting of 2 adults and 3 children were 2,470 NIS and 1,974 NIS, respectively (PCBS, 2020). The results are inconsistent with the findings of PCBs (2020), which indicate that 53% of individuals in the GS live below the poverty line. NIS. The high poverty rates among families who have children with PH underline the importance of providing health services to their children free of charge.

Table (4.1) Distribution of the study participants by selected sociodemographic factors

Items	**No.**	**%**
Age of Children		
5 years and less	83	41.1
From 6 to 9	77	38.1
More than 9 to 12 years	42	20.8
Total	**202**	**100.0**
Mean = 6.47, MD = 6.00, Std = 3.15		
Respondent		
Mother	121	59.9
Father	81	40.1
Total	**202**	**100.0**
Gender of the child with PH		
Female	122	60.4
Male	80	39.6
Total	**202**	**100.0**

Table (4.1): Continued

Mother age at delivery of the concerned child		
20 years and less	31	15.3
From 21 to 25 years	84	41.6
From 26 to 29 years	49	24.3
30 years and more	38	18.8
Total	**202**	**100.0**
Mean = 25.32, MD = 25.00, Std = 5.04		
Mother complete of schooling		
Elementary school	57	28.2
High school	97	48.0
University	48	23.8
Total	**202**	**100.0**
Mother's Employment Status		
Unemployed	188	93.1
Employed (Teacher, Police)	9	4.5
Self-employed (Hair Dresser)	5	2.4
Total	**202**	**100.0**
Father's Employment Status		
Unemployed	65	32.2
Employed	36	17.8
Self-employed	101	50.0
Total	**202**	**100.0**
Monthly income of your family (Poverty Line 1974)		
Under Poverty Line	194	96.0
Above Poverty Line	8	4.0
Total	**202**	**100.0**
Mean = 755.45, MD = 800.00, Std = 596.25		
Reason for your today's visit		
To scheduled appointed- follow up	105	52.0
To do laboratory tests	97	48.0
Total	**202**	**100.0**

4.1.3 Reason for today's visit

The main reason for the visit during the data collection was mainly to monitor the child's growth and development and to refill the drug prescription, with (52%). Additionally, 48% of study participants visited the clinic to do the follow-up laboratory test.

4.1.4 Family History

4.1.4.1 Age of child diagnosed with PH

Table (4.2) illustrates that the majority of children (65.3%) were diagnosed with PH at the age of less than 1 month, 11.8 were diagnosed when they aged 2 months and 16.8% were diagnosed when they aged from 3 to 5 months. Finally, 6.1% of children were diagnosed with PH at age 6 to 8 months. The main reasons for the delay in the diagnosis are infant hospitalization in the neonatal intensive care unit due to different health issues. This result was also supported qualitative data in which the key informants mentioned that the main reason of the delay in diagnosing PH is hospitalization. The Head of the CHD stated, *"Sometimes there is a delay in diagnosing children with PH as a result of being admitted to the neonatal intensive care unit, whether s/he suffers from a health problem or due to immaturity, and this leads to a delay in conducting the screening t, which may reach 4 to 6 months. "*

The second reason for delayed diagnosis of children with PH due to primary TSH screening program which does not diagnose thyroxin-binding globulin (TBG) deficit (Cherella & Wassner, 2017). In total, 22.7% of children diagnosed with PH are considered late in terms of diagnosis time, which could lead to irreversible damage to the brain as the diagnosis of PH is recommended to be done in the first month of birth to avoid any deterioration of mental development (Rodriguez Sanchez et al., 2019).

Regarding other family members diagnosed with PH, the findings of the study have shown that 10.9% of the study participants have a positive family history. Worldwide, between 15 to 20% of the PH causes are due to genetic factors (Grasberger & Refetoff, 2011). The study result was consistent with the finding of the Zeinab (2004) study, which revealed that 15% of study participants have a positive family history (Zeinab et al., 2004).

4.1.4.2 Presence of morbidities among Mothers of children with PH

As shown in Table (4.2), about 16.8% of mothers of children with PH have morbidities. The main morbidities are diabetes mellitus, hypertension, asthma, thyroid problems, and others, as shown in Figure (4.3).

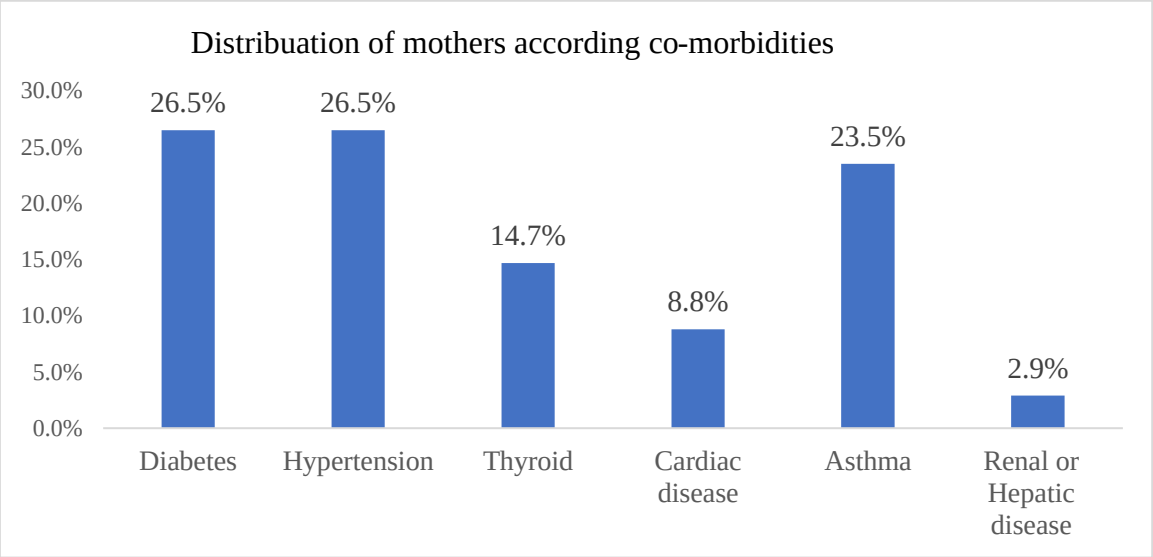

Figure (4.3): Presence of morbidities among Mothers of children with PH

4.1.4.3 Food rich in iodine

As shown in Table (4.2), 67.7% of the mothers of the study participants didn't take foods rich in iodine during their pregnancy. This finding is consistent with the findings of Wassner (2018) that revealed that the most common reason for PH is a deficit in taking food rich in iodine during pregnancy (Wassner, 2018). Regarding vitamin A and & iron supplements, the study findings show that about two-thirds (69.3%) of children with PH were taking vitamin A and iron supplements during the time of data collection. While more than one-third (30.7%) of children with PH didn't take these supplements. Iron and vitamin D supplements are important micronutrients for children with thyroid gland problems, as the supplements activate the thyroid gland to function normally. According to Starchl and Colleagues (2021), it is common for children diagnosed with PH to suffer from vitamin D and iron deficiency. Hence, it is important for those children with PH to regularly take vitamin A&D and iron supplements.

4.1.4.4 Early Child Development (ECD)

ECD is a vital program for children aged from birth to six years old. It focuses on aspects of development, including physical, social, emotional, spiritual, moral, and cognitive language development (Tadesse, 2016).

The findings of the study have revealed that less than half (41.3%) of children diagnosed with PH were enrolled in the ECD program. When asked the nurse in the child health department about the effect of this ECD service on children diagnosed with PH, she stated, *"This service stopped at the end of 2019 until now due to the COVID-19 pandemic.*" Another nurse said, "*service stopped due to a shortage in manpower."* Key informants confirmed the above. She said, "*It had a significant impact on improving the health status of children who received service to control their PH, and also the caregivers became aware of what the stages of growth and development are and how their children can be monitored and followed up, but unfortunately now the department is suspended due to the Corona pandemic and the shortage of manpower."*

When asked about the children who are found to have problems in growth and development, how are they followed up? The head nurse said, *"Children who are found to have a problem in growth and development are referred to the physician to do the necessary tests and examinations. If the problems are related to development, the child is transferred to the Early Childhood Care Department to make a full assessment of the child's problems, identify the problem, and educate the caregivers with the required skills. Then re-evaluate again. If the delay is still and the child has not improved, he is referred to the competent authorities according to the degree of delay."*

When asked by key informants about whether there is a program for psychological support for these children, and how is it determined if the child needs psychological support? All of them said, *"The Al Remal clinic does not have psychologists to deal with these children, but it is the personal efforts of the health staff to provide psychological support.*"

4.1.4.5 Screening program to early identify cases of PH

When asked about key informants, is this program available in all clinics, and are the staff trained on how to properly perform the screening to early identify PH cases? Said " *availability of screening services in all UNRWA clinics and all level four government clinics, and the screening is done through obtaining a blood sample from a child's foot*". The findings of key informants' interviews revealed that all nursing staff trained on how to take the sample in the correct way and how to enter it into the computerized program and send it to the central laboratory. The findings of the key informants interview also have

shown that health staff have good knowledge of PH screening, including the procedure of doing the screening, the timing, and follow up care for children diagnosed with PH.

When asked by the key informants about the steps to be taken if the test result is positive. One key informant stated, "*If the result is positive, a re-examination is done again to confirm it, and if the result is positive again, a file is opened for the child and he is diagnosed with PH, and after that, a follow-up is done based on the results of the tests and according to the system in place. The medical and nursing staff explain in detail the nature of the disease and the role of the caregivers in the treatment plan.*"

Table (4.2) Distribution of the study participants according to medical history

Items	**No.**	**%**
Age of child when diagnosed with PH		
Less than 1 month	132	65.3
2 months	24	11.8
from 3- 5 months	34	16.8
from 6-8 months	12	6.1
Total	**202**	**100.0**
Having family member diagnosed with PH		
No	180	89.1
Yes	22	10.9
Total	**202**	**100.0**
Mother have chronic diseases (yes is it n = 34)		
No	168	83.2
Yes	34	16.8
Total	**202**	**100.0**
History of taking any medication during pregnancy		
No	182	90.1
Yes	20	9.9
Total	**202**	**100.0**
The family especially mother's consume food rich in iodine		
No	155	76.7
Yes	47	23.3
Total	**202**	**100.0**
Receiving supplements vitamin, A&D & Iron)		
No	62	30.7
Yes	140	69.3
Total	**202**	**100.0**
The child registered at the Early Child Development (ECD) program		
No	117	59.7
Yes	85	41.3
Total	**202**	**100.0**

4.1.5 Medical information

4.1.5.1 TSH & T4 level at diagnosis

The normal level of TSH ranges from 0.5 to 5.0 mlU/dl & total T4 ranges from 5 to 12 mcg/dl. Table (4.3) illustrates the mean TSH level for children diagnosed with PH was 189.55 mlU/dl with (SD, 125.02). The result shows that all children have an abnormal level of TSH of more than 5.0mlU/dl. In addition, the mean T4 level during diagnosis was 7.54 mcg/dl with (SD, 5.68). This finding significantly deviates from the normal level, but the breakdown of T4 level results showed 28.8% of children with PH had normal T4 levels and the majority (71.2 %) had abnormal levels. As expected, 80.2% of study participants were diagnosed by a general practitioner and only 19.3% were diagnosed by an pediatrician. Finally, all children diagnosed with PH use Thyroxine medication at a suitable dose, according to their age and the functions of the thyroid gland. This result is consistent with the Barham (2014) study that showed 100% used thyroxine medication for the threat of hypothyroidism (Barham et al., 2014).

But even so, when asked by the Deputy Director General of PHC about whether laboratory tests are available all the time, and what is the alternative if they are unavailable, he said, "*Laboratory tests are often available, but sometimes there is a shortage, but if they are unavailable, children are transferred to hospitals, and if they are not available in hospitals, they are transferred to private laboratories, but before stock runs out, international institutions and international cooperation are contacted to provide them urgently*." The of key informants' interviews clearly revealed that most of the time the screening kits are available, however, sometimes the screening kits are not available due to the financial problems that the MoH face.

4.1.5.2 Latest TSH & T4 result

As shown in Table (4.3), the mean TSH level of children diagnosed with PH was 8.57 mlU/dl with (SD, 15.52). Of the total number of children, 63.8% have normal levels, while 36.2% have abnormally high levels. Regarding the latest T4 results, the mean T4 level was 4.07 mcg/dl with (SD, 3.84). The breakdown of these results showed two-thirds (75.3%) of children diagnosed with PH had a normal level of T4, but also one-third (24.7%) had an abnormally low level. These results may be due to the knowledge deficit of caregivers,

not having children take their medicine regularly, and not following up thoroughly with the service providers.

4.1.5.3 Chronic diseases among children with PH

As shown in Table (4.3), 92.6% of children diagnosed with PH didn't have other chronic diseases, while 7.4 % of study participants had chronic diseases such as epilepsy, ear problems, and eye problems. This finding is inconsistent with Leger's (2015) study that revealed that 88% of children with PH also suffer from other co-morbidities such as visual impairment, hearing impairment, and other neurologic problems (Léger, 2015).

Table (4.3) Distribution of the study participants about medical information

Items	Number	%
TSH level at diagnosis		
Normal	0	0
Abnormal	202	100
Total	**202**	**100.0**
Mean = 189.55, Median 170.0, Std = 125.02		
Latest TSH result		
Normal	127	63.8
Abnormal (above normal level)	72	36.2
Total	**199**	**100.0**
Mean = 8.57, Median 3.40, Std = 15.52		
T4 level at diagnosis with PH		
Normal	55	28.8
Abnormal (under normal level)	147	71.2
Total	**202**	**100.0**
Mean = 7.54, Median 6.80, Std = 5.68		
Latest T4 result		
Normal	143	75.3
Abnormal (under normal level)	47	24.7
Total	**190**	**100.0**
Mean = 4.07, Median 2.80, Std = 3.84		
having other associated chronic diseases		
No	187	92.6
Yes	15	7.4
Total	**202**	**100.0**
Who has diagnosed the child with Primary Hypothyroidism?		
General physician	162	80.2
pediatrician	39	19.3
I do not remember	1	0.5
Total	**202**	**100.0**
What was the first treatment given to the child?		
Thyroxine	202	100.0
Total	**202**	**100.0**

4.1.6 Health care services

Table (4.4) shows that 86.1% of study participants acknowledged the availability of pediatrician to provide services to PH clients, while 83.7% acknowledged the availability of specialized nurses. With regard to the services received at Al Remal clinic for children diagnosed with PH, 93.6% of the study participants arrived to do laboratory tests, 83.7% to dispense medications, and 52.5% of them did counseling and follow-up. The availability of services at Al Remal clinic increases the burden of children and their caregivers in terms of transportation costs, especially for caregivers living outside the Gaza governorate, and the time they need to access the services. It is also important to include professional psychological support in the services provided to children diagnosed with PH, in which only 2.5% of study participants confirmed that they had received psychological support services from healthcare providers.

4.1.6.1 Receiving services from other service providers, in addition to the MoH services

As shown in Table (4.4), 86.1% of study participants received services such as follow-up, lab analysis, and drug dispensing from the Al Remal clinic. At the same time, a total of 13.9% of the study participants receive services from other service providers when services are not available at Al Remal clinic, mainly the ultrasound services. Other reasons for receiving services from other service providers are lack of medication, and difficulty in reaching Al- Remal clinics, particularly for clients living in areas Rafah, and Khanyounis Governorates due to financial barriers to accessing Al-Remal clinic, namely the transportation cost to reach Al-Remal clinics.

4.1.6.2 Essential medicines

The availability of essential medicines for children with PH is substatinal to save their lives. Thus, essential medicine should be accessible, available, affordable, of high quality, and used properly (Ki-moon, 2015). Table (4.4) illustrates that 88.1% of study participants reported that they received Levothyroxine medications from PHC, mainly from the Al Remal clinic, and 14.9% reported that they received medications from UNRWA clinics. Additionally, 58.9% of the study participants caregivers reported period of lack of medications in the Al Remal clinic, thus, they buy the the Levothyroxine from private pharmacies. A total of 23.8% of study participants caregivers reported that medication is

available all the time, 49.5% reported that medication is not available all the time, and 26.7% reported a lack of medication all the time.

The findings of the qualitative data are consistent with the quantitative data in which key informants confirmed that medicine is not available all the time. One key informant stated *"Medicine are not available all the time and they are not free. Caregivers pay a small fee of one shekel if children are less than five years old and three shekels if they are more than three years old. Caregivers of children buy the medicine out of their pocket in case medicine is not available."*

But, Deputy Director General of PHC said, "*Medicines are rarely cut off, but if they are not available, they are purchased from private pharmacies, and now the Ministry has introduced the subsidized drug initiative at a low price, and this is an alternative if they are not available*."

As shown in Table (4.4) 86.1% of study participants didn't receive medications from other health care providers, while 13.9% do so. The majority of caregivers of children with PH are refugees and thus can access UNRWA clinics' services free of charge. A total of 91.7% of the study participants received services from other health care providers when medications is not available, mainly from UNRWA. However, the available dosages at UNRWA clinics are either 100mcg or 200mcg, and most of the time, the dosage needed is about 50mcg. So, caregivers faced some difficulty in dividing the tablets to maintain the right the dosage. Regarding the last time to receive health care services from Al Remal clinic, Table (4.4) shows that the mean was 5.18 months (SD, 6.069).

Table (4.4) Distribution of the study participants about Input

Items	**No.**	**%**
Knowledge about availability of pediatrician at Al Remal clinic		
No	5	2.5
Yes	174	86.1
I don't know dedicated staff for the child	23	11.4
Total	**202**	**100.0**
Knowledge about availability of dedicated Thyroid Disease Nurse Al Remal clinic?		
No	5	2.5
Yes	169	83.7
I don't know dedicated staff for the child	28	13.9
Total	**202**	**100.0**

Table (44.4): Continued

Receive services regarding your child Primary Hypothyroidism from places other than Al Remal clinic		
No	174	86.1
Yes	28	13.9
Total	**202**	**100.0**
If yes, from where do you receive these services?		
European Hospital	1	**3.7**
privet doctor	27	**96.3**
Total	**28**	**100.0**
The services that children with PH receive from Al Remal clinic		
Counseling and Follow-up	106	52.5
Lab Test	189	93.6
Medication Dispensing	169	83.7
Psychological support	5	2.5
Nutritional counseling	1	0.5
From where do the children patient with Primary Hypothyroidism get his medications		
Hospital	5	2.5
Primary health care	178	88.1
UNRWA	25	12.4
Buy from pharmacy	119	58.9
Other	0	0.0
Availability of drugs all the time		
Yes	48	23.8
Not all the time	100	49.5
No medication available	54	26.7
Total	**202**	**100.0**
Is the child receiving medications from another service provider?		
No	174	86.1
Yes	28	13.9
Total	202	100.0
If yes which service providers? Specify		
Private Doctor	2	8.3
UNRWA	22	91.7
Total	**24**	**100.0**
The last time to receive services by months		
One month and less	59	29.4
From 2 to 4 Months	68	33.8
From 5 to 9 Months	36	17.9
10 months and more	38	18.9
Total	**201**	**100.0**
Mean = 5.18, Median = 2.00, Std = 6.069		

4.1.7 Availability of e-health records

One of the main issues that face the Palestinian health system in the Gaza Strip is the absences of a unified computerized e-health system. A key informant when asked about the availability of e-health records, the Deputy Director General of PHC said, *"The files are still saved on papers, but there is a plan to fully computerize the child's file, including the files of children with PH."* The same view was expressed with all the key informants.

4.1.8 Availability of guideline/ protocols for PH treatment

A key informant when asked about guidelines or protocols for children that have been diagnosed with PH, the Deputy Director General of PHC said, "*There is a protocol in the MoH and we always look at the new evidence. The protocol is up to date taking into account recent evidence. It is a national protocol and has been adapted based on international protocols and guidelines*." Interestingly, few key informants expressed dissatisfaction with protocol as the current protocol includes only diagnostic criteria and a referral pathway Thus, the need to update the existing protocol for treatment of PH is highly and urgently needed. The main gaps of the current protocol are (1) limited information about treatment options, (2) absence of guidelines when it comes to laboratory findings, and (3) absence of clear follow up for children with PH.

Finally, not all the staff of the Department of Child Health are aware of the existence of the protocol. One nurse stated "*There are no policies or protocols, they are all personal judgments*."

Regarding the availability of a protocol for screening program, key informants said, "*There is no written protocol, but the Department of Child Health follows the instructions received from the World Health Organization regarding this category of children "* nurse said, "*I don't know if there is a protocol for screening*."

4.1.9 Waiting time & contact time

As shown in Table (4.5), the mean waiting time to receive the services for children with PH was 4.63 minutes, with (SD, 3.94). The breakdown of the waiting time for study participants shows that 49.5% waited less than five minutes, 31.2% waited five minutes, and 19.3% waited more than five minutes. The mean time that physicians spent with children during the follow-up visit was 12.40 minutes, with (SD, 4.89). The breakdown of

the time spent with physicians by study participants shows that 56.4% spent 10 minutes and less, 30.7% spent from 11 to 15 minutes, and 12.9% spent more than 15 minutes.

Also, as shown in Table (4.5), 93.6% of study participants' caregivers reported that they didn't wait a long time before meeting their treating physicians. Also, 92.1% of study participants' caregivers reported that they didn't wait a long time to collect a blood sample for lab tests. In addition, 89.6% of study participants' caregivers mentioned that they didn't wait a long time to dispense medications. In conclusion, most caregivers of children who are diagnosed with PH report that the waiting time is suitable for them in all aspects, including waiting time with to meet their treating physicians, nurses, pharmacists, and laboratories.

4.1.10 Accessibility

4.1.10.1 Physical accessibility & workforce

As shown in Table (4.5), around two-thirds (59.4%) of study participants reported that it was not easy to reach the Al Remal clinic. The main difficulties are the high transportation costs, as stated by 95.8% of study participants caregivers. As Jeklin's (2017) study shows, the transportation cost negatively impacts the access to services provided. In general, long-distance to reach service providers and transportation costs, are the main challenges that could delay or miss appointments for health care providers' services (Jeklin, 2017).

When asked key informants about whether there is a future plan to provide services to children with PH in other PHCs in other geographical areas. Deputy Director General of PHC said, "*Since the number of cases is small, providing the service in one center, according to our experience, is better at the present time. In order to provide the service in more than one PH center, we need qualified physicians and nurses, so there is a future plan to train physicians and nurses to provide a high-quality health service to children with PH.*"

Another key informant, director of the Department of Maternal and Child Health said, "*All clinics must provide services for this category of children, but unfortunately all clinics refer cases to the Child Health Department in Al-Rimal clinic. Therefore, it is necessary to emphasize that the clinics that have family medicine deals with this category of children. This also makes the caregivers aware that the service is not only present in the Al Remal clinic, is will be available in all clinics*."

4.1.10.2 Challenges for children with PH services

The main challenges for children diagnosed with PH to receive services in the Al Remal clinic as shown in Figure (4.4), are the lack of specialized services such as ultrasound, the lack of appointments, and the limited availability of medication all the time.

First, the lack of specialized services such as ultrasound: When asked key informants about the reason for the lack of an ultrasound device in Al Remal clinic and what the alternative was, the Deputy Director General of PHC said, "*It is not available because the problem is not in having the ultrasound device, but in having a trained and specialized staff in radiology. The alternative option is to transfer cases to hospitals to conduct the ultrasound, and this is done without any obstacles. The MoH does not have plan to provide ultrasound services within Al-Rimal clinic.*" The above views were expressed by all key informants.

Second, when it comes to appointment system, around two-thirds of study participants' caregivers didn't have an exact time for their next appointment. Most of the time, service providers do not book appointments for follow-up visits. The lack of a well-functioning appointment system increases the chances of missing appointments and not following up regularly.

Third, the limited availability of medication all the time. When asked the key informants about the main challenges that affect the continuity of services, they said that "*lack of availability of medicine at the time*."

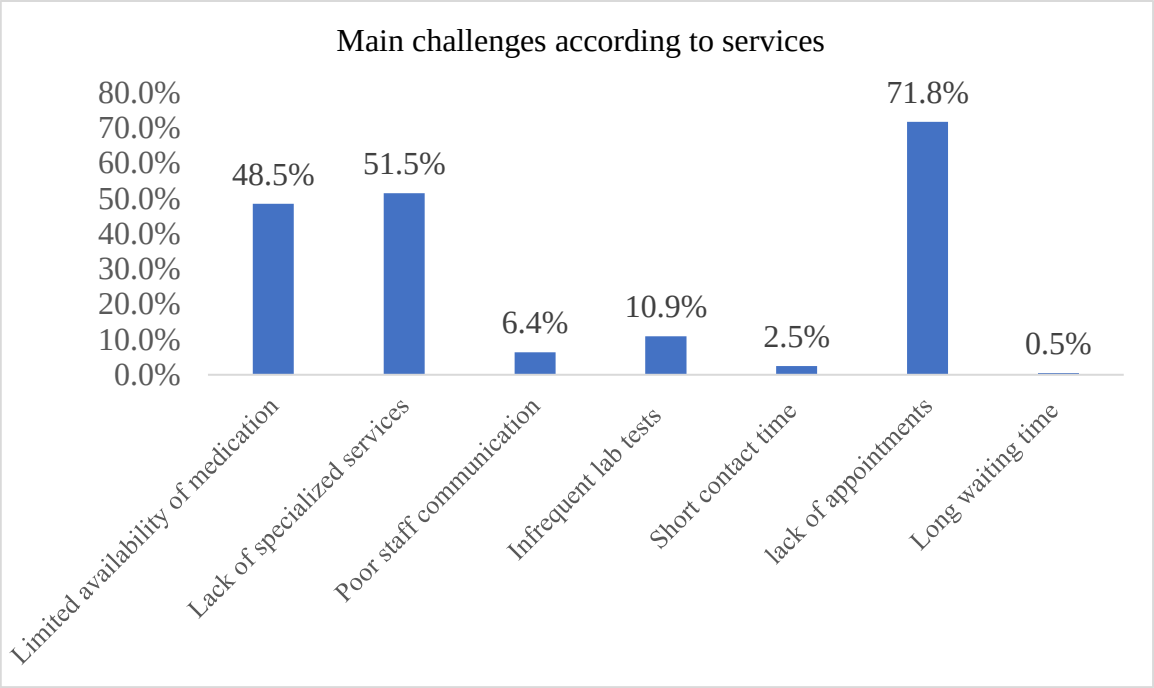

Figure (4.4): Main barriers regard to services at Al Remal Clinic

Table (4.5) Distribution of the study participants according to respondent about waiting time & appointment time in Al Remal Clinic

Items	No.	%
Easy to reach Al Remal Clinic		
No	120	59.4
Yes	82	40.6
Total	**202**	**100.0**
If no, why:		
We come on foot and it take a long time	5	4.2
We come by public transportation and it is cost money	115	95.8
Total	**120**	**100.0**
How long do you wait for your child to be served from the Al Remal Clinic staff? .....Minutes		
Less than 5	100	49.5
5 minutes	63	31.2
More than 5	39	19.3
Total	**202**	**100.0**
Mean = 4.63, Median = 5.00, Std = 3.94		
If the child had a follow-up session in Al Remal Clinic, was there a long waiting list before his turn?		
No	189	93.6
Yes	3	1.5
To some extent	10	5.0
Total	**202**	**100.0**

Table (4.5): Continued

How much time the physicians generally spend with your child during the examination and follow-up? minutes		
10 and less	114	56.4
From 11 to 15	62	30.7
More than 15	26	12.9
Total	**202**	**100.0**
Mean = 12.40, Median = 10.00, Std = 4.89		
If you dispense medications for the child patient with Primary Hypothyroidism, do you wait for a long time to get the services?		
No	181	89.6
Yes	4	2.0
To some extent	17	8.4
Total	**202**	**100.0**
In the past months, have you ever been returned home without receiving the services that the child came to receive?		
No	129	63.9
Yes	73	36.1
Total	**202**	**100.0**
If yes, indicate why		
Absent of physician	1	1.4
Hormone's examination not available	7	9.9
Ultrasound not available	22	31.0
medication not available	41	57.7
Total	**71**	**100.0**

4.1.11 User-provider interaction & physician - patient communication

This domain contains 32 items, including the interaction between providers, physicians, nurses, and pharmacists. The Doctor-Patient Communication (DPC) scale tool was adapted and used to assess the interaction between physicians and clients (Sustersic et al., 2018). As shown in Table (4.6), the majority of study participants, caregivers of children who were diagnosed with PH, reported an average mean of satisfaction with the interaction with the health providers, with a total mean of 76.3% (SD, 5.91).

As shown in Table (4.6), the majority of study participants agreed and strongly agreed that physicians listen to them carefully during the follow-up visits, with a mean of 84%. Also, the second higher mean was the physicians' understanding of the needs of the patients, with a mean of 83%. On the other hand, the lowest mean of the caregiver-physician interaction domain was the physician explaining the advantages and disadvantages of treatment, with a mean of 72%.

In addition, Table (4.6) shows that most of the study participants agreed and strongly agreed that the nursing staff was knowledgeable, with a mean of 81.2%. On the other hand, the lowest mean of caregiver-nurse interaction domain was related to booking the next appointment, in which nurses do not book a precise date for the next appointment for follow-up, with a mean of 54.4%. From the interaction with caregivers, it turned out that most caregivers agree on the next appointment with the treating physician, and in case there is a need for any change in the appointment, caregivers contact their treating physician directly, either by a phone call or come to the clinic.

Table (4.6) shows that most of the study participants either agreed or strongly agreed that if caregivers want to ask pharmacists anything about the medications, it is easy to do so, with a mean of 78%. On contrary, the lowest mean of caregiver-pharmacist interaction was the pharmacists' notifying the nurses if the patient does not receive medication, with a mean of 60%.

Table (4.6) Distribution of the study participants according to respondent about provider interaction & physician - Patient communication

Paragraph		Strongly Disagree	Disagree	Natural	Agree	Strongly Agree	Weighted Mean %
The physician pays attention to the beliefs and emotions of patients and their caregivers	No.	0	6	28	134	34	79.4
	%	0.0	3.0	13.9	66.3	16.8	
During visiting, you were allowed to say everything that you think is important	No.	0	10	28	106	58	81.0
	%	0.0	5.0	13.9	52.5	28.7	
The physician listens carefully to everything you say	No.	3	8	25	118	47	79.8
	%	1.5	4.0	12.4	58.7	23.4	
You feel that the physician understands you	No.	1	11	29	128	33	78.0
	%	0.5	5.4	14.4	63.4	16.3	
The physician makes sure that you understand his explanations and instructions	No.	0	1	35	155	11	77.4
	%	0.0	0.5	17.3	76.7	5.4	

Table (4.6): Continued

The physician understands the needs of the patients	No.	0	1	18	132	51	83.0
	%	0.0	0.5	8.9	65.3	25.2	
The physician responses to your questions	No.	0	4	15	137	46	82.2
	%	0.0	2.0	7.4	67.8	22.8	
The physician always willing to help you.	No.	0	2	25	127	47	81.8
	%	0.0	1.0	12.4	63.2	23.4	
The physician never too busy to respond to your questions	No.	1	7	23	134	37	79.8
	%	0.5	3.5	11.4	66.3	18.3	
The physician respects patient's appointments	No.	3	8	19	145	27	78.4
	%	1.5	4.0	9.4	71.8	13.4	
Does the physician inform you when to come for the next follow-up	No.	4	4	14	142	38	80.4
	%	2.0	2.0	6.9	70.3	18.8	
The physician listens to you carefully during the consultation.	No.	0	2	14	127	59	84.0
	%	0.0	1.0	6.9	62.9	29.2	
The physician allows you to talk without interrupting you.	No.	0	3	20	140	39	81.2
	%	0.0	1.5	9.9	69.3	19.3	
The physician examines the child patient with Primary Hypothyroidism thoroughly.	No.	0	9	27	109	57	81.2
	%	0.0	4.5	13.4	54.0	28.2	
You feel you were given all the necessary information.	No.	3	23	34	113	29	74.0
	%	1.5	11.4	16.8	55.9	14.4	
The physicians explain the advantages and disadvantages of the treatment	No.	5	38	33	79	44	72.0
	%	2.5	19.1	16.6	39.7	22.1	

Table (4.6): Continued

The physicians involve you in the decision-making.	No.	7	25	26	91	53	75.6
	%	3.5	12.4	12.9	45.0	26.2	
In your opinion, the physician has a reassuring attitude	No.	0	7	16	136	43	81.2
	%	0.0	3.5	7.9	67.3	21.3	
You think the physician told the truth about the child's condition	No.	0	4	12	140	46	82.6
	%	0.0	2.0	5.9	69.3	22.8	
You have confidence in the physician	No.	2	18	27	104	51	78.2
	%	1.0	8.9	13.4	51.5	25.2	
Al Remal Clinic nursing staff knowledgeable	No.	0	6	16	140	40	81.2
	%	0.0	3.0	7.9	69.3	19.8	
Does the nurse deal with you respectfully	No.	2	4	16	148	32	80.2
	%	1.0	2.0	7.9	73.3	15.8	
Nurses at the child health department have specific expertise to deal with the child.	No.	0	8	37	152	5	75.2
	%	0.0	4	18.3	75.2	2.5	
The nurse takes into account the patient’s interest	No.	5	17	40	125	15	72.6
	%	2.5	8.4	19.8	61.9	7.4	
The nurse identifies you the next appointment for follow-up	No.	18	87	47	34	16	54.4
	%	8.9	43.1	23.3	16.8	7.9	
The nurse call with the pharmacist to ask about medication	No.	4	69	58	52	19	61.2
	%	2.0	34.2	28.7	25.7	9.4	
medication is not available; the nurse contacts the pharmacist to try to provide this medication	No.	3	72	61	51	15	60.2
	%	1.5	35.6	30.2	25.2	7.4	

Table (4.6): Continued

Pharmacists deal with you respectfully	No.	2	5	39	130	26	77.2
	%	1.0	2.5	19.3	64.4	12.9	
If you want to ask pharmacist anything about the medications, you find it easy to do so.	No.	1	13	44	91	53	78.0
	%	0.5	6.4	21.8	45.0	26.2	
The pharmacists inform you how to take the child his medication every visit	No.	2	10	34	119	37	77.8
	%	1.0	5.0	16.8	58.9	18.3	
The pharmacists notify the nurses if the patient does not receive medication	No.	3	71	61	52	15	60.4
	%	1.5	35.1	30.2	25.7	7.4	
You receive feedback about the results of these laboratory tests	No.	4	11	24	143	20	76.2
	%	2.0	5.4	11.9	70.8	9.9	
Weighted mean = 76.33%, MD = 76.88, Std = 5.91							

4.1.12 Follow up

Table (4.7) illustrates that around half of the study participants (49%) reported that the follow-up for their children was inadequate, and 56.9% reported that they didn't have a regular visit for follow-up. As the caregivers mentioned, the main reasons for not committing to appointment time for follow up are the transportation costs and not booking an appointment.

Table (4.7) shows that 90.6% of study participants didn't conduct diagnostic tests, namely ultrasound last year. Just 19 caregivers out of all of the study participants reported having conducted a diagnostic test for their children with a mean of 7.11 months (SD, 4.40). On the other hand, 59.9% of study participants' caregivers reported having done the test and only 57.9% received feedback on the laboratory tests. Unexpectedly, 60% of children with PH did not conduct the annual test.

Table (4.7) Distribution of the study participants according to respondent about Follow-up

Items	No.	%
Follow-up visits are adequate		
No	99	49.0
Yes	87	43.1
To some extent	16	7.9
Total	**202**	**100.0**
Have regular visits with physicians for your child		
No	115	56.9
Yes	87	43.1
Total	**202**	**100.0**
If no Why?		
I cannot afford transportation cost	99	86.1
My movement is uneasy	13	11.3
I do not have time-work issues-leave	0	0.0
There is no identified date for follow-up	77	67.0
I do not trust my provider	2	1.7
The providers are not qualified enough to deal with	2	1.7
Total	**202**	**100.0**
Have you been approached by provider because the child did not follow up regularly?		
No	161	79.7
Yes	41	20.3
Total	**202**	**100.0**
Child patient with PH done the diagnostic test (Ultra Sound) last year?		
No	183	90.6
Yes	19	9.4
Total	**202**	**100.0**
If yes, when it was? Before .....Months		
5 Months and less	7	36.8
From 6 to 9 months	5	26.4
10 months and more	7	36.8
Total	**19**	**100.0**
Mean = 7.11, MD = 6.00, Std = 4.40		
Received feedback about that diagnostic test?		
No	185	91.6
Yes	17	8.4
Total	**202**	**100.0**
Child patient with PH done annual laboratory analysis last year?		
No	81	40.1
Yes	121	59.9
Total	**202**	**100.0**
If yes, when it was? Before .....Months		

Table (4.7): Continued

5 and less	61	51.3
6 and more	58	48.7
Total	**119**	**100.0**
Mean = 5.25, MD = 5.00, Std = 3.21		
Received feedback about the results of annual laboratory analysis?		
No	85	42.1
Yes	117	57.9
Total	**202**	**100.0**
If No Why?		
I have not been notified of the results	60	70.6
The child is less than a year old	51	60.0
Missing appointments	3	3.5
I did an external examination	3	3.5
Health care providers contact you to inform you of the test result and adjust the dose?		
No	59	29.2
Yes	143	70.8
Total	**202**	**100.0**

4.1.13 Perspective regarding availability & affordability of services

This domain includes 10 items about the availability and affordability of services. As shown in Table (4.8), more than half of the study participants were not satisfied with the availability and affordability of services, with a mean of 61.15%, with (SD, 15.05).

Findings in Table (4.8) show that most of the study participants agreed and strongly agreed that the caregivers can reach easily to health care providers by telephone with a mean of 76.0%. On the other hand, about half of the study participants strongly disagreed or disagreed that medication should be available all the time, with a mean of 48.8%. In addition, around half of the study participants strongly disagreed and disagreed that the follow-up tests TSH, T4, are available all the time, with a mean of 49.2%.

In conclusion, around half of the study participants are not satisfied with the availability and affordability of services, mainly medication and laboratory tests.

Table (4.8) Distribution of the study participants according to respondent about perspectives about the availability & affordability of service

Paragraph		Strongly Disagree	Disagree	Natural	Agree	Strongly Agree	Weighted Mean %
It is easy to access the clinic	No.	54	58	0	80	10	53.4
	%	26.7	28.7	0.0	39.6	5.0	
The medications your child takes are always available	No.	41	96	7	52	6	48.8
	%	20.3	47.5	3.5	25.7	3.0	
The time you need to reach the clinic is reasonable, not lengthy	No.	43	62	2	80	15	56.2
	%	21.3	30.7	1.0	39.6	7.4	
The follow-up tests TSH & T4 are available all the time	No.	43	94	5	49	11	49.2
	%	21.3	46.5	2.5	24.3	5.4	
Do can easy to reach the health care provider by telephone	No.	9	11	12	150	20	76.0
	%	4.5	5.4	5.9	74.3	9.9	
The transportation costs from home to and from the clinic is affordable	No.	36	57	6	92	11	58.6
	%	17.8	28.2	3.0	45.5	5.4	
Were you asked to pay for services you received or medication	No.	17	25	6	146	8	70.2
	%	8.4	12.4	3.0	72.3	4.0	

Table (4.8): Continued

The services in this clinic affordable to most people across the Gaza Strip	No.	8	23	49	113	9	69.2
	%	4.0	11.4	24.3	55.9	4.5	
The health insurance covers all services that the child needs	No.	5	29	94	71	3	63.8
	%	2.5	14.4	46.5	35.1	1.5	
The provided services met your expectations	No.	4	56	26	104	12	66.4
	%	2.0	27.7	12.9	51.5	5.9	
Mean = 61.15, MD = 58.00, Std = 15.05							

4.1.14 Satisfaction

As shown in Table (4.9) nearly two-thirds of the study participants' caregivers were satisfied with the services received, with a total mean of 73.94% (SD, 6.98).

In the satisfaction domains, the majority of study participants' caregivers agreed and strongly agreed that the waiting area of the CHD department is clean, with a mean of 88.4%. Also, most of them agreed and strongly agreed that the primary health center operating hours are convenient for caregivers, with a mean of 86.8%. In addition, the majority of study participants' caregivers agreed and strongly agreed that the waiting time to receive services is suitable for caregivers, with a mean of 86.6%. Also, most of them agreed and strongly agreed that primary health center toilets are clean, with a mean of 86.4%.

On the other hand, as shown in Table (4.9), half of the study participants strongly disagreed and disagreed that the medication is available all the time, with a mean of 50.2%. Also, nearly half of them strongly disagree and disagree about some of the physicians' lack of experience with child health problems, with a mean of 52.6%.

Table (4.9) Distribution of the study participants according to respondent about Satisfaction

Paragraph		Strongly Disagree	Disagree	Natural	Agree	Strongly Agree	Weighted Mean %
The child disease is under control	No.	21	51	22	104	4	61.8
	%	10.4	25.2	10.9	51.5	2.0	
The child's health status improves to better.	No.	18	58	19	91	16	62.8
	%	8.9	28.7	9.4	45.0	7.9	
The treatment plan is suitable and adequate for your child.	No.	24	74	2	62	40	62.0
	%	11.9	36.6	1.0	30.7	19.8	
The medication is available all the time	No.	54	76	13	32	27	50.2
	%	26.7	37.6	6.4	15.8	13.4	
The child usually has difficulty get a referral for diagnostic tests	No.	27	52	49	60	13	58.0
	%	13.4	25.9	24.4	29.9	6.5	
You have easy access to the specialists your child need	No.	3	25	39	125	10	71.2
	%	1.5	12.4	19.3	61.9	5.0	
Some of the physician you have seen lack experience with child medical problems	No.	19	96	35	44	8	52.6
	%	9.4	47.5	17.3	21.8	4.0	
The medical care that the child with Primary Hypothyroidism has been receiving is just about perfect	No.	7	39	61	81	14	65.6
	%	3.5	19.3	30.2	40.1	6.9	

Table (4.9): Continued

The physician explains to you the importance of doing medical examinations to follow up on the child's condition	No.	0	21	19	133	29	76.8
	%	0.0	10.4	9.4	65.8	14.4	
Primary health center environment is comfortable (cleanliness, space, quiet and, so on).	No.	0	5	5	129	63	84.8
	%	0.0	2.5	2.5	63.9	31.2	
The primary health center is equipped with modern and up-to-date equipment.	No.	1	2	8	125	66	85.0
	%	0.5	1.0	4.0	61.9	32.7	
The primary health center operating hours are convenient for you.	No.	0	2	4	119	77	86.8
	%	0.0	1.0	2.0	58.9	38.1	
Booking an appointment is easy	No.	5	6	5	102	84	85.2
	%	2.5	3.0	2.5	50.5	41.6	
Making an appointment for follow up visits	No.	8	19	13	95	67	79.2
	%	4.0	9.4	6.4	47.0	33.2	
Waiting time to receive services is suitable for you	No.	0	1	6	120	75	86.6
	%	0.0	0.5	3.0	59.4	37.1	
The waiting area located in the child health department is clean	No.	0	0	0	117	85	88.4
	%	0.0	0.0	0.0	57.9	42.1	
The Primary health center toilets are clean.	No.	2	0	9	112	79	86.4
	%	1.0	0.0	4.5	55.4	39.1	

Table (4.9): Continued

The time that the health providers spend with the patient is enough	No.	1	4	15	120	62	83.6
	%	0.5	2.0	7.4	59.4	30.7	
When the child undergoes a medical examination, you are sure that is the examination is comprehensive	No.	4	15	27	112	44	77.6
	%	2.0	7.4	13.4	55.4	21.8	
You are satisfied with the medical care that the child is receiving	No.	2	14	28	113	45	78.4
	%	1.0	6.9	13.9	55.9	22.3	
The physician is very competent and well trained	No.	0	9	15	124	54	82.0
	%	0.0	4.5	7.4	61.4	26.7	
The physician will spend enough time to assess and examine your child	No.	1	6	6	148	41	82.0
	%	0.5	3.0	3.0	73.3	20.3	
The services providers' explanations about Primary Hypothyroidism services.	No.	3	9	10	158	22	78.6
	%	1.5	4.5	5.0	78.2	10.9	
The services providers' respect patient's privacy	No.	6	11	24	138	23	76.0
	%	3.0	5.4	11.9	68.3	11.4	
Your service providers use a suitable manner to teach you about improving the child's health	No.	20	22	42	102	15	67.0
	%	10.0	10.9	20.9	50.7	7.5	

Table (4.9): Continued

Covid-19 pandemic makes it difficult to obtain medical services	No.	3	14	28	126	31	76.6
	%	1.5	6.9	13.9	62.4	15.3	
From your perspective, there is an appropriate and safe process of care during Covid-19 pandemic for your child.	No.	3	20	70	85	24	70.6
	%	1.5	9.9	34.7	42.1	11.9	
The health care providers' compliant with infection control and prevention when dealing with your child during the Covid-19 Pandemic	No.	3	6	100	76	17	69.8
	%	1.5	3.0	49.5	37.6	8.4	
Mean = 73.94, MD = 75.00, Std = 6.98							

4.1.15 Quality of care

As reported in Table (4.10), 89.9% of study participants reported the drugs were not available all the time. The second point shows that 81.9% of them reported that laboratory tests were not available all the time. On the other hand, just 26.2% of study participants were satisfied with the availability of services. According to the accessibility of services as indicated in Table (4.10), 62.9% of study participants answered that they had difficulties with accessibility to the services. The majority of study participants have a problem with financial accessibility with 95.3%, and geographical accessibility with 82.7%. Furthermore, 57.4% of study participants reported that the services that they received met their expectations, but 42.6% of them reported that they did not meet their expectations.

In conclusion, around two-thirds of study participants were not satisfied with the availability of services; they faced difficulties in accessibility to the services. Overall, most of the study participants were unsatisfied with services that affected the quality of care.

Table (4.10) Distribution of the study participants according to respondent about Quality of care

Items	**No.**	**%**
Are the health services needed for your child always available at the Clinic		
No	149	73.8
Yes	53	26.2
Total	**202**	**100.0**
If no, list the unavailable services:		
Certain drugs	134	89.9
Laboratory tests	122	81.9
Diagnostic Tests	73	49.0
Specialized services like examine (growth & development)	5	3.4
Are you facing any problems with accessibility of services?		
No	75	37.1
Yes	127	62.9
Total	**202**	**100.0**
If yes, why?		
Physical access	9	7.1
Financial Access	121	95.3
Information Access	3	2.4
Social Access	6	4.7
Geographical Access	105	82.7
Have the PH health services that your child has received meet your expectation?		
No (Hormone's examination & medication not available)	86	42.6
Yes	116	57.4
Total	**202**	**100.0**

4.1.16 Health-related quality of life using SDQ tool

SDQ is used for early detection and early management of behavioral and emotional problems in children below the age of 8. It's used to primarily evaluate the mental health development and well-being of children (Mieloo et al., 2012). The caregivers of the study participants have filled out this questionnaire.

Table (4.11) illustrates that 90.3% of children have a significant problem in the peer domain (abnormal), and 8.4% were on the borderline, but just 1.3% of children have no significant problem in peer relationships. Also, the finding revealed that 58.7% of children have a high risk of having a significant problem in the emotional domain. A total of 45% of children have a high risk of a significant problem in the conducted domain. A total of 12.3% of children with PH have a high risk of having a significant problem in the hyperactivity domain. Finally, 59.4% of children with PH have a significant actual problem in their total difficulties score: emotional, conduct, hyperactivity, and peer; A total of 25.8% of children with PH were on the borderline; and just 14.8% of children with PH have no significant problem in their total difficulties score. The results of this study were inconsistent with Razavi's study (2019), which revealed that there are developmental disorders common among children with PH, including motor delay in 40.6 % of children, difficulty solving problems in 34.3 % of children, communication impairment in 15.6 % of children, fine motor impairment in 6.2 %, and impairment in social skills in 3.1 % of children (Razavi, 2019).

This study indicated that PH has a significant negative impact on the emotional and behavioral aspects of children who were diagnosed with PH. The above findings underline the importance of providing psychological support services for children diagnosed with PH. The finding of this study were inconsistent with Chao and Colleagues' studies (2009), that revealed 29.8% of children with PH have emotional and behavioral problems (Chao et al., 2009).

Table (4.11) Distribution of the study participants according to their responses to SDQ questionnaire

Domains	Normal		Borderline		Abnormal	
	No.	%	No.	%	No.	%
Emotional	33	21.3	31	20.0	91	58.7
Conducted	53	34.2	31	20.0	71	45.8
Hyperactivity	110	71.0	26	16.8	19	12.3
Peer	2	1.3	13	8.4	140	90.3
Total	**23**	**14.8**	**40**	**25.8**	**92**	**59.4**
Prosocial	140	90.0	13	8.4	2	1.3

4.1.17 Health-related quality of life by using KIDSCREEN.tool

The KIDSCREEN instruments assess children's and adolescents' subjective health and well-being (health-related quality of life). They were developed as self-report measures applicable for healthy and chronically ill children and adolescents aged from 8 to 18 years. The Quality of life (QOL) describes the level of physical, emotional, and psychological well-being experienced by an individual. To assess the quality of life, the long version of the KIDSCREEN scale was used to evaluate the well-being of children who were diagnosed with PH.

Table (4.12) shows that 51.8% of children with PH are very often or always full of energy and the ability to be physically active, and about 55.2% of them are satisfied with their lives. With regard to the general mood, although nearly half of the study participants didn't enjoy their life, 27% of them felt sad in the last week, and 17.7% of children felt everything was bad and they did not want to do anything.

Regarding the about yourself domain, it shows that 40% of children were happy with the way they looked, and 49.4% of them were worried about the way they looked. Regarding free time, it shows that 67.3% of children have enough time for themselves, and 63.5% of them are able to do the things that they want to do in their free time. In terms of family and home life, 67% of the children reported their parents understood them, and 70.6% of them felt loved by their parents. The money matter domain shows that 38.8% of children reported that they never and seldom have had enough money to do the same things as their friends, and 45.9% of them reported not having enough money to do things with their friends.

On the other hand, 47% of children reported that they spent time with their friends regardless of their financial situation. The school and learning domain show that 32.9% of children reported that were very and extremely happy at school, 36.5% of them were satisfied with their teachers, 35.3% of them enjoyed going to school, and 35.7% of them were able to pay attention of their teachers. The bullying domain shows that 83.5% of children reported that they never and seldom felt afraid of other girls and boys. To conclude, most children are happy with their family and home life with (78.4%) of all domains, and the lowest reported mean was in the bullying domains, with (27.8%).

Table (4.12) Distribution of the study participants according to their respondent about KIDSCREEN instrument

Items	Excellent		Very Good		Good		Fair		Poor		Weighted Mean%
	No.	%	No.	%	No.	%	No.	%	No.	%	
In general, how would your child rate her/his health?	18	21.2	15	21.2	30	35.3	4	4.7	15	17.6	64.8
Physical Activity											
Items	**Not At All**		**Slightly**		**Moderately**		**Very**		**Extremely**		**Weighted Mean%**
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have you ever felt fit and well?	0	0.0	13	15.3	30	35.3	25	29.4	17	20.0	70.8
Have you ever been physically active (e.g., running, climbing, biking)?	0	0.0	14	16.5	27	31.8	30	35.3	14	16.5	70.4
Have you ever been able to run well	2	2.4	7	8.2	19	22.4	41	48.2	16	18.8	74.6
Items	**Never**		**Seldom**		**Quit often**		**Very Often**		**Always**		**Weighted Mean%**
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have you ever felt full of energy	2	2.4	8	9.4	31	36.5	26	30.6	18	21.2	71.80
Mean = 70.45, MD = 72.00, Std = 17.80											

Table (4.12): Continued

Feeling											
Items	**Not At All**		**Slightly**		**Moderately**		**Very**		**Extremely**		**Weighted Mean%**
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Has your life ever been enjoyable?	3	3.5	20	23.5	19	22.4	30	35.3	13	15.3	67.0
Have you ever felt pleased that you are alive?	2	2.4	18	21.2	16	18.8	35	41.2	14	16.5	69.6
Have you ever felt satisfied with your life?	4	4.7	16	18.8	18	21.2	32	37.6	15	17.6	69.0
Items	**Never**		**Seldom**		**Quit often**		**Very Often**		**Always**		**Weighted Mean%**
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have you ever been in a good mood?	0	0.0	7	8.2	39	45.9	27	31.8	12	14.1	70.4
Have you ever felt cheerful?	0	0.0	11	12.9	27	31.8	35	41.2	12	14.1	71.2
Have you had fun?	4	4.7	12	14.1	23	27.1	21	24.7	25	29.4	72.0
Mean = 69.88, MD = 73.33, Std = 18.72											
General Mood											
Items	**Never**		**Seldom**		**Quit often**		**Very Often**		**Always**		**Weighted Mean%**
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have you ever felt that you do everything badly?	23	27.1	37	43.5	10	11.8	14	16.5	1	1.2	44.2
Have you ever felt sad?	14	16.5	32	37.6	16	18.8	16	18.8	7	8.2	53.0

Table (4.12): Continued

Have you ever felt so bad that you didn't want to do anything?	23	27.1	27	31.8	18	21.2	9	10.6	8	9.4	48.8
Have you ever felt that everything in your life goes wrong?	30	35.3	25	29.4	8	9.4	15	17.6	7	8.2	46.8
Have you ever felt fed up?	28	32.9	30	35.3	8	9.4	13	15.3	6	7.1	45.6
Have you ever felt lonely?	32	37.6	26	30.6	10	11.8	11	12.9	6	7.1	44.2
Have you ever felt under pressure?	24	28.2	25	29.4	17	20.0	11	12.9	8	9.4	49.2
Mean = 47.40, MD = 40.00, Std = 20.70											
About Yourself											
Items	**Never**		**Seldom**		**Quit often**		**Very Often**		**Always**		**Weighted Mean%**
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have you ever been happy with the way you are?	2	2.4	7	8.2	42	49.4	28	32.9	6	7.1	66.8
Have you ever been happy with your clothes?	4	4.7	6	7.1	39	45.9	32	37.6	4	4.7	66.2
Have you ever been worried about the way you look?	3	3.5	8	9.4	32	376	37	43.5	5	5.9	67.8

Table (4.12): Continued

Have you ever felt jealous of the way other girls and boys look?	1	1.2	8	9.4	24	28.2	37	43.5	15	17.6	73.4
Would you ever like to change something about your body?	3	3.5	4	4.7	31	36.5	35	41.2	12	14.1	71.6
Mean = 56.05, MD = 56.00, Std = 7.34											
Free Time											
Items	**Never**		**Seldom**		**Quit often**		**Very Often**		**Always**		**Weighted Mean%**
	No	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have you ever had enough time for yourself?	0	0.0	8	9.4	20	23.5	45	52.9	12	14.1	74.4
Have you ever been able to do the things that you want to do in your free time?	0	0.0	9	10.6	22	25.9	45	52.9	9	10.6	72.8
Have you ever had enough opportunity to be outside?	1	1.2	9	10.6	24	28.2	34	40.0	17	20.0	73.4

Table (4.12): Continued

Have you ever had enough time to meet friends?	1	1.2	9	10.6	30	35.3	28	32.9	17	20.0	72.0
Have you ever been able to choose what to do in your free time?	1	1.2	9	10.6	24	28.2	38	44.7	13	15.3	72.4
Mean = 72.99, MD = 72.00, Std = 15.00											
Family and home life											
Items	**Not At All**		**Slightly**		**Moderately**		**Very**		**Extremely**		**Weighted Mean%**
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have your parent(s) understood you?	0	0.0	2	2.4	26	30.6	32	37.6	25	29.4	78.8
Have you ever felt loved by your parent(s)?	0	0.0	4	4.7	21	24.7	31	36.5	29	34.1	80.0
Items	**Never**		**Seldom**		**Quit often**		**Very Often**		**Always**		**Weighted Mean%**
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have you ever been happy at home?	1	1.2	5	5.9	26	30.6	30	35.3	23	27.1	76.2
Have your parent(s) ever had enough time for you?	2	2.4	5	5.9	25	29.4	26	30.6	27	31.8	76.8

Table (4.12): Continued

Have your parent(s) ever treated you fairly?	2	2.4	7	8.2	11	12.9	39	45.9	26	30.6	78.8
Have you ever been able to talk to your parent(s) when you wanted to?	2	2.4	7	8.2	16	18.8	24	28.2	36	42.4	80.0
Mean = 78.43, MD = 83.33, Std = 16.31											
Money Matters											
Items	**Never**		**Seldom**		**Quit often**		**Very Often**		**Always**		**Weighted Mean%**
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have you ever had enough money to do the same things as your friends	4	4.7	29	34.1	34	40.0	12	14.1	6	7.1	57.0
Have you had enough money for your expenses?	4	4.7	29	34.1	32	37.6	16	18.8	4	4.7	57.0
Do you have enough money to do things with your friends?	9	10.6	30	35.3	33	38.8	10	11.8	3	3.5	52.4
Mean = 55.45, MD = 53.33, Std = 17.97											

Table (4.12): Continued

Friends											
Items	**Never**		**Seldom**		**Quit often**		**Very Often**		**Always**		**Weighted Mean%**
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have you ever spent time with your friends?	1	1.2	8	9.4	36	42.4	33	38.8	7	8.2	68.8
Have you ever done things with other girls and boys?	2	2.4	9	10.6	35	41.2	31	36.5	8	9.4	68.0
Have you ever had fun with your friends?	2	2.4	9	10.6	26	30.6	32	37.6	16	18.8	72.0
Have you ever and your friends helped each other?	2	2.4	8	9.4	23	27.1	32	37.6	20	23.5	74.2
Have you ever been able to talk about everything with your friends?	4	4.7	15	17.6	17	20.0	35	41.2	14	16.5	69.4
Have you ever been able to rely on your friends?	7	8.2	11	12.9	33	38.8	25	29.4	9	10.6	64.2
Mean = 69.41, MD = 70.00, Std = 16.41											

Table (4.12): Continued

School and Learning											
Items	**Not At All**		**Slightly**		**Moderately**		**Very**		**Extremely**		**Weighted Mean%**
	No	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have you ever been happy at school?	15	17.6	20	23.5	22	25.9	20	23.5	8	9.4	56.8
Have you ever got on well at school?	14	16.5	19	22.4	21	24.7	23	27.1	8	9.4	58.2
Have you ever been satisfied with your teachers?	18	21.2	15	17.6	21	24.7	22	25.9	9	10.6	57.4
Items	**Never**		**Seldom**		**Quit often**		**Very Often**		**Always**		**Weighted Mean%**
	No	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have you been ever able to pay attention?	16	19.0	19	22.6	19	22.6	22	26.2	8	9.5	57.0
Have you ever enjoyed going to school?	16	18.8	19	22.4	20	23.5	18	21.2	12	14.1	57.8
Have you ever got along well with your teachers?	22	25.9	12	14.1	19	22.4	16	18.8	16	18.8	58.2
Mean = 47.37, MD = 47.92, Std = 29.30											

Table (4.12): Continued

Bullying											
Items	**Never**		**Seldom**		**Quit often**		**Very Often**		**Always**		**Weighted Mean%**
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	
Have you ever been afraid of other girls and boys?	56	65.9	15	17.6	10	1.8	2	2.4	2	2.4	31.6
Have other girls and boys ever made fun of you?	66	77.6	15	17.6	1	1.2	1	1.2	2	2.4	26.6
Have other girls and boys bullied you?	70	82.4	11	12.9	0	0.0	2	2.4	2	2.4	25.4
Mean = 27.84, MD = 20.00, Std = 14.44											
Total mean= 62.1, MD= 60.8, Std= 8.3											

Figure (4.5) shows the overall children's well-being. After combining them, the total mean of well-being score for the children with PH in our sample was 62.1% with (SD, 8.3).

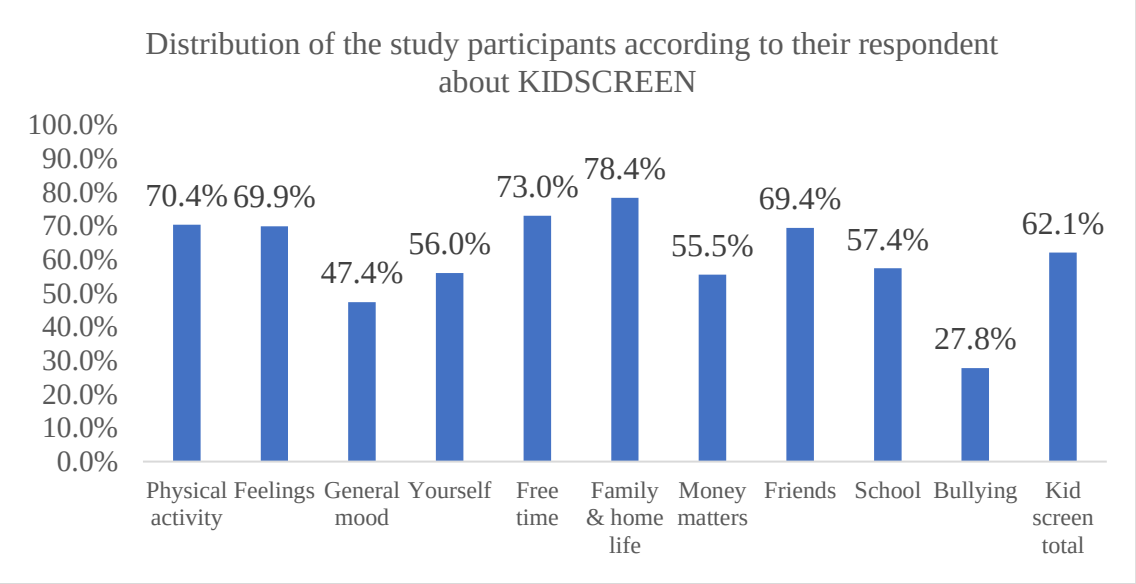

Figure (4.5): Quality of life and well-being among children with PH

The result of this study was congruent with a study that was done in Egypt at the pediatric department at the hospital to evaluate the quality of life (QOL) among children with PH in Egypt, which illustrated that the total mean percentage of the QOL among children with PH was 65% using the Pediatric Quality of Life Inventory (El-Gamasy & Abdelmageed, 2017). The findings of this study were inconsistent with the findings of several studies that have revealed that the quality of life among children with PH was low (Dassie-Leite et al., 2018; Nur, 2020; (Rochmah et al., 2020).

4.1.18 Findings from the medical records review

The medical record contains complete information about the patient, and all files (202) of children who were diagnosed with PH in the Al Remal clinic were reviewed.

As shown in Table (4.13), 99 % of medical records contain the patient's name on all the pages. Contrary to Makki's (2021) study about ulcerative colitis that used a medical record checklist to evaluate medical files in PHC in the Gaza Strip, only 40.7% of all pages in medical records contain the patient's name (Makki, 2021). In terms of date of birth, it shows that 99% of medical files contain the date of birth on all pages, followed by 98.5% for gender documentation, followed by 93.1% for patient identification, and then 88.6% for telephone number documentation. Makki's (2021) study found that 99.3% of medical files contain the date of birth. Regarding the children's age documentation, only 12.4% of medical files contain the age of children on all pages, and 15.3% contain the address on all of the pages. This finding is lower than what Makki (2021) found, as 68.3% of medical files contain the address on all pages (Makki, 2021).

Table (4.13) The Medical File contain the demographic characteristics of patients

Domains	**No**		**Incomplete**		**Yes**	
	No.	**%**	**No.**	**%**	**No.**	**%**
Name	0	0.0	2	1.0	200	99.0
ID number	14	6.9	0	0.0	188	93.1
Age	177	87.6	0	0.0	25	12.4
Date of Birth	2	1.0	0	0.0	200	99.0
Gender	3	1.5	0	0.0	199	98.5
Address	11	5.4	160	79.2	31	15.3
Telephone Number	19	9.4	4	2.0	179	88.6
Mean = 78.15, MD = 78.57, Std = 10.70						

As shown in Table (4.14), the highest average of complete documentation in all entries in the medical record was dated, as it was documented in 91.6% of the medical records reviewed. That means a total of 70.8% of the records have the main purpose of the patient's visit clearly documented. Per UNRWA and MoH guidelines, referral forms should be used to refer cases to T4 and TSH analysis. Unfortunately, only 12.4% of all medical records have this form.

Table (4.14) The Medical File contain the Medical related data

Domains	**No**		**Incomplete**		**Yes**	
	No.	**%**	**No.**	**%**	**No.**	**%**
The main purpose of the patient's visit is clearly documented	7	3.5	52	25.7	143	70.8
Appropriated professional diagnoses are recorded	4	2.0	16	7.9	182	90.1
Plan of diagnosis: Diagnostic tests laboratory & physical examination are listed for each visit	10	5.0	70	34.8	121	60.2
All entries in the Medical Record contain the author's identification	34	16.8	61	30.2	107	53.0
All entries in the Medical Record are dated	7	3.5	10	5.0	185	91.6
Is the record an Electronic Medical Record (EMR)?	202	100.0	0	0.0	0	0.0
Relevant Government PHCs or UNRWA referral summaries are included with medical record	173	85.6	4	2.0	25	12.4
If consultation or diagnostic test is requested, there is a note or report from the consultant in the record	51	25.2	10	5.0	141	69.8
Mean = 63.46, MD = 68.75, Std = 15.86						

Table (4.15) shows that the highest average of complete documentation in medical examination and follow-up was 66.3% of medical records. The lowest average was 30.2% of medical records for children with PH who have other significant illnesses. This result was inconsistent with the Makki study that reported that 10.3% of medical files were completely documented as a previous illness of children. 41.6% of medical records complete documented the physical and mental assessment for growth and development is applied at each visit. Followed by 32.2% for medical history of parents and/or siblings. While Makki's study showed that 18.6% of medical files were completely documented with the medical history of parents (Makki, 2021).

Table (4.15) The Medical File contain the history and physical examination

Domains	**No**		**Incomplete**		**Yes**	
	No.	**%**	**No.**	**%**	**No.**	**%**
Family history- including the medical history of parents and/or sibling	61	30.2	76	37.6	65	32.2
Does the physical & mental assessment for growth and development is applied at each visit	44	21.8	74	36.6	84	41.6
Medical- surgical history including surgical, injuries, operations and acute or chronic diseases/illnesses	103	51.0	33	16.3	66	32.7
Significant illnesses and medical condition are indicated on the special list	116	57.4	25	12.4	61	30.2
Medical examination and follow up done as a protocol from 0- 6 months / every 6 weeks, from 6months- 3 years/ every 3 months & more than 3 months / every 6 months follow up	51	25.2	17	8.4	134	66.3
Mean = 51.73, MD = 50.00, Std = 27.62						

As shown in Table (4.16) the highest average of complete documentation of the treatment plan of action was 74.8% of medical records. This result was consistent with Makki's (2021) study that reported an 82.8% complete documented plan of treatment. At least average of 10.9% of medical records revealed that allergies and adverse reactions are prominently noted in the records. 72.3% completely documented the medication prescribed at each visit. Followed by 68.8% for medication record/list including dosages and dates for initial and refilling the prescription, and 34.2% for discussion of medication side effects and symptoms with a caregiver. This finding was inconsistent with Makki's study, which showed 100% incomplete documentation of the side effects of medication.

Table (4.16) The Medical File contain the Medication

Domains	**No**		**Incomplete**		**Yes**	
	No.	**%**	**No.**	**%**	**No.**	**%**
Medications are documented for each visit	18	8.9	38	18.8	146	72.3
A medication record/list includes dosages and dates for initial and refill prescription	17	8.4	46	22.8	139	68.8
Discussion of medication side effects and symptoms with caregiver and documented	86	42.6	47	23.3	69	34.2
The plan of action and treatment is consistent with the diagnosis	32	15.8	19	9.4	151	74.8
Allergies and adverse reactions are prominently noted in the record. Prominently noted in the front of the chart or inside the front cover of the chart or on a designated problem list or medication page or at the time of each office visit	177	87.6	3	1.5	22	10.9
Mean = 59.75, MD = 60.00, Std = 21.70						

As mentioned in Table (4.17) shows the highest average of complete documentation for the availability of medication all the time was 56.9% of medical records. The least average was 13.9% of medical records for nursing notes completed at each visit. Anthropometric measurements were documented in 53.7% of records. Regarding early child development, it shows that 40.1% was completely documented. This result was inconsistent with Makki's study showed that 97.2% of medical records didn't document the mental status examinations. 38.6% of medical records complete documented follow-up Levothyroxine level in the blood, followed by 38.1% for lab investigation results, followed by 35.6% for lab investigation equipment was available all the time, and finally, 21.8% of medical records completely documented an ultrasound examination. This finding was inconsistent with Makki's study, which shows that 98.6% of medical records have incomplete documentation ultrasound examination (Makki, 2021).

Table (4.17) Primary Hypothyroidism related characteristics

Domains	No		Incomplete		Yes	
	No.	%	No.	%	No.	%
Does the Early Child Development (ECD) do every 3 months at first year of conformed diagnosis or every 6 months from age 1 year to 6 years	121	59.9	0	0.0	81	40.1
Does the Ultrasound done to determine the place of the Thyroid gland mentioned	156	77.2	2	1.0	44	21.8
Do the Anthropometric measurements are applied at each visit	27	13.4	66	32.8	108	53.7
Does the lab investigation result such as (T4, TSH) mentioned	13	6.4	112	55.4	77	38.1
Does the follow up Levothyroxine level in the blood	96	47.5	28	13.9	78	38.6
Does the nursing note record complete at each visit	129	63.9	45	22.3	28	13.9
Does the medication for these cases available all the time	35	17.3	52	25.7	115	56.9
Does the lab investigation equipment is available all the time for these cases	24	11.9	106	52.5	72	35.6
Mean = 50.03, MD = 50.0, Std = 23.42						

4.2 Inferential statistics

4.2.1 Differences in user provider-interaction, perspective, satisfaction and control of PH

Table (4.18), illustrates the differences among study participants between the control and the uncontrol TSH level after received medication of PH with regard to user-provider interaction, perspective, satisfaction, and SDQ score. By using an independent sample t-test to explore whether there were statistically significant differences. The result showed that there were statistically significant differences between interaction, satisfaction, and control of PH. The differences were for control of PH with a mean (77.4) in interaction (T=2.126, P value= 0.035), and (74.92) in satisfaction (T=2.417, P value= 0.017). Contrary to perspective and SDQ score, the results showed there were no statistically significant differences between study participants.

Table (4.18) Differences between domains and control of Hypothyroidism

	control Hypothyroidism	No.	Mean %	Std	T Test	Sig.
Interaction	Control	123	77.04	5.36	2.126	0.035*
	Uncontrolled	71	75.18	6.71		
Perspective	Control	127	62.41	15.25	1.413	0.159
	Uncontrolled	72	59.28	14.62		
Satisfaction	Control	127	74.92	6.53	2.417	0.017*
	Uncontrolled	72	72.51	7.12		
SDQ Score	Control	101	45.82	11.54	0.746	0.457
	Uncontrolled	51	44.41	9.72		

* Significant at 95% CI

4.2.2 Differences in user provider-interaction, perspective, satisfaction and gender

Table (4.19) shows the differences between males and females with regard to user-provider interaction, perspective, satisfaction, and SDQ score. An independent sample t-test was conducted and its result revealed that the male's group had a higher mean (64.60) than the female's group (58.89) and there were statistically significant differences between perspective and gender (T= 2.679, P value= 0.008). Regarding user-provider interaction, satisfaction, and SDQ score, the result has shown there were no statistically significant differences between study participants.

Table (4.19) Differences between domains and Gender

	Gender	No.	Mean %	Std	T Test	Sig.
Interaction	Male	77	76.62	6.08	0.553	0.581
	Female	120	76.15	5.81		
Perspective	Male	80	64.60	14.78	2.679	0.008*
	Female	122	58.89	14.85		
Satisfaction	Male	80	74.18	7.05	0.394	0.694
	Female	122	73.78	6.95		
SDQ Score	Male	60	45.50	11.87	0.058	0.954
	Female	95	45.39	10.37		

* Significant at 95% CI

4.2.3 Differences in user provider-interaction, perspective, satisfaction and Governorates

Table (4.20) is used to identify the existence of differences between governorates with regard to user-provider interaction, perspective, satisfaction, and SDQ score by using a one-way ANOVA test. The result showed that there were statistically significant differences between perspective, satisfaction, and governorates. Regarding the perspective aspect, it showed that Gaza Governorate has the highest mean score, with (68.96) and Khanyounis has the lowest mean score, with (54.17), there were statistically significant differences between perspective and governorates (F= 12.063, P value= 0.000). In addition, regarding the satisfaction aspect, it showed that Gaza Governorate has the highest mean, with (75.75) and Khanyounis has the lowest mean score, with (71.59), there were statistically significant differences between satisfaction and governorates (F= 2.848, P value= 0.025). By using the post hoc (LSD) test with perspective **Annex (10),** the mean difference between Gaza was (68.96), Rafeh (14.18), Khanyounis (14.79), Deir Al-Balah (10.53), and Gaza North Governorate (13.87). Also, by using the post hoc (LSD) test for satisfaction **Annex (10),** the mean difference between Gaza was (75.75), Khanyounis (4.15), and Gaza North Governorate (2.93). On the other hand, regarding user-provider interaction, the result showed there was no statistically significant difference between study participants.

Table (4.20) Differences between domains and Governorates

	Governorates	No.	Mean %	Std	F Test	Sig.
Interaction	Rafah	18	76.35	5.48	1.289	0.276
	Khanyounis	33	75.72	6.16		
	Deir Al-Balah	33	76.25	6.54		
	Gaza	81	77.28	5.54		
	Gaza North Governorate	32	74.63	5.97		
	Total	197	76.33	5.91		
Perspective	Rafah	18	54.78	15.87	12.063	0.000*
	Khanyounis	35	54.17	13.78		
	Deir Al-Balah	33	58.42	14.44		
	Gaza	83	68.96	12.84		
	Gaza North Governorate	33	55.09	13.30		
	Total	202	61.15	15.05		
Satisfaction	Rafah	18	72.74	7.52	2.848	0.025*
	Khanyounis	35	71.59	7.68		
	Deir Al-Balah	33	73.66	6.40		
	Gaza	83	75.75	6.54		
	Gaza North Governorate	33	72.81	6.77		

* Significant at 95% CI

4.2.4 Differences between control of PH and income

As reported in Table (4.21), to explore if there were differences between control PH with income, a non-parametric Mann Whitney test was used, and the result showed that there was a statistically significant difference between control PH and income with a mean of (106.30) for study participants (U= 3771.5, P value= 0.038). The Researcher concludes that the participants were in control because they were from a family with a good income, who could provide medication, and investigations for their children, and attend the appointment time for follow-up easily.

Table (4.21) Differences between control of PH and Income

	Control of PH	No.	Mean Rank %	Sum of Rank	Mann Whitney Test	Sig.
Control of PH	Control	127	106.30	13500.50	3771.50	0.038*
	Uncontrolled	72	76.15	6399.50		

* Significant at 95% CI

4.2.5 Differences between domains and whether the children have any associated chronic diseases

Table (4.24) examines differences between whether children with PH have any associated chronic diseases and user-provider interaction, perspective, satisfaction, and SDQ score. An independent sample t-test was conducted, and its result showed that there was a statistically significant difference between children who have chronic diseases and SDQ scores (T=2.477, P value= 0.014), the mean difference of participants who have chronic diseases is 53.18. On the other hand, according to user-provider interaction, perspective, and satisfaction, the result showed there were no statistically significant differences between study participants.

Table (4.22) Differences between domains and whether the children have any associated chronic diseases

	children have any associated chronic diseases	No.	Mean %	Std	T Test	Sig.
Interaction	Yes	15	78.21	4.97	1.282	0.201
	No	182	76.18	5.96		
Perspective	Yes	15	58.67	17.92	0.663	0.508
	No	187	61.35	14.84		
Satisfaction	Yes	15	73.48	10.72	0.266	0.790
	No	187	73.98	6.63		
SDQ Score	Yes	11	53.18	13.23	2.477	0.014*
	No	144	44.84	10.57		

* Significant at 95% CI

4.2.6 Differences between KIDSCREEN domains and gender

Table (4.25) shows the differences between males and females study participants with regard to the KIDSCREEN domains, an independent t-test was used. The finding illustrates that there were statistically significant differences between some domains such as (free time, family home life, friend, school, and KIDSCREEN score) and gender.

Regarding the free time, it showed females have a higher mean (76.36) than males (66.80). There were statistically significant differences (T=2.933, P value= 0.004). Also, regarding the family home life, the result revealed females have a higher mean (80.91) than males (73.89). Another domain in the KIDSCREEN is friends, the finding showed females have a higher mean (71.94) than males (64.78) also, there were statistically significant differences (T=1.955, P value= 0.054). The school domain in the KIDSCREEN, also illustrates that females have a higher mean (62.06) than males (48.84) and there were also statistically significant differences (T=2.523, P value= 0.014). The overall mean of the KIDSCREEN domains shows that females have a higher mean (63.77) than males (49.08) and there were also statistically significant differences (T=2.562, P value= 0.012). The Researcher concluded these results can happen because the female's participants were more successful in building a relationship with their family and their friends than male's participants, and female's participants have more free time than males due to most of the time they are staying at home, which explains why females are more successful in school than males. in addition, females like school and hours of studying more than males. The results of other domains in the KIDSCREEN such as physical activity, feelings, good mood, yourself, money matter, and bullying illustrate that there were no statistically significant differences between the gender of study participants and KIDSCREEN domains.

Table (4.23) Differences between KIDSCREEN domains and Gender

KIDSCREEN domains	Gender	No.	Mean %	Std	T Test	Sig.
Physical Activity	Male	30	67.33	16.04	1.194	0.236
	Female	55	72.15	18.62		
Feelings	Male	30	67.89	16.29	0.723	0.472
	Female	55	70.97	19.98		
General Mood	Male	30	48.86	22.80	0.479	0.633
	Female	55	46.60	19.64		
Yourself	Male	30	54.93	5.35	1.033	0.304
	Female	55	56.65	8.21		
Free Time	Male	30	66.80	14.18	2.933	0.004*
	Female	55	76.36	14.47		
Family home life	Male	30	73.89	18.01	1.926	0.058*
	Female	55	80.91	14.91		
Money matters	Male	30	54.89	16.95	0.212	0.833
	Female	55	55.76	18.65		
Friends	Male	30	64.78	16.09	1.955	0.054*
	Female	55	71.94	16.17		
School	Male	30	48.89	23.40	2.523	0.014*
	Female	55	62.06	22.79		
Bullying	Male	30	29.11	19.14	0.595	0.553
	Female	55	27.15	11.25		
KIDSCREEN score	Male	30	59.08	7.61	2.562	0.012*
	Female	55	63.77	8.31		

* Significant at 95% CI

4.2.7 Differences between KIDSCREEN domains and Type of School

An independent sample t-test was conducted to explore if there were statistically significant differences between KIDSCREEN domains and the type of schooling for study participants. As shown in Table (4.26), there were statistically significant differences between some KIDSCREEN domains such as physical activity, feelings, friends, and the type of school. The results of the physical activity domain showed that the children studying at governmental schools had a higher mean (74.38) than the children studying at UNRWA schools (65.58), and there were statistically significant differences (T=2.35, P value= 0.022). The finding of the feeling domain illustrates that the children studying at governmental schools have a higher mean (74.74) than the children studying at UNRWA schools (64.21), and there were statistically significant differences (T=2.596, P value= 0.011). Finally, the result of the friends' domain also showed that the children studying at governmental school have a higher mean (73.40) than the children studying at UNRWA

schools (64.47). There were statistically significant differences (T=2.577, P value= 0.012). Based on these results, the Researcher summarized the relationship between children and teachers at governmental schools is more powerful than the relationship in UNRWA schools. On the other side, the results of other domains in KIDSCREEN such as good mood, yourself, free time, family home life, money matter, school, and bullying revealed there were no statistically significant differences between the type of school of study participants and KIDSCREEN domains.

Table (4.24) Differences between KIDSCREEN domains and Type of School

KIDSCREEN domains	Gender	No.	Mean %	Std	T Test	Sig.
Physical Activity	Government	47	74.38	17.35	2.325	0.022*
	UNRWA	38	65.58	17.36		
Feelings	Government	47	74.47	17.04	2.596	0.011*
	UNRWA	38	64.21	19.35		
General Mood	Government	47	43.59	21.01	1.916	0.059
	UNRWA	38	52.11	19.58		
Yourself	Government	47	54.89	7.01	1.627	0.108
	UNRWA	38	57.47	7.58		
Free Time	Government	47	74.04	14.82	0.718	0.475
	UNRWA	38	71.68	15.32		
Family home life	Government	47	80.71	16.06	1.44	0.154
	UNRWA	38	75.61	16.41		
Money matters	Government	47	57.87	16.97	1.389	0.169
	UNRWA	38	52.46	18.93		
Friends	Government	47	73.40	15.73	2.577	0.012*
	UNRWA	38	64.47	16.08		
School	Government	47	59.86	23.21	1.058	0.293
	UNRWA	38	54.39	24.32		
Bullying	Government	47	26.10	13.47	1.242	0.218
	UNRWA	38	30.00	15.48		
KIDSCREEN Score	Government	47	63.54	8.03	1.783	0.078
	UNRWA	38	60.34	8.46		

* Significant at 95% CI

4.2.8 Differences between KIDSCREEN domains and education attainment level

Table (4.27) identifies the existence of differences between KIDSCREEN domains and education attainment levels, a one-way ANOVA test was used, and the finding revealed that there were statistically significant differences between most KIDSCREEN domains such as physical activity, feeling, good mood, free time, family home life, money matters, friend, school, and overall KIDSCREEN score and education attainment level. By using the Post hoc (LSD) test with education attainment level with overall KIDSCREEN domains **Annex (11),** it showed there were statistically significant differences in high education attainment level for physical activity, feeling, free time, family home life, money matters, friend, school, and overall KIDSCREEN score, except general mood domain with a mean of 63.6%, there were statistically significant differences in low education attainment level (F= 20.377, P value= 0.000). The Researcher summarized these results was normal because most of the time the children are active and have good feelings, friends, and support from their family which leads to getting high education attainment level. On contrary, the children who didn't have any friends or support from their family were inactive. On the other hand, the results of other domains in KIDSCREEN such as (yourself, and bullying) showed there were no statistically significant differences between education attainment levels and overall KIDSCREEN domains among study participants.

Table (4.25) Differences between KIDSCREEN domains and education attainment level

KIDSCREEN domains	education attainment level	No.	Mean %	Std	F Test	Sig.
Physical Activity	Low	27	56.74	18.37	32.395	0.000*
	Moderate	31	68.77	11.33		
	High	27	86.07	9.31		
	Total	85	70.45	17.80		
Feelings	Low	27	56.05	17.10	30.680	0.000*
	Moderate	31	67.63	13.39		
	High	27	86.30	12.17		
	Total	85	69.88	18.72		
General Mood	Low	27	63.60	22.59	20.377	0.000*
	Moderate	31	44.70	15.92		
	High	27	34.29	11.07		
	Total	85	47.40	20.70		

Table (4.25): Continued

Yourself	Low	27	57.78	6.96		
	Moderate	31	56.26	6.61		
	High	27	54.07	8.26	1.770	0.177
	Total	85	56.05	7.34		
Free Time	Low	27	60.89	13.69		
	Moderate	31	72.52	8.75		
	High	27	85.63	11.54	31.900	0.000*
	Total	85	72.99	15.00		
Family home life	Low	27	65.31	16.85		
	Moderate	31	78.60	11.73		
	High	27	91.36	8.07	28.444	0.000*
	Total	85	78.43	16.32		
Money matters	Low	27	47.65	12.22		
	Moderate	31	53.98	17.07		
	High	27	64.94	19.97	7.381	0.001*
	Total	85	55.45	17.97		
Friends	Low	27	59.38	15.02		
	Moderate	31	68.71	12.70		
	High	27	80.25	15.22	14.465	0.000*
	Total	85	69.41	16.41		
School	Low	27	33.46	14.51		
	Moderate	31	58.82	14.31		
	High	27	79.75	15.98	65.166	0.000*
	Total	85	57.41	23.73		
Bullying	Low	27	29.63	15.62		
	Moderate	31	30.54	17.62		
	High	27	22.96	5.94	2.361	0.101
	Total	85	27.84	14.44		
KIDSCREEN Score	Low	27	54.60	6.24		
	Moderate	31	61.48	4.97		
	High	27	70.36	5.22	56.181	0.000*
	Total	85	62.11	8.33		

* Significant at 95% CI

4.2.9 Differences between KIDSCREEN domains and father education level

As in Table (4.28 there were statistically significant differences between KIDSCREEN domains and father education level, a one-way ANOVA test was conducted, and the finding showed that there were statistically significant differences between most KIDSCREEN domains such as physical activity, feeling, good mood, family home life, money matters, friend, and overall KIDSCREEN score and father education level. By using the Post hoc (LSD) test with father education level and overall KIDSCREEN domains **Annex (12),** it revealed there were statistically significant differences. It showed that most of the KIDSCREEN domains physical activity, feeling, family home life, money matters, friend, and overall KIDSCREEN score whose fathers have university education level have the highest mean category of education levels. Also, among the fathers who have a primary education level, showed there were statistically significant differences. The results showed that the general mood in KIDSCREEN domain has the highest mean compared to another education level (F= 3.137, P value= 0.019). The Researcher concluded from the results that fathers with high education level are interested in knowing more information about their children's disease, and they will be serious about an appointment time for follow-up and observation of any deterioration in their children.

Table (4.26) Differences between KIDSCREEN domains and father education level

KIDSCREEN domains	father education level	No.	Mean %	Std	F Test	Sig.
Physical Activity	Primary School	6	64.67	11.15	5.461	0.001*
	preparatory School	25	60.16	18.99		
	Secondary School	38	72.74	15.53		
	University	3	86.67	14.05		
	Post Graduate	13	82.46	13.91		
	Total	85	70.45	17.80		
Feelings	Primary School	6	58.89	13.28	2.458	0.052*
	preparatory School	25	64.27	22.33		
	Secondary School	38	71.05	16.26		
	University	3	82.22	16.44		
	Post Graduate	13	79.49	15.92		
	Total	85	69.88	18.72		

Table (4.26): Continued

General Mood	Primary School	6	60.48	23.52	3.137	0.019*
	preparatory School	25	55.09	21.56		
	Secondary School	38	45.19	19.75		
	University	3	37.14	10.30		
	Post Graduate	13	35.38	14.59		
	Total	85	47.40	20.70		
Yourself	Primary School	6	59.33	8.55	0.797	0.53
	preparatory School	25	56.48	6.96		
	Secondary School	38	56.21	7.02		
	University	3	56.00	10.58		
	Post Graduate	13	53.23	8.06		
	Total	85	56.05	7.34		
Free Time	Primary School	6	76.67	13.49	2.091	0.09
	preparatory School	25	66.56	18.18		
	Secondary School	38	74.11	12.40		
	University	3	82.67	10.07		
	Post Graduate	13	78.15	14.11		
	Total	85	72.99	15.00		
Family home life	Primary School	6	78.33	10.90	3.351	0.014*
	preparatory School	25	71.60	19.05		
	Secondary School	38	78.25	14.68		
	University	3	93.33	6.67		
	Post Graduate	13	88.72	12.21		
	Total	85	78.43	16.32		
Money matters	Primary School	6	36.67	11.74	3.333	0.014*
	preparatory School	25	51.73	17.14		
	Secondary School	38	57.19	17.09		
	University	3	68.89	15.40		
	Post Graduate	13	63.08	18.78		
	Total	85	55.45	17.97		
Friends	Primary School	6	53.33	9.89	3.372	0.013*
	preparatory School	25	65.20	16.08		
	Secondary School	38	71.23	15.85		
	University	3	81.11	16.78		
	Post Graduate	13	76.92	15.30		
	Total	85	69.41	16.41		

Table (4.26): Continued

School	Primary School	6	63.33	20.00	2.271	0.069
	preparatory School	25	49.60	23.06		
	Secondary School	38	55.96	23.69		
	University	3	76.67	3.33		
	Post Graduate	13	69.49	24.03		
	Total	85	57.41	23.73		
Bullying	Primary School	6	40.00	21.50	1.411	0.238
	preparatory School	25	26.93	9.71		
	Secondary School	38	27.89	16.97		
	University	3	20.00	0.00		
	Post Graduate	13	25.64	9.75		
	Total	85	27.84	14.44		
KIDSCREEN Score	Primary School	6	61.15	4.65	3.249	0.016*
	preparatory School	25	58.49	9.71		
	Secondary School	38	62.42	7.40		
	University	3	70.26	4.59		
	Post Graduate	13	66.75	6.92		
	Total	85	62.11	8.33		

* Significant at 95% CI

4.2.10 Differences between KIDSCREEN domains and Mother education level

As in Table (4.29), a One-way ANOVA test was conducted to explore if there were statistically significant differences between KIDSCREEN domains and mother education level, and its result revealed that there were a statistically significant differences between most KIDSCREEN domains such as physical activity, feeling, general mood, family home life, money matters, friend, and overall KIDSCREEN score and mother education level. The results of the Post hoc (LSD) test with mother education level and overall KIDSCREEN domains **Annex (13),** showed that there were statistically significant differences in most of the KIDSCREEN domains physical activity, feeling, good mood, family home life, money matters, friend, and overall KIDSCREEN score whose mothers have a postgraduate level of education have highest mean compere to all category of education levels. Meanwhile, the results were different in the general mode domain, there was a statistically significant difference, but this was for mothers who have preparatory

school level. The mean is 60.48% which the highest compared to other categories of education levels (F= 3.137, P value= 0.019). From the result, the Researcher concludes that mothers with postgraduate education level are interested in knowing more information about their children's disease, and they will be interested in an appointment time for follow-up and observation of any deterioration of their children. On the contrary, the results of the KIDSCREEN domains yourself, free time, school, and bullying revealed that there were no statistically significant differences between the mother's education level and overall KIDSCREEN domains among study participants.

Table (4.27) Differences between KIDSCREEN domains and mother education level

KIDSCREEN domains	father education level	No.	Mean %	Std	F Test	Sig.
Physical Activity	Preparatory School	6	64.67	11.15	5.461	0.001*
	Secondary School	25	60.16	18.99		
	University	38	72.74	15.53		
	Post Graduate	13	82.46	13.91		
	Total	85	70.45	17.80		
Feelings	Preparatory School	6	58.89	13.28	2.458	0.052*
	Secondary School	25	64.27	22.33		
	University	38	71.05	16.26		
	Post Graduate	13	79.49	15.92		
	Total	85	69.88	18.72		
General Mood	Preparatory School	6	60.48	23.52	3.137	0.019*
	Secondary School	25	55.09	21.56		
	University	38	45.19	19.75		
	Post Graduate	13	35.38	14.59		
	Total	85	47.40	20.70		
Yourself	Preparatory School	6	59.33	8.55	0.797	0.53
	Secondary School	25	56.48	6.96		
	University	38	56.21	7.02		
	Post Graduate	13	53.23	8.06		
	Total	85	56.05	7.34		
Free Time	Preparatory School	6	76.67	13.49	2.091	0.09
	Secondary School	25	66.56	18.18		
	University	38	74.11	12.40		
	Post Graduate	13	78.15	14.11		
	Total	85	72.99	15.00		
Family home life	Preparatory School	6	78.33	10.90	3.351	0.014*
	Secondary School	25	71.60	19.05		
	University	38	78.25	14.68		
	Post Graduate	13	88.72	12.21		
	Total	85	78.43	16.32		

Table (4.27): Continued

Money matters	Preparatory School	6	36.67	11.74	3.333	0.014*
	Secondary School	25	51.73	17.14		
	University	38	57.19	17.09		
	Post Graduate	13	63.08	18.78		
	Total	85	55.45	17.97		
Friends	Preparatory School	6	53.33	9.89	3.372	0.013*
	Secondary School	25	65.20	16.08		
	University	38	71.23	15.85		
	Post Graduate	13	76.92	15.30		
	Total	85	69.41	16.41		
School	Preparatory School	6	63.33	20.00	2.271	0.069
	Secondary School	25	49.60	23.06		
	University	38	55.96	23.69		
	Post Graduate	13	69.49	24.03		
	Total	85	57.41	23.73		
Bullying	Preparatory School	6	40.00	21.50	1.411	0.238
	Secondary School	25	26.93	9.71		
	University	38	27.89	16.97		
	Post Graduate	13	25.64	9.75		
	Total	85	27.84	14.44		
KIDSCREEN Score	Preparatory School	6	61.15	4.65	3.249	0.016*
	Secondary School	25	58.49	9.71		
	University	38	62.42	7.40		
	Post Graduate	13	66.75	6.92		
	Total	85	62.11	8.33		

* Significant at 95% CI

4.2.11 Correlation between age and KIDSCREEN Score

Table (4.30) illustrates the differences between age and KIDSCREEN domains. to explore whether there were statistically significant differences, the Researcher used the person correlation test. The result showed that there were statistically significant differences between age and most of the KIDSCREEN domains such as feeling, yourself, money matters, friends, and bullying, but the results were different in KIDSCREEN domains physical activity, general mood, free time, family home life, school, and overall KIDSCREEN score, it shows there were no statistically significant differences between age and overall KIDSCREEN domains among study participants.

Table (4.28) correlation between age and KIDSCREEN Score

KIDSCREEN	Pearson Correlation	Sig. (2-tailed)
Physical Activity	0.162	0.139
Feelings	0.249	0.021*
General Mood	0.119	0.276
Yourself	0.243	0.025*
Free Time	0	0.998
Family home life	0.02	0.857
Money matters	0.328	0.002*
Friends	0.296	0.006*
School	0.047	0.666
Bullying	0.342	0.001*
KIDSCREEN total	0.091	0.406

* Significant at 95% CI

Chapter Five
Conclusion and Recommendation

5.1 Conclusion

This study was conducted to evaluate PH management in the PHC at the GS. The design of the study is triangulated cross-sectional study, as it entitles both quantitative and qualitative data.

The main barriers to access health services for children diagnosed with PH are the geographical and financial barriers; delays in diagnoses; limited availability of early child development service; shortages in the workforce and training health care providers to deal with children with PH; absence of diagnostic equipment such as ultrasound; shortages in essential medicines; shortages of lab tests; absence of national updated protocols for early identification and PH and proper management.

There are shortages of many specialists such as pediatrician, family medicine physicians, and psychologists. There is also a shortage of nurses working in the child health department and a lack of PHCs providing services for children diagnosed with PH except at Al Remal clinic, which adversely affects the management process.

Delays in diagnosis of PH is another challenge facing children diagnosed with PH. Nearly one-third of children suffer from a delay in diagnosis, mainly due to hospitalization There is sometimes a shortage of kits needed to conduct TSH tests. This delay in management effects the growth and development of children and increases the chance of mental retardation. The information system for PH children, including the registry, medical files, and follow-up, has many gaps. Medical files are still paper format, even though, there are a few services that are computerized such as laboratories services.

Access to essential medicine results reflected that less than one-third of the participants caregivers expressed that the medications is available all the time The limited availability of medications and lab tests is found to be the most frequent cause of a return without having the needed health care service. Around half of the study participants' caregivers are not satisfied with the availability and affordability of services, mainly medication and laboratory tests.

The mean waiting time was short in Al Remal PHC center, and the study participants' caregivers were satisfied with it. The contact time between children diagnosed with PH and their physician is suitable and accepted for study participants' caregivers. For the user-provider interaction domain, the average mean is found to be high and there are no statistically significant differences were found in it between males and females.

Qualitative results were consistent with quantitative findings in general. Key informants' interviews underlined the importance of updating the current protocol, scaling up the provision of services to the South of Gaza to reduce the access barriers, and to develop follow up guidelines, along with screening protocols.

5.2 Recommendations

1. Health education during antenatal care should underline and focus on the importance of consuming food-rich iodine or iodine supplements in order to reduce the risk of having a child due to iodine deficiency during pregnancy.
2. To ensure early identification and diagnosis of PH, it is highly recommended that the MoH change its protocol of TSH screening to be conducted during the first week of life for all newborn, including newborn admitted to hospitals.
3. Provision of multidisciplinary support for children diagnosed with PH according to the associated disease is a complication, especially the psychosocial support.
4. The MoH and UNRWA should ensure availability of all PH medicine, and it is also necessary to make available PH medicine in the right doses either 50 mcg or 100 mcg, according to children's needs to avoid drug errors.
5. It is recommended that the MoH scale up the provision of health services for children with PH to at least another clinic in the Sothern of Gaza Strip to overcome the access barriers and the financial barriers due to the high transportation costs to reach Gaza governorate.
6. Availability of TSH tests services is a must. Thus, the MoH and UNRWA should ensure the availability of TSH testing all the time.
7. The lack of updated protocols and standards indicates a significant gap in the provision of appropriate and standardized services to children diagnosed with PH, hence appropriate protocols for the Palestinian context should be developed to fulfill the needs of health care providers and children.
8. The MoH and UNRWA should continue to provide ECD services for all children, including children with PH.

5.3 Recommendations for further research

1. To conduct mixed methods studies to assess the current psychological support provided to children with PH.
2. To conduct cohort studies to examine the impact of iodine deficiency on pregnancy outcomes.
3. To conduct similar studies to evaluate the management of services provided to patients diagnosed with PH aged 12 and more.

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Annexes

Annex (1) study activities timetable

year		2020		2021												2022	
Activity	**Duration**	**11**	**12**	**01**	**02**	**03**	**04**	**05**	**06**	**07**	**08**	**09**	**10**	**11**	**12**	**01**	**07**
Proposal writing	2 months																
Proposal Discussion and approval	1 month																
Development instruments	1 month																
Experts check for validity of instruments	1 month																
Pilot study	1 month																
Modification	1 month																
Data collection	6 months																
Data entry	6 months																
Data Analysis	6 months																
Writing report	5 months																

Annex (2) Estimated Budget

No	Item	Unit	Expected USD	Comments
1	**Study Tools**	MP3 recorder	100	
2	**Transportation**	3 months	740	Patients 216 x 2.5 USD Data collectors 2 X100
3	**Training workshop**	For data collectors	50	Refreshments
4	**SIM card & balance**	To call study sample	50	
5	**Data Collectors**	216 x 5 USD for questionnaires	1080	
6	**Photocopying for Research papers**	10copy x 15 USD	200	
7	**Dissemination of results** **-Workshops** **- Publication**	Refreshments	200 300	
8	**Data entry and analysis**		500	
	Total		**3220 USD**	**Expected to be less or more**

Annex (3) Academic approval from the School of Public Health

Al-Quds University
Jerusalem
School of Public Health

جامعة القدس
القدس
كلية الصحة العامة

التاريخ: 2021/4/27

حضرة الدكتور/ رامي العبادلة المحترم
مدير عام تنمية القوى البشرية–وزارة الصحة

تحية طيبة وبعد،،،

الموضوع: مساعدة الطالب هيثم منصور

نشكر لكم دعمكم الدائم لمسيرة العلم والتعليم وخصوصاً دعم كلية الصحة العامة وطلابها، ونود أعلامكم بأن الطالب المذكور أعلاه يقوم بعمل بحث كمتطلب للحصول على درجة الماجستير في السياسات والإدارة الصحية– مسار الجودة وسلامة المريض بعنوان:

"Evaluation of Management of Primary Hypothyroidism among Children in the Gaza Strip"

وعليه نرجو من سيادتكم التكرم بالموافقة على تسهيل مهمة الطالب في إنجاز هذا البحث حيث أن عينة الدراسة هم الأطفال المصابين بقصور الغدة الدرقية والمسجلين في عيادة شهداء الرمال التابعة لوزارتكم الموقرة. علما بأنه سيتم استخدام استبيان وتعبئتها عن طريق مقابلة مع أهل الطفل المصاب، كما سيتم مراجعة ملفات المرضى باستخدام استبيان آخر

و اقبلوا فائق التحية و الاحترام،،،

د. بسام أبو حمد
منسق عام برامج الصحة العامة
فرع غزة

نسخة:
- الملف

Jerusalem Branch/Telefax 02-2799234
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ص.ب. 51000 القدس

Annex (4): Helsinki Committee research approval

المجلس الفلسطيني للبحث الصحي
Palestinian Health Research Council

تعزيز النظام الصحي الفلسطيني من خلال مأسسة استخدام المعلومات البحثية في صنع القرار
Developing the Palestinian health system through institutionalizing the use of information in decision making

Helsinki Committee
For Ethical Approval

Date: 15\02\2021 **Number:** PHRC/HC/856/21

Name: Haytham Mahmoud Foaad Mansour الاسم:

We would like to inform you that the committee had discussed the proposal of your study about: نفيدكم علماً بأن اللجنة قد ناقشت مقترح دراستكم حول:

Evaluation of Management of Primary Hypothyroidism among Children in the Gaza Strip.

The committee has decided to approve the above mentioned research. Approval number PHRC/HC/856/21 in its meeting on 15\02\2021 و قد قررت الموافقة على البحث المذكور عاليه بالرقم والتاريخ المذكوران عاليه

Signature

Member **Member**

Chairman

Genral Conditions:-
1. Valid for 2 years from the date of approval.
2. It is necessary to notify the committee of any change in the approved study protocol.
3. The committee appreciates receiving a copy of your final research when completed.

Specific Conditions:-

E-Mail:pal.phrc@gmail.com

Gaza - Palestine غزة - فلسطين
شارع النصر - مفترق العيون

Annex (5) Administrative approval from HR department in the MoH

State of Palestine
Ministry of health

دولة فلسطين
وزارة الصحة

التاريخ:25/05/2021
رقم المراسلة 693544

السيد : رامي عبد العبادله المحترم

مدير عام بالوزارة /الإدارة العامة لتنمية القوى البشرية/وزارة الصحة

السلام عليكم ,,,

الموضوع/ تسهيل مهمة الباحث/ هيثم منصور

التفاصيل //
بخصوص الموضوع أعلاه، يرجي تسهيل مهمة الباحث/ هيثم محمود منصور
الملتحق ببرنامج ماجستير السياسات والإدارة الصحية – مسار الجودة وسلامة المرضى – جامعة القدس أبو ديس بغزة
في إجراء بحث بعنوان:
"Evaluation of Management of Primary Hypothyroidism among Children in the Gaza Strip"
حيث الباحث بحاجه للاطلاع على الملف الطبي وتعبئة استبانة من ذوي عدد من الأطفال الذين يعانون من قصور افراز الغده الدرقية المترددين على عيادة الامراض المزمنة في مركز صحي شهداء الرمال، اضافة لعقد مقابلات معمقة مع عدد من اصحاب القرار بالخصوص في الوزارة مقدمي الخدمات الصحية لهؤلاء الاطفال.
نأمل توجيهاتكم لذوي الاختصاص بضرورة الحصول على الموافقة المستنيرة من أولياء امور الاطفال الذين هم على استعداد للمشاركة في الدراسة ومن ثم تمكين الباحث من التواصل معهم ، بما لا يتعارض مع مصلحة العمل وضمن أخلاقيات البحث العلمي ودون تحمل الوزارة أي أعباء أو مسئولية.
وتفضلوا بقبول التحية والتقدير،

ملاحظة /
1. الدراسة اعلاه حاصلة على موافقة لجنة اخلاقيات البحث الصحي
2. تسهيل المهمة الخاص بالدراسة أعلاه صالح لمدة 6 أشهر من تاريخه.

محمد ابراهيم السرساوي
مدير دائرة/الإدارة العامة لتنمية القوى البشرية

Gaza Tel. (+970) 8-2846949 Fax. (+970) 8-2826295
غزة تلفون. (+970) 8-2846949 فاكس. (+970) 8-2826295

Annex (6) List of experts

Expert name	**Place of work**
Prof. Yehia Abed	Al-Quds University
Dr Bassam Abu Hamad	Al-Quds University
Dr. Noha Al Shareef	Al-Quds University
Dr Adnan Alwahidi	Ard El Insan Palestinian Association
Dr Jamel Al Bahnsawey	Rantissi Hospital
Dr Hanaa Kishko	Al Remal clinic
Dr Maha Abu Jahel	Al Remal clinic
Jehad Akasha	Health Research Department

Annex (7): Caregiver's questionnaire- English

Evaluation of Management of Primary Hypothyroidism among Children in the Gaza Strip

Dear participant:

I am Haytham Mansour, a student at the master degree of Health Policy and Management/ Quality and Patient safety track at Al Quds University, conducting a research study about Evaluation of Management of Primary Hypothyroidism (PH) among Children in the Gaza Strip. Caregivers of children patients with PH will be selected in this study and your participation has no direct or indirect negative implications on you or your family. This study is as fulfillment requirement for the master degree of public health.

The aim of the study is to assess the PH management of pediatric patients in order to provide service providers and policymakers with evidence-based information and recommendations to the improvement in the quality of provided services to pediatric clients with PH. The study is looking ultimately to provide health care providers with recommendations that might help in prevention or decreasing the occurrence complication of PH. The questionnaire gives you the opportunity to tell us about status of services are provided to children patients with PH in the Gaza strip and your perspective about it.

Approximately 212 children will participate in this study and the researcher will include the entire registered cases diagnosed with PH and aged 12 years or less. If you agree to participate, you will be asked to fill an interviewed questionnaire. This will take approximately 25 minutes of your valuable time. Although your participation in this study is highly appreciated, it is voluntary. You are free not to answer any questions.

The Researcher: **Haytham Mansour**

Serial Number…….			Date of Birth……
Part I			
Section 1: Demographic & Socioeconomic data			
File number……	Patient ID ……		Age of the child ……. Years
1	Respondent ☐ Mother ☐ Father ☐ Others specify…….		
2	Gender of the child with PH ☐ Male ☐ Female		
3	Residency Governorate ☐ Rafah ☐ Khanyounis ☐ Deir Al-Balah ☐ Gaza ☐ Gaza North Governorates		
4	Current Mother's age ……...	**5**	Mother age at delivery of the concerned child ……...
6	Mother complete years of schooling…….		
7	What is Mother's Employment Status? ☐ Unemployed ☐ Employed ☐ Self-employed ☐ Waged employee	**8**	What is Father's Employment Status? ☐ Unemployed ☐ Employed ☐ Self-employed ☐ Waged employee
9	If employed, what is mother current occupation? ……	If employed, what is father current occupation? …….	
10	What is the monthly income of your family (from all sources)	……. ILS	
11	Monthly family expenditure on the child health with Primary Hypothyroidism (cost of drug, special food, transportation cost to clinic, supplement, etc.)	..... ILS	
12	What is the reason for your today's visit? ☐ To scheduled appointed- follow up ☐ To do laboratory tests ☐ To take medication from Pharmacy ☐ Others ……?		

Section 2: Family history		
1	At which age your child was diagnosed with Primary Hypothyroidism? ……	
2	Other family member diagnosed with Primary Hypothyroidism? ☐ Yes ☐ No	If yes, whom? ☐ Father ☐ Mother ☐ Brother ☐ Sister ☐ Other, **specify** ……
3	If yes, What is the age at time of diagnosis of other family members with Primary Hypothyroidism? …… months	
4	Does the mother have chronic diseases? ☐ Yes ☐ No	If yes, you which disease (can choose more than one option) ☐ Diabetes ☐ Hypertension ☐ Thyroid ☐ Cancer ☐ Cardiac disease ☐ Asthma ☐ Renal or Hepatic disease ☐ Other **specify……...**
5	Did the mother take any medication during pregnancy? ☐ Yes ☐ No	If yes, what it is ……...
6	Does the family especially mother's take food rich in iodine? ☐ Yes ☐ No	
7	Does the child take supplements such as (vitame A+D & Iron)? ☐ Yes ☐ No	
8	Does the child registered at the Early Child Development (ECD) program & committed with it? ☐ Yes ☐ No	

Section 3: Medical information about the child patient with Primary Hypothyroidism			
1	TSH level at diagnosis……. Latest TSH result……	**2**	Free T4 level at diagnosis…… Latest T4 result……

3	Has the TSH& PKU test been done at the first visit to the MCHC or PHCC after birth? ☐ Yes ☐ No	If yes when ☐ At the first week ☐ At the second week ☐ At the third week or more
4	Does the child with Primary Hypothyroidism have any associated chronic diseases? ☐ Yes ☐ No	If yes, Mention the chronic disease or other diseases of the child have?.....

5	Who has diagnosed the child with Primary Hypothyroidism? ☐ General physician ☐ pediatrician ☐ Other I☐ not remember
6	What was the first treatment given to the child?.....
Part II: Input	
Section 4	
1	In Al Remal clinic where the child gets his health care services, is there at least one pediatrician ? ☐ Yes ☐ No ☐ I don't know dedicated staff for the child
2	In Al Remal clinic where the child gets his health care services, is there a dedicated Thyroid Disease Nurse? ☐ Yes ☐ No ☐ I don't know dedicated staff for the child
3	Your main source of information about the child, s disease is from? ☐ Internet ☐ Other, please specify……..… ☐ Physician's ☐ Nurse ☐ Family member ☐ Friend
4	Do you receive services regarding your child Primary Hypothyroidism from places other than Al Remal clinic? ☐ Yes ☐ No If yes, from where do you receive these services?.....
5	What services does the child receive from Al Remal clinic? (can choose more than one option) ☐ Counseling ☐ Follow-up ☐ lab tests ☐ Medication dispensing ☐ Psychological support ☐ Nutritional counseling ☐ Health education about Primary Hypothyroidism ☐ Others ……
6	From where does the child patient with Primary Hypothyroidism get his medications? (Could be more than one option) ☐ Hospital ☐ Primary health care ☐ UNRWA ☐ Buy from pharmacy ☐ Others specify……
7	If the child takes his medications from Al Remal clinic, do you find it available every time? ☐ Yes ☐ Not all the time ☐ No medication available
8	Is the child receiving medications from another service provider? ☐ No ☐ Yes ☐ Sometimes If yes which service providers? Specify…….
9	When was the last time to receive services? Before …… months
Part III: Process	
Section 5: Waiting time & appointment time in Al Remal Clinic	

1	Was it easy to reach Al Remal Clinic? ☐ Yes ☐ No	If no, why: ☐ We come on foot and it take a long time ☐ We come by public transportation and it is cost money ☐ Others reasons, specify…….
2	How long do you wait for your child to be served from the Al Remal Clinic staff? .....Minutes	
3	Are there any governmental health centers, UNRWA or, NGOs that provide health care services for children with Primary Hypothyroidism? ☐ Yes ☐ No ☐ I don't know	
4	If the child had a follow-up session in Al Remal Clinic, was there a long waiting list before his turn? ☐ Yes ☐ To some extent ☐ No	
5	In the case of an Al Remal Clinic visit for a follow-up, do you wait for a long time to see the physician? ☐ Yes ☐ To some extent ☐ No	
6	If the child has performed lab tests in Al Remal Clinic, have you to wait for a long time to get the services? ☐ Yes ☐ To some extent ☐ No	
7	How much time the physicians generally spend with your child during the examination and follow-up? …….. minutes	
8	Average waiting time in the clinic before seeing the physician? …….. minutes	
9	If you dispense medications for the child patient with Primary Hypothyroidism, do you wait for a long time to get the services? ☐ Yes ☐ To some extent ☐ No	
10	What are the main challenges/barriers you face with regard to services that the child receives from this Clinic? (You can select more than one option) ☐ Limited availability of medication ☐ Lack of specialized services ☐ Poor staff communication ☐ Long waiting time ☐ Short contact time with the provider ☐ Infrequent appointments ☐ Infrequent lab. Analysis ☐ Other	
11	In the past months, have you ever been returned home without receiving the services that the child came to receive? ☐ Yes ☐ No	If yes, indicate why ……

Section 6: User -provider interaction & **physician - Patient communication**						
For each of the below statement, please select one of the five options 1=Strongly disagree, 2=Disagree, 3=Natural, 4=Agree, 5=strongly agree						
User -provider interaction		**Strongly disagree**	**Disagree**	**Natural**	**Agree**	**strongly agree**
1	The physician is polite and deals with patients and their caregivers in a friendly way.					
2	The physician pays attention to the beliefs and emotions of patients and their caregivers.					
3	During visiting, you were allowed to say everything that you think is important.					
4	The physician listens carefully to everything you say.					
5	Physician often don't listen to what you have to say.					
6	If you have some questions of a medical nature, you can contact a physician without problems?					
7	You feel that the physician understands you?					
8	The physician makes sure that you understand his explanations and instructions.					
9	The physician takes into account the patient's interest.					
10	The physician understands the needs of the patients.					
11	The physician responses to your questions.					
12	The physician always willing to help you.					
13	The physician never too busy to respond to your questions.					
14	In many times the physician uses a language difficult for you to understand without adequate explanation.					
15	The physician respects patient's appointments.					

16	Does the physician inform you when to come for the next follow-up?					
17	Al Remal Clinic nursing staff knowledgeable.					
18	Does the nurse deal with you respectfully?					
19	Nurses at the child health department have specific expertise to deal with the child have Primary Hypothyroidism.					
20	The nurse takes into account the patient's interest.					
21	The nurse identifies you the next appointment for follow-up					
22	Pharmacists deal with you respectfully.					
23	If you want to ask pharmacist anything about the medications, you find it easy to do so.					
24	The pharmacists inform you how to take the child his medication every visit.					
25	The physician listens to you carefully during the consultation.					
26	The physician allows you to talk without interrupting you.					
27	The physician examines the child patient with Primary Hypothyroidism thoroughly.					
28	You feel you were given all the necessary information.					
29	The physicians explain the advantages and disadvantages of the treatment.					
30	The physicians involve you in the decision-making.					
31	In your opinion, the physician has a reassuring attitude.					
32	You think the physician told the truth about the child's condition.					
33	You have confidence in the physician.					
34	The nurse call with the pharmacist to ask about medication.					

35	If a medication is not available, the nurse contacts the pharmacist to try to provide this medication.					
36	The pharmacists notify the nurses if the patient does not receive medication.					
37	You receive a feedback about the results of these laboratory tests.					

Section 7: Follow up		
1	Do you think that your follow-up visits are adequate? ☐ No ☐ Yes ☐ To some extent	
2	Do you have regular visits with physicians for your child's follow-up? ☐ Yes ☐ No	If no, why? (You can select more than one) ☐ I cannot afford transportation cost ☐ My movement is uneasy ☐ I do not have time—work issues-leave ☐ There is no identified date for follow-up ☐ I do not trust my provider ☐ The providers are not qualified enough to deal with child patient with Primary Hypothyroidism case ☐ Others, specify…….
3	Have you been approached by provider because the child did not follow up regularly? ☐ Yes ☐ No	
4	Has the child patient with PH done the diagnostic test (Ultra Sound) last year? ☐ Yes ☐ No	If yes, when it was? Before .....Months
5	Have you received a feedback about that diagnostic test? ☐ Yes ☐ No	
6	Has the child patient with PH done annual laboratory analysis last year? ☐ Yes ☐ No	If yes, when it was? Before .....Months
7	Have you received a feedback about the results of annual laboratory analysis? ☐ Yes ☐ No	If No, why… ☐ I have not been notified of the results ☐ The child is less than a year old ☐ Missing appointments ☐ I did an external examination

8	Does the health care providers contact you to inform you of the test result and adjust the dose? ☐ Yes No

Section 8: Participant's perspectives about the availability & affordability of services.						
For each of the below statement, please select one of the five options 1=Strongly disagree 2= Disagree 3=Natural 4=Agree 5=Strongly agree						
Participant's perspectives about the availability and affordability services.		**Strongly disagree**	**Disagree**	**Natural**	**Agree**	**strongly agree**
1	It is easy to access the clinic?					
2	The medications your child takes are always available?					
3	The time you need to reach the clinic is reasonable, not lengthy.					
4	The follow-up tests TSH & T4 are available all the time?					
5	Do can easy to reach the health care provider by telephone?					
6	The transportation costs from home to and from the clinic is affordable?					
7	Were you asked to pay for services you received or medication?					
8	The services in this clinic affordable to most people across the Gaza Strip.					
9	The health insurance covers all services that the child needs?					
10	The provided services met your expectations?					

Part IV: Output/Outcome
Section 9: Satisfaction
For each of the below statement, please select one of the five options 1=Strongly disagree 2= Disagree 3=Natural 4=Agree 5=Strongly agree

Satisfaction		Strongly disagree	Disagree	Natural	Agree	strongly agree
1	The child disease is under control.					
2	The child's health status improves to better.					
3	The treatment plan is suitable and adequate for your child.					
4	The medication is available all the time.					
5	The child usually has difficulty get a referral for diagnostic tests.					
6	You have easy access to the specialists your child need.					
7	Some of the physician you have seen lack experience with child medical problems.					
8	The medical care that the child with Primary Hypothyroidism has been receiving is just about perfect.					
9	The physician explains to you the importance of doing medical examinations to follow up on the child's condition.					
10	Primary health center environment is comfortable (cleanliness, space, quiet and, so on).					
11	The primary health center is equipped with modern and up-to-date equipment.					
12	The primary health center operating hours are convenient for you.					
13	Booking an appointment is easy.					
14	Making an appointment for follow up visits.					
15	Waiting time to receive services is suitable for you.					
16	The waiting area located in the child health department is clean					
17	The Primary health center toilets are clean.					

18	The time that the health providers spend with the patient is enough.					
19	When the child undergoes a medical examination, you are sure that is the examination is comprehensive.					
20	You are satisfied with the medical care that the child is receiving.					
21	The physician is very competent and well trained.					
22	The physician will spend enough time to assess and examine your child.					
23	The services providers' explanations about Primary Hypothyroidism services.					
24	The services providers' respect patient's privacy.					
25	Your service providers use a suitable manner to teach you about improving the child's health.					
26	Covid-19 pandemic makes it difficult to obtain medical services.					
27	From your perspective, there is an appropriate and safe process of care during Covid-19 pandemic for your child.					
28	The health care providers' compliant with infection control and prevention when dealing with your child during the Covid-19 Pandemic.					

Section 10: Quality of care		
1	Are the health services needed for your child always available at the Clinic? ☐ Yes ☐ No	If no, list the unavailable services: (you can select more than one) ☐ Certain drugs ☐ Laboratory tests ☐ Diagnostic tests ☐ Specialized services ☐ Other reasons specify…….

2	Are you facing any problems with accessibility of services? ☐ Yes ☐ No	If yes, why? (You can select more than one) ☐ Physical access ☐ Financial access ☐ Information access ☐ Social access ☐ Geographical access
3	Have the PH health services that your child has received meet your expectation? ☐ Yes ☐ No	If no, why, please specify……..

Thank you for participation

Annex (8) Record checklist

Primary Hypothyroidism Children medical records evaluation checklist:

Serial Number:	File NO:
Age:	Member ID:
Provider Name:	
Gender	Date of Birth:
The Medical Records	

For each of the below statement, the options are 0= No, 1= Incomplete, 2= Yes

A. Demographic characteristics:

1. Each page within the Medical Record contains the patient's name

0 1 2

2. Each page within the Medical Record contains the patient's ID number

0 1 2

3. Each page within the Medical Record contains the patient's age

0 1 2

4. Each page within the Medical Record contains the patient's DOB

0 1 2

5. Each page within the Medical Record contains the patient's gender

0 1 2

6. Each page within the Medical Record contains the patient's address

0 1 2

7. Each page within the Medical Record contains the patient's home telephone number

0 1 2

B. Medical record characteristics

8. The main purpose of the patient’s visit is clearly documented

0 1 2

9. Appropriated professional diagnoses are recorded

0 1 2

10. Plan of diagnosis: Diagnostic tests laboratory & physical examination are listed for each visit

0 1 2

11. All entries in the Medical Record contain the author’s identification

Author identification may be a handwritten signature, an initials-stamped signature, or an electronic identifier

0 1 2

12. All entries in the Medical Record are dated

0 1 2

13. Is the record an Electronic Medical Record (EMR)?

0 1 2

14. relevant Government PHCs or UNRWA referral summaries are included with medical record

0 1 2

15. If consultation or diagnostic test is requested, there is a note or report from the consultant in the record

0 1 2

C. The history and physical examination

16. Family history- including the medical history of parents and/or sibling (s)

0 1 2

17. Does the physical & mental assessment for growth and development is applied at each visit?

0 1 2

18. Medical- surgical history including surgical, injuries, operations and acute or

chronic diseases/illnesses

0 1 2

19. Significant illnesses and medical condition are indicated on the special list

0 1 2

20. Medical examination and follow up done as a protocol from 0- 6 months / every 6 weeks, from 6months- 3 years/ every 3 months & more than 3 months / every 6 months follow up.

0 1 2

D. Medication record:

21. Medications are documented for each visit

0 1 2

22. A medication record/list includes dosages and dates for initial and refill prescription

0 1 2

23. Discussion of medication side effects and symptoms with caregiver and documented

0 1 2

24. The plan of action and treatment is consistent with the diagnosis

0 1 2

25. Allergies and adverse reactions are prominently noted in the record. Prominently noted in the front of the chart or inside the front cover of the chart or on a designated problem list or medication page or at the time of each office visit

0 1 2

E. Primary Hypothyroidism related characteristics

26. Does the Early Child Development (ECD) do every 3 months at first year of conformed diagnosis or every 6 months from age 1 year to 6 years?

0 1 2

27. Does the Ultrasound done to determine the place of the Thyroid gland mentioned?

0 1 2

28. Do the Anthropometric measurements are applied at each visit?

0 1 2

29. Does the lab investigation result such as (T4, TSH) mentioned?

0 1 2

30. Does the follow up Levothyroxine level in the blood?

0 1 2

31. Does the nursing note record complete at each visit?

0 1 2

32. Does the medication for these cases available all the time?

0	1	2

33. Does the lab investigation equipment is available all the time for these cases?

0	1	2

Annex (9) Key informant's interview

In-depth interview questionnaire with key informants

1. Since Al-Rimal Clinic is the only primary care center that provides special services for children with hypothyroidism, which leads to some families suffer from the possibility of receiving the service due to the geographical distance and economic conditions.

- Is there a future plan to provide these services in other centers within the primary care centers according to geographical distribution and when?
- What are the solutions offered to solve the problem of the possibility of receiving services due to the geographical distance?
- Are laboratory tests available all the time, and what is the alternative if they are not available?
- Are medicines available all the time, are they free, and what is the alternative if they are not available?

2. Many children's caregivers suffer from the lack of ultrasound device to diagnose children with hypothyroidism.

- What is the reason for the unavailability of this device, and what is the alternative?
- Are children referral to other government institutions to make this test, or is it done at their personal expense?
- Is there a future plan to provide this device inside the center?

3. All government and UNRWA clinics have screening program to discover diseases that affect newborns.

- Is this program available in all clinics, and are the staff trained on how to properly perform the screening?
- When are the investigation samples tested in the laboratory, and how are the parents informed of the test result if it is positive?
- What are the steps to be taken if the test result is positive?
- Is there a policy or protocol in the clinic that explains the method of screening of diseases, and is it updated?

4. Are there policies or protocols for dealing with children with hypothyroidism that service providers are committed to, and are service providers trained on them, and are they updated periodically?

5. The Al Remal clinic has been providing early child development (ECD) services for several years.

- How did these services affect the children's physical and psychological health?
- Is there a program for psychological support for these children, and how is it determined if the child needs psychological support?
- Children who are discovered to have problems in growth and development, how are they followed up?

6. What kind of training do service providers receive, whether inside or outside government institutions?

7. How is patient information stored (paper or electronic), is there an integrated computerized system that is being used, and is there privacy and confidentiality in this information? please clarify

8. From your point of view, what are the services that are required but not available, and what are the obstacles that may affect the continuity of service provision for this group of children?

9. What are your suggestions for developing and improving the services provided to children with hypothyroidism?

Do you have any additions.....? Thank you for your cooperation

Note: Questions are directed according to the service provider being interviewed, whether (doctor - nurse - laboratory specialist - pharmacist)

Annex (10) Scheffe test for differences between domains and Governorates

Multiple Comparisons				
LSD				
Dependent Variable	(I) Residency Governorate	(J) Residency Governorate	Mean Difference (I-J)	Sig.
Section8_Total	Rafah	Khanyounis	.60635	.878
		Deir Al-Balah	-3.64646	.362
		Gaza	-14.18608	.000
		Gaza North Governorates	-.31313	.938
	Khanyounis	Rafah	-.60635	.878
		Deir Al-Balah	-4.25281	.200
		Gaza	-14.79243	.000
		Gaza North Governorates	-.91948	.781
	Deir Al-Balah	Rafah	3.64646	.362
		Khanyounis	4.25281	.200
		Gaza	-10.53961	.000
		Gaza North Governorates	3.33333	.322
	Gaza	Rafah	14.18608	.000
		Khanyounis	14.79243	.000
		Deir Al-Balah	10.53961	.000
		Gaza North Governorates	13.87295	.000
	Gaza North Governorates	Rafah	.31313	.938
		Khanyounis	.91948	.781
		Deir Al-Balah	-3.33333	.322
		Gaza	-13.87295	.000
Section9_total	Rafah	Khanyounis	1.14626	.565
		Deir Al-Balah	-.91991	.647
		Gaza	-3.01061	.093
		Gaza North Governorates	-.07576	.970
	Khanyounis	Rafah	-1.14626	.565

		Deir Al-Balah	-2.06617	.216
		Gaza	-4.15687	.003
		Gaza North Governorates	-1.22202	.463
	Deir Al-Balah	Rafah	.91991	.647
		Khanyounis	2.06617	.216
		Gaza	-2.09070	.140
		Gaza North Governorates	.84416	.617
	Gaza	Rafah	3.01061	.093
		Khanyounis	4.15687	.003
		Deir Al-Balah	2.09070	.140
		Gaza North Governorates	2.93486	.039
	Gaza North Governorates	Rafah	.07576	.970
		Khanyounis	1.22202	.463
		Deir Al-Balah	-.84416	.617
		Gaza	-2.93486	.039

Annex (11) Scheffe test for differences between KIDSCREEN domains and education attainment level

Multiple Comparisons				
LSD				
Dependent Variable	(I) Educational attainment level	(J) Educational attainment level	Mean Difference (I-J)	Sig.
Physical_Activity	Low	Moderate	-12.03345*	.001
		High	-29.33333*	.000
	Moderate	Low	12.03345*	.001
		High	-17.29988*	.000
	High	Low	29.33333*	.000
		Moderate	17.29988*	.000
Feelings	Low	Moderate	-11.58503*	.003
		High	-30.24691*	.000
	Moderate	Low	11.58503*	.003
		High	-18.66189*	.000
	High	Low	30.24691*	.000
		Moderate	18.66189*	.000
General_Mood	Low	Moderate	18.89742*	.000
		High	29.31217*	.000
	Moderate	Low	-18.89742*	.000
		High	10.41475*	.023
	High	Low	-29.31217*	.000
		Moderate	-10.41475*	.023
Youself	Low	Moderate	1.51971	.430
		High	3.70370	.065
	Moderate	Low	-1.51971	.430
		High	2.18399	.257
	High	Low	-3.70370	.065
		Moderate	-2.18399	.257
Free_Time	Low	Moderate	-11.62724*	.000
		High	-24.74074*	.000
	Moderate	Low	11.62724*	.000
		High	-13.11350*	.000
	High	Low	24.74074*	.000
		Moderate	13.11350*	.000
Family_home_life	Low	Moderate	-13.29351*	.000
		High	-26.04938*	.000
	Moderate	Low	13.29351*	.000
		High	-12.75587*	.000
	High	Low	26.04938*	.000

		Moderate	12.75587*	.000
Money_matters	Low	Moderate	-6.32417	.155
		High	-17.28395*	.000
	Moderate	Low	6.32417	.155
		High	-10.95978*	.015
	High	Low	17.28395*	.000
		Moderate	10.95978*	.015
Friends	Low	Moderate	-9.32696*	.015
		High	-20.86420*	.000
	Moderate	Low	9.32696*	.015
		High	-11.53724*	.003
	High	Low	20.86420*	.000
		Moderate	11.53724*	.003
School	Low	Moderate	-25.36041*	.000
		High	-46.29630*	.000
	Moderate	Low	25.36041*	.000
		High	-20.93588*	.000
	High	Low	46.29630*	.000
		Moderate	20.93588*	.000
Bullying	Low	Moderate	-.90800	.809
		High	6.66667	.089
	Moderate	Low	.90800	.809
		High	7.57467*	.046
	High	Low	-6.66667	.089
		Moderate	-7.57467*	.046
KidScreen_total	Low	Moderate	-6.87529*	.000
		High	-15.75499*	.000
	Moderate	Low	6.87529*	.000
		High	-8.87970*	.000
	High	Low	15.75499*	.000
		Moderate	8.87970*	.000

*. The mean difference is significant at the 0.05 level.

Annex (12) Scheffe test for differences between KIDSCREEN domains and father education level

Multiple Comparisons				
LSD				
Dependent Variable	(I) Father education level	(J) Father education level	Mean Difference (I-J)	Sig.
Physical_Activity	Primary School	preparatory School	4.50667	.542
		Secondary School	-8.07018	.259
		University	-22.00000	.058
		Post Graduate	-17.79487*	.029
	preparatory School	Primary School	-4.50667	.542
		Secondary School	-12.57684*	.003
		University	-26.50667*	.009
		Post Graduate	-22.30154*	.000
	Secondary School	Primary School	8.07018	.259
		preparatory School	12.57684*	.003
		University	-13.92982	.155
		Post Graduate	-9.72470	.065
	University	Primary School	22.00000	.058
		preparatory School	26.50667*	.009
		Secondary School	13.92982	.155
		Post Graduate	4.20513	.686
	Post Graduate	Primary School	17.79487*	.029
		preparatory School	22.30154*	.000
		Secondary School	9.72470	.065
		University	-4.20513	.686
Feelings	Primary School	preparatory School	-5.37778	.515
		Secondary School	-12.16374	.130
		University	-23.33333	.072
		Post Graduate	-20.59829*	.024
	preparatory School	Primary School	5.37778	.515
		Secondary School	-6.78596	.149
		University	-17.95556	.108
		Post Graduate	-15.22051*	.016
	Secondary School	Primary School	12.16374	.130
		preparatory School	6.78596	.149
		University	-11.16959	.307
		Post Graduate	-8.43455	.151
	University	Primary School	23.33333	.072
		preparatory School	17.95556	.108
		Secondary School	11.16959	.307

		Post Graduate	2.73504	.814
	Post Graduate	Primary School	20.59829*	.024
		preparatory School	15.22051*	.016
		Secondary School	8.43455	.151
		University	-2.73504	.814
General_Mood	Primary School	preparatory School	5.39048	.549
		Secondary School	15.28822	.081
		University	23.33333	.098
		Post Graduate	25.09158*	.012
	preparatory School	Primary School	-5.39048	.549
		Secondary School	9.89774	.055
		University	17.94286	.140
		Post Graduate	19.70110*	.005
	Secondary School	Primary School	-15.28822	.081
		preparatory School	-9.89774	.055
		University	8.04511	.498
		Post Graduate	9.80335	.126
	University	Primary School	-23.33333	.098
		preparatory School	-17.94286	.140
		Secondary School	-8.04511	.498
		Post Graduate	1.75824	.890
	Post Graduate	Primary School	-25.09158*	.012
		preparatory School	-19.70110*	.005
		Secondary School	-9.80335	.126
		University	-1.75824	.890
Youself	Primary School	preparatory School	2.85333	.397
		Secondary School	3.12281	.338
		University	3.33333	.525
		Post Graduate	6.10256	.098
	preparatory School	Primary School	-2.85333	.397
		Secondary School	.26947	.888
		University	.48000	.915
		Post Graduate	3.24923	.201
	Secondary School	Primary School	-3.12281	.338
		preparatory School	-.26947	.888
		University	.21053	.962
		Post Graduate	2.97976	.212
	University	Primary School	-3.33333	.525
		preparatory School	-.48000	.915
		Secondary School	-.21053	.962
		Post Graduate	2.76923	.560

	Post Graduate	Primary School	-6.10256	.098
		preparatory School	-3.24923	.201
		Secondary School	-2.97976	.212
		University	-2.76923	.560
Free_Time	Primary School	preparatory School	10.10667	.133
		Secondary School	2.56140	.691
		University	-6.00000	.564
		Post Graduate	-1.48718	.837
	preparatory School	Primary School	-10.10667	.133
		Secondary School	-7.54526*	.049
		University	-16.10667	.075
		Post Graduate	-11.59385*	.023
	Secondary School	Primary School	-2.56140	.691
		preparatory School	7.54526*	.049
		University	-8.56140	.332
		Post Graduate	-4.04858	.392
	University	Primary School	6.00000	.564
		preparatory School	16.10667	.075
		Secondary School	8.56140	.332
		Post Graduate	4.51282	.631
	Post Graduate	Primary School	1.48718	.837
		preparatory School	11.59385*	.023
		Secondary School	4.04858	.392
		University	-4.51282	.631
Family_home_life	Primary School	preparatory School	6.73333	.341
		Secondary School	.08772	.990
		University	-15.00000	.174
		Post Graduate	-10.38462	.178
	preparatory School	Primary School	-6.73333	.341
		Secondary School	-6.64561	.099
		University	-21.73333*	.024
		Post Graduate	-17.11795*	.002
	Secondary School	Primary School	-.08772	.990
		preparatory School	6.64561	.099
		University	-15.08772	.108
		Post Graduate	-10.47233*	.038
	University	Primary School	15.00000	.174
		preparatory School	21.73333*	.024
		Secondary School	15.08772	.108
		Post Graduate	4.61538	.643
	Post Graduate	Primary School	10.38462	.178

		preparatory School	17.11795*	.002
		Secondary School	10.47233*	.038
		University	-4.61538	.643
Money_matters	Primary School	preparatory School	-15.06667	.055
		Secondary School	-20.52632*	.008
		University	-32.22222*	.009
		Post Graduate	-26.41026*	.002
	preparatory School	Primary School	15.06667	.055
		Secondary School	-5.45965	.217
		University	-17.15556	.104
		Post Graduate	-11.34359	.055
	Secondary School	Primary School	20.52632*	.008
		preparatory School	5.45965	.217
		University	-11.69591	.256
		Post Graduate	-5.88394	.286
	University	Primary School	32.22222*	.009
		preparatory School	17.15556	.104
		Secondary School	11.69591	.256
		Post Graduate	5.81197	.596
	Post Graduate	Primary School	26.41026*	.002
		preparatory School	11.34359	.055
		Secondary School	5.88394	.286
		University	-5.81197	.596
Friends	Primary School	preparatory School	-11.86667	.097
		Secondary School	-17.89474*	.011
		University	-27.77778*	.014
		Post Graduate	-23.58974*	.003
	preparatory School	Primary School	11.86667	.097
		Secondary School	-6.02807	.136
		University	-15.91111	.098
		Post Graduate	-11.72308*	.030
	Secondary School	Primary School	17.89474*	.011
		preparatory School	6.02807	.136
		University	-9.88304	.293
		Post Graduate	-5.69501	.258
	University	Primary School	27.77778*	.014
		preparatory School	15.91111	.098
		Secondary School	9.88304	.293
		Post Graduate	4.18803	.675
	Post Graduate	Primary School	23.58974*	.003
		preparatory School	11.72308*	.030

		Secondary School	5.69501	.258
		University	-4.18803	.675
School	Primary School	preparatory School	13.73333	.194
		Secondary School	7.36842	.469
		University	-13.33333	.416
		Post Graduate	-6.15385	.590
	preparatory School	Primary School	-13.73333	.194
		Secondary School	-6.36491	.287
		University	-27.06667	.058
		Post Graduate	-19.88718*	.014
	Secondary School	Primary School	-7.36842	.469
		preparatory School	6.36491	.287
		University	-20.70175	.138
		Post Graduate	-13.52227	.072
	University	Primary School	13.33333	.416
		preparatory School	27.06667	.058
		Secondary School	20.70175	.138
		Post Graduate	7.17949	.628
	Post Graduate	Primary School	6.15385	.590
		preparatory School	19.88718*	.014
		Secondary School	13.52227	.072
		University	-7.17949	.628
Bullying	Primary School	preparatory School	13.06667*	.048
		Secondary School	12.10526	.058
		University	20.00000	.051
		Post Graduate	14.35897*	.045
	preparatory School	Primary School	-13.06667*	.048
		Secondary School	-.96140	.795
		University	6.93333	.430
		Post Graduate	1.29231	.792
	Secondary School	Primary School	-12.10526	.058
		preparatory School	.96140	.795
		University	7.89474	.360
		Post Graduate	2.25371	.625
	University	Primary School	-20.00000	.051
		preparatory School	-6.93333	.430
		Secondary School	-7.89474	.360
		Post Graduate	-5.64103	.540
	Post Graduate	Primary School	-14.35897*	.045
		preparatory School	-1.29231	.792
		Secondary School	-2.25371	.625

		University	5.64103	.540
KidScreen_total	Primary School	preparatory School	2.66154	.462
		Secondary School	-1.26518	.717
		University	-9.10256	.108
		Post Graduate	-5.59172	.156
	preparatory School	Primary School	-2.66154	.462
		Secondary School	-3.92672	.058
		University	-11.76410*	.017
		Post Graduate	-8.25325*	.003
	Secondary School	Primary School	1.26518	.717
		preparatory School	3.92672	.058
		University	-7.83738	.103
		Post Graduate	-4.32653	.093
	University	Primary School	9.10256	.108
		preparatory School	11.76410*	.017
		Secondary School	7.83738	.103
		Post Graduate	3.51085	.491
	Post Graduate	Primary School	5.59172	.156
		preparatory School	8.25325*	.003
		Secondary School	4.32653	.093
		University	-3.51085	.491

*. The mean difference is significant at the 0.05 level.

Annex (13) Scheffe test for differences between KIDSCREEN domains and Mother education level

Multiple Comparisons				
LSD				
Dependent Variable	(I) Mother education level	(J) Mother education level	Mean Difference (I-J)	Sig.
Physical_Activity	preparatory School	Secondary School	-1.28620	.761
		University	-18.07407	.089
		Post Graduate	-14.55892*	.021
	Secondary School	preparatory School	1.28620	.761
		University	-16.78788	.107
		Post Graduate	-13.27273*	.025
	University	preparatory School	18.07407	.089
		Secondary School	16.78788	.107
		Post Graduate	3.51515	.755
	Post Graduate	preparatory School	14.55892*	.021
		Secondary School	13.27273*	.025
		University	-3.51515	.755
Feelings	preparatory School	Secondary School	2.09035	.643
		University	-17.53086	.121
		Post Graduate	-9.34905	.159
	Secondary School	preparatory School	-2.09035	.643
		University	-19.62121	.078
		Post Graduate	-11.43939	.069
	University	preparatory School	17.53086	.121
		Secondary School	19.62121	.078
		Post Graduate	8.18182	.497
	Post Graduate	preparatory School	9.34905	.159
		Secondary School	11.43939	.069
		University	-8.18182	.497
General_Mood	preparatory School	Secondary School	-1.28187	.798
		University	15.44974	.218
		Post Graduate	11.64021	.116
	Secondary School	preparatory School	1.28187	.798
		University	16.73160	.174
		Post Graduate	12.92208	.065
	University	preparatory School	-15.44974	.218
		Secondary School	-16.73160	.174
		Post Graduate	-3.80952	.776
	Post Graduate	preparatory School	-11.64021	.116
		Secondary School	-12.92208	.065

		University	3.80952	.776
Youself	preparatory School	Secondary School	-2.84512	.115
		University	-4.14815	.353
		Post Graduate	.70034	.789
	Secondary School	preparatory School	2.84512	.115
		University	-1.30303	.766
		Post Graduate	3.54545	.153
	University	preparatory School	4.14815	.353
		Secondary School	1.30303	.766
		Post Graduate	4.84848	.311
	Post Graduate	preparatory School	-.70034	.789
		Secondary School	-3.54545	.153
		University	-4.84848	.311
Free_Time	preparatory School	Secondary School	-4.11111	.257
		University	-11.11111	.219
		Post Graduate	-12.20202*	.023
	Secondary School	preparatory School	4.11111	.257
		University	-7.00000	.428
		Post Graduate	-8.09091	.107
	University	preparatory School	11.11111	.219
		Secondary School	7.00000	.428
		Post Graduate	-1.09091	.910
	Post Graduate	preparatory School	12.20202*	.023
		Secondary School	8.09091	.107
		University	1.09091	.910
Family_home_life	preparatory School	Secondary School	.15993	.967
		University	-20.37037*	.036
		Post Graduate	-11.58249*	.043
	Secondary School	preparatory School	-.15993	.967
		University	-20.53030*	.032
		Post Graduate	-11.74242*	.030
	University	preparatory School	20.37037*	.036
		Secondary School	20.53030*	.032
		Post Graduate	8.78788	.393
	Post Graduate	preparatory School	11.58249*	.043
		Secondary School	11.74242*	.030
		University	-8.78788	.393
Money_matters	preparatory School	Secondary School	-4.47811	.291
		University	-27.40741*	.011
		Post Graduate	-13.87205*	.027
	Secondary School	preparatory School	4.47811	.291

		University	-22.92929*	.029
		Post Graduate	-9.39394	.110
	University	preparatory School	27.40741*	.011
		Secondary School	22.92929*	.029
		Post Graduate	13.53535	.232
	Post Graduate	preparatory School	13.87205*	.027
		Secondary School	9.39394	.110
		University	-13.53535	.232
Friends	preparatory School	Secondary School	-3.36420	.398
		University	-18.64198	.062
		Post Graduate	-9.34905	.110
	Secondary School	preparatory School	3.36420	.398
		University	-15.27778	.118
		Post Graduate	-5.98485	.276
	University	preparatory School	18.64198	.062
		Secondary School	15.27778	.118
		Post Graduate	9.29293	.381
	Post Graduate	preparatory School	9.34905	.110
		Secondary School	5.98485	.276
		University	-9.29293	.381
School	preparatory School	Secondary School	-1.16442	.835
		University	-34.32099*	.015
		Post Graduate	-16.54321*	.046
	Secondary School	preparatory School	1.16442	.835
		University	-33.15657*	.017
		Post Graduate	-15.37879*	.049
	University	preparatory School	34.32099*	.015
		Secondary School	33.15657*	.017
		Post Graduate	17.77778	.234
	Post Graduate	preparatory School	16.54321*	.046
		Secondary School	15.37879*	.049
		University	-17.77778	.234
Bullying	preparatory School	Secondary School	-6.21773	.080
		University	.24691	.978
		Post Graduate	.44893	.930
	Secondary School	preparatory School	6.21773	.080
		University	6.46465	.452
		Post Graduate	6.66667	.172
	University	preparatory School	-.24691	.978
		Secondary School	-6.46465	.452
		Post Graduate	.20202	.983

	Post Graduate	preparatory School	-.44893	.930
		Secondary School	-6.66667	.172
		University	-.20202	.983
KidScreen_total	preparatory School	Secondary School	-1.84505	.343
		University	-13.17664*	.008
		Post Graduate	-7.11603*	.014
	Secondary School	preparatory School	1.84505	.343
		University	-11.33159*	.019
		Post Graduate	-5.27098	.051
	University	preparatory School	13.17664*	.008
		Secondary School	11.33159*	.019
		Post Graduate	6.06061	.243
	Post Graduate	preparatory School	7.11603*	.014
		Secondary School	5.27098	.051
		University	-6.06061	.243
*. The mean difference is significant at the 0.05 level.				

Abstract in Arabic

عنوان الدراسة: تقييم علاج قصور الغدة الدرقية الأولى لدى الأطفال في قطاع غزة

إعداد: هيثم محمود فؤاد منصور

إشراف: د. ختام أبو حمد

ملخص الدراسة

نظرة عامة:

يعد قصور الغدة الدرقية الأولي أحد أكثر اضطرابات الغدد الصماء خطورة التي تصيب الإنسان عند الولادة. وهو سبب رئيسي لاضطرابات النمو العقلي والجسدي.

مبررات الدراسة:

تم إجراء هذه الدراسة لتقييم عملية علاج قصور الغدة الدرقية عند الأطفال والتي تضمنت توافر الخدمات للتشخيص المبكر لحالات قصور الغدة وتوفير الأدوية الموصوفة والتحاليل المخبرية وغيرها.

أهداف الدراسة:

تهدف هذه الدراسة إلى تقييم الخدمات المقدمة للأطفال المصابين بقصور الغدة الدرقية الأولي في العيادات الحكومية في قطاع غزة والتي تضمنت تقييم الخدمات الصحية المقدمة وجودة الحياة لدى الأطفال المصابين بقصور الغدة الدرقية، وتحديد نقاط الضعف والقوة في الخدمات المقدمة، وتقييم وجهات نظر أهالي الأطفال المصابين بقصور الغدة الدرقية، واقتراح توصيات لتحسين جودة الخدمات المقدمة لهم.

منهجية الدراسة:

تصميم هذه الدراسة هو أسلوب مختلط استلزم تثليث طرق جمع البيانات الكمية والنوعية. استخدمت الدراسة الكمية ثلاث أدوات: الأداة الأولى هي استبيانات منظمة لجمع البيانات الكمية من مقدمي الرعاية للأطفال المصابين بقصور الغدة الدرقية الأولي. الأداة الثانية هي استبيان جودة الحياة، والأداة الثالثة هي استبيان نقاط القوة والصعوبات. في المجموع، تم جمع البيانات الكمية من 202 من مقدمي الرعاية. استخدمت الدراسة النوعية أداتين، الأولى هي المقابلات المتعمقة والأداة الثانية هي ورقة التجريد التي تم تطويرها لجمع البيانات من السجلات الطبية. تضمنت البيانات النوعية مقابلات متعمقة مع 10 مخبرين رئيسيين. تم استخدام الحزمة الإحصائية للعلوم الاجتماعية الإصدار 25 لتحليل البيانات الكمية لتحليل البيانات الكمية واستخدمت الطريقة الموضوعية للترميز المفتوح لتحليل البيانات النوعية.

أهم نتائج الدراسة:

كشفت الدراسة أن متوسط عمر الأطفال المصابين بقصور الغدة الدرقية الأولي بلغ 6.47 سنة وأن 60.4٪ منهم إناث. يعاني ما يقرب من ثلث الأطفال من تأخر في التشخيص، قد تم تشخيصهم على عمر شهرين أو أكثر. ما يقرب ثلثي (65.3٪) الأطفال تم تشخيصهم على عمر شهر أو أقل حسب ما تم توثيقه في الملفات الطبية.

تلقى غالبية الأطفال المصابين بقصور الغدة الدرقية الأولي (88.1٪) أدوية من مراكز الرعاية الصحية الأولية الحكومية، وخاصة من عيادة الرمال، وأفاد 14.9٪ أنهم تلقوا أدوية من عيادات الأونروا. وبشكل غير متوقع، حصل 2.5٪ فقط على الدعم النفسي. بالنسبة لاستخدام الخدمة، أفاد 81.9٪ من مقدمي الرعاية المشاركين بوجود نقص في الفحوصات المخبرية و89.9٪ أفادوا بوجود نقص في بعض الأدوية في العيادات الحكومية.

أفاد مقدمو الرعاية للأطفال الذين تم تشخيص إصابتهم بقصور الغدة الدرقية الأولي أن التحديات والعوائق الرئيسية أمام الاستفادة من الخدمات تتمثل في عدم وجود نظام للمواعيد (71.8٪)؛ نقص الخدمات المتخصصة (51.5٪)؛ نقص الأدوية (48.5٪)؛ والعوائق المالية (95.3٪). بالإضافة إلى ذلك، أظهرت نتائج الدراسة أن هناك فجوات في تقديم الخدمة، بما في ذلك نقص العديد من المتخصصين، مثل أطباء أطفال وأطباء طب الأسرة والممرضات وأخصائيين نفسيين وخبراء التغذية. كشفت نتائج البيانات النوعية عن وجود بروتوكولات لإدارة قصور الغدة الدرقية الأولي، ومع ذلك، فإن هذه البروتوكولات غير محدثة وليست شاملة. البنية التحتية لقسم صحة الطفل ضمن عيادة الرمال مناسبة. وقت الانتظار في هذا القسم مناسب، ومنطقة الانتظار مريحة ومناسبة للأطفال. كان متوسط الوقت المستغرق بشكل عام لتلقي الخدمات من الدخول إلى الخروج من عيادة الرمال 12.40 دقيقة.

بلغ معدل اكتمال وثائق الملف الطبي 60.62٪. كان تفاعل وتواصل الأهالي مع مزود الخدمة بنسبة المئوية هي 76.3٪، ورضا الأهالي عن الخدمات المقدمة كانت النسبة المئوية هي 73.94٪. ومع ذلك، باستخدام استبيان نقاط القوة والصعوبات، أوضحت الدراسة أن (90.3٪) من الأطفال تم تصنيفهم على أنهم يعانون من مشاكل الأقران، وأن (58.7٪) يعانون من مشاكل نفسية. باستخدام استبيان KIDSCREEN، كشفت النتائج أن المعدل الإجمالي لدرجة رفاهية الأطفال هو 62.11٪. كان المشاركون ذوي الدخل الجيد قد سيطروا على قصور الغدة الدرقية الأولي، وكانت الفروق بينهم ذات دلالة إحصائية.

الخلاصة والتوصيات:

لتحسين جودة الخدمات المقدمة للأطفال المصابين بقصور الغدة الدرقية، من المهم تحديث البروتوكولات الوطنية لقصور الغدة الدرقية الأساسي، وضمان توافر الفحوصات المخبرية والأدوية في الوقت المناسب. من المهم أيضًا تحسين نظام المعلومات الصحية مع مراكز الرعاية الصحية الأولية لتوثيق ومتابعة الخدمات المتلقاه بشكل صحيح. أخيرًا، من المهم للغاية إعادة تنشيط خدمات تنمية الطفولة المبكرة للأطفال المصابين بقصور الغدة الدرقية الأولي، وتوسيع نطاق الخدمات المقدمة لتشمل الدعم النفسي المنهجي والدعم الغذائي.