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Evaluation of Ulcerative Colitis Management in the Gaza Strip

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Dedication

To my father’s soul, my pacemaker who taught me the means of work appreciation and humility.
To my mother, the source of endless giving,
To my brother and sister, for their continuous support and encouragement,
To the academic staff in Al-Quds University,
To every person who have a role in making this study real,

I dedicate this work for all of you
Hanaa Azmi Rasheed Makki

Declaration

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

Signed

Hanaa Azmi Rasheed Makki

Date: 21/12/2021

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Abstract

Background: *Ulcerative colitis is an inflammatory bowel disease, it has a complex nature and its prevalence is increasing globally. This study aims to evaluate services provided to persons with ulcerative colitis through governmental health care facilities in the Gaza Strip.*

Methodology: *A mixed method was used by the triangulation of quantitative and qualitative approaches. Quantitative methods was used in collecting data from all registered ulcerative colitis patients via a questionnaire which was completed by 157 patients and reviewing patients' files in the primary health care centers using a checklist (145 files). Qualitative data were collected through in-depth interviews from 10 ulcerative colitis patients or their family members and 10 key informants to probe for their perspectives about the provided health care services. The statistical Package of Social Sciences software was used for the data entry and analysis of the questionnaire, the excel program was used for the data entry and analysis of the checklist and open coding thematic analysis was used for the qualitative part.*

Results: *The study revealed that the mean age of participants was 40.9 years and that 58% of them were males. It is found that 63.7% of the study participants perceived that they were in remission phase and 36.3% of them were in relapse. Nearly one third of participants were found to have other chronic disease/s. Services provided from governmental primary health care centers are medications dispensing, laboratory tests, health education and nutritional counseling services. These services are provided also through governmental hospitals in addition to colonoscopy, emergency department and inpatient care services. Most of the study participants (77.7%) do not know if there is a psychologist or not at governmental facilities, 19.7% said that there is no such specialty and only 2.5% agreed that there is a psychologist in governmental health care facilities. The place of dispensing medications for most of the study participants was governmental primary health care centers (98.7%), followed by community pharmacies (36.3%). Of the participants surveyed, 41.4% agreed that they found their medications all the time and 44.1% found colonoscopy available in governmental hospitals all the time. The average waiting time for follow-up was long at hospitals from clients' perspectives (102.8 minutes), while it was found 11.6 minutes at primary health care centers. The average contact time with the physician in hospitals was 12.3 minutes and 5.7 minutes in primary health care centers. Nearly half (52.2%) of the participants agreed that they received health education in governmental facilities regarding ulcerative colitis. Nearly two thirds of participants (68.6%) were returned back home at least once in the past year without receiving services they came to receive. User-provider interaction mean percentage was high (85.7%) and high satisfaction was elicited from the provided services. The total health-related quality of life for the study participants was found 4.46 out of 7. Inferential statistics results revealed that there were statistically significant relationships between user-provider interaction and both gender and governorate. Females scored better user-provider interaction than males and patients from Rafah have the highest mean in user-provider interaction. Also, the study results revealed that the higher the education level, the higher the health-related quality of life. Retired patients was found to have the highest health-related quality of life, then the working people, while patients who were not working have the lowest average of health-related quality of life. Patients who do not experience flare-ups since starting to take their medications have the highest health-related quality of life mean, while those who experience them in a frequency of less than a month or irregularly have lower mean than others. Patients who had their last attack for longer periods of time have better health-related quality of life as well as those who were in remission state. Documentation completeness average score was 26.1% for patients' files in the primary health care centers, it is very low. The qualitative part results are generally consistent with the obtained quantitative data and support the need for improvement of the provided services.*

Conclusion: *The study concluded that the provided health care services regarding ulcerative colitis are still in need for more improvement especially in providing psychological support, reducing waiting time, increasing contact time, the need to increase the number of specialists such as gastroenterologist and nutritionists, enhancing coordination and cooperation between health care levels and improving documentation practices.*

Table of Contents

List of Tables

List of Figures

List of Annexes

List of Abbreviations

5-ASA	5-amino salicylic acid
6-MP	6-mercaptopurine
CCC	Crohn's and Colitis Canada website
COVID-19	Coronavirus Disease 2019
CSA	Cyclosporine
DPC	Doctor-patient communication
ECCO	The European Crohn's and Colitis Organization
EIMs	Extra-intestinal manifestations
EMR	Electronic medical record
GHQ-12	Short form general health questionnaire
GIT	Gastrointestinal tract
GP	General practitioner
GS	Gaza Strip
HIS	Health information system
HR	Human resources
HRQoL	Health-related quality of life
IBD	Inflammatory bowel disease
IgG	Immunoglobulin G
IL	Interleukin
KI	Key informants
MARS	Medication Adherence Report Scale
MDT	Multidisciplinary team
MoH	Ministry of Health
NCDs	Non-communicable diseases
NGOs	Non-governmental organizations
NIVEL	The Netherlands Institute for Health Services Research
PCBS	Palestinian Central Bureau of statistics
PEDL	Palestinian essential drug list
PHC	Primary health care
PMMS	The Palestinian Military Medical Services
QoL	Quality of life
QUOTE-IBD	Quality of Care Through the Patient's Eyes for IBD patients
SD	Standard deviation
SIBDQ	Short inflammatory bowel disease questionnaire
TNF-α	Tumor necrosis factor alpha
UC	Ulcerative colitis
UNRWA	United Nations Relief and Works Agency for Palestine Refugees in the Near East
WHO	World Health Organization

Chapter One
Introduction

1.1 Background

Ulcerative colitis (UC) is one of the main subtypes of inflammatory bowel disease (IBD) collectively with crohn's disease (Bruining, 2015). It is a chronic inflammatory condition of the large intestine that is limited to the mucosal layer of the colon. It involves the rectum mostly, and may extend in a proximal and continuous fashion to involve other portions of the colon (Cohen & Stein, 2020). UC disease includes periods of remission exchanging with periods of active disease. During exacerbation, medical therapy is directed towards remission induction (Gelber et al., 2019).

Individuals with UC are at risk of consequences ranging from nutritional deficiencies due to decreased nutrient intake, malabsorption, increased energy expenditure, and/or increased losses of proteins. The most common deficiencies are iron, vitamin D, vitamin B_{12}, and zinc (Lee, 2019). The consequences of UC may protrude to colonic epithelial dysplasia and carcinoma in the case of long-standing disease (Friedman & Blumberg, 2018). In addition to its health consequences, UC has a high economic burden represented by both direct and indirect costs (Cohen et al., 2010) as well as its psycho-social burden affecting patients' lives as well as their families lives (Becker et al., 2015). To enable patients with UC to have longer lives of a higher quality, their chronic condition should be controlled (Sachar, 2015). UC management involves medical management, controlling diet and exercise (Davis et al., 2017). People with UC also need nutritional counseling and psychological support to prevent the development of depression (Hwang & Yu, 2019). Generally, UC severity is classified as mild, moderate or severe (Cohen & Stein, 2020). Patients are turned to anti-inflammatory drugs to manage mild symptoms or to potent steroids or immune-modulators to control more severe cases. However, many people do not obtain complete remission and around 15% of them pass surgical operations to remove all or part of their colon within 20 years of their disease diagnosis (Eisenstein, 2018).

In the Gaza Strip (GS), health care services for UC patients are primarily provided through governmental primary health care (PHC) centers and hospitals distributed through the GS. According to the World Health Organization (WHO), UC patients are affected by medicine

shortages and part of them requires referrals because their medications are unavailable in the GS (WHO, 2017a).

1.2 Research problem

UC management is a crucial step that affects the progression and severity of the disease. It includes several steps beginning from UC diagnosis, follow-up, counseling about how to live with it, choosing suitable medication/s, dispensing these medications up to surgical intervention and psychological support. In the complex context of the GS that is accompanied by scarcity of resources and the resulting protracted humanitarian crisis, the status of caring for UC patients is not clear enough as well as how the provided services are being managed. This study fills the gap by focusing on the existing services which are provided for UC patients by evaluating them from the time of UC diagnosis till drug dispensing passing through follow-up and medical intervention for some cases. The study sheds the light on the existing resources (input items), the suitability of process items and the result of these variables (output/outcomes).

1.3 Justification

UC is a complex disease and it is considered as a predisposing factor for other health complications including colorectal cancer (Friedman & Blumberg, 2018). Good UC management includes appropriate service provision like the early diagnosis accompanied by the presence of appropriate tools and tests, qualified staff, patients' adherence to their prescribed medication/s and introducing an appropriate diet for each patient according to his/her individualized case. This study is carried out to explore these variables. The study tries to identify areas of weakness to concentrate on them and address them, areas of strengths to sustain them and introduce continuous improvements on them. This study also tries to identify areas where opportunities exists to try achieving them and to search for areas of threats to be aware and avoid them, this will be reflected on outputs like improving the provided services what will be reflected in turn on health outcomes of UC patients as stabilization of the patient's case, preventing health consequences, enhance their satisfaction and improving their quality of life (QoL).

The study is beneficial to the researcher herself as UC is a field of her interest; the study helps in deepening her knowledge about this subject and helps her in her work as a pharmacist while dealing with UC patients. The study findings will be disseminated and

will participate in enriching the body of knowledge. The study will provide a reference in this area which is neglected to some extent at the same time that UC patients have a lot of suffering due to their disease and they need more care and attention. Moreover, the study will be beneficial for researchers who are interested in this field and will help them in conducting further research. This study sheds the light on the requirements of UC patients what will be beneficial for the interested organizations. The study findings are expected to be of benefit also for PHC centers' health staff and technical people who work in hospitals like internists, gastroenterologists and nurses, it will help them to realize the current status of the provided services and will help them in identifying areas that need more improvement. Also, this study will help policy makers to specify areas of prioritization in this regard and help them in implementing future plans that would be beneficial in improving the quality of the provided services to UC patients.

1.4 Aim of the study

The study aims to assess the UC management in the GS in order to provide policy makers with evidence-based information and recommendations that may contribute in boosting the UC patients' health and decrease mortality and morbidity among them.

1.5 Objectives of the study

- To assess the provided services for UC patients using Donabedian's model including structure (input), process and output/outcomes components.
- To identify areas of strength, weakness, threats and opportunities of the provided services in the context of the GS.
- To explore the perspectives of both clients and working staff concerning the provided services.
- To explore variations in patients’ perspectives and experience in reference to their characteristics and disease related variables.
- To suggest recommendations that may be helpful in improving services provided to UC patients what will lead to the enhancement of their health status.

1.6 Research questions

1. What is the status of the provided services to UC patients in the GS?
2. To what extent do the inputs of the provided services are adequate and suitable?
3. To what extent do the processes of the provided services are suitable?
4. To what extent do the provided services are sustainable?
5. To what extent do the outputs/outcomes meet the needed requirements?
6. What are the areas of strengths and weaknesses of the services provided?
7. What are the likely threats and opportunities concerning the provided services?
8. What are the perspectives of clients concerning the available services?
9. What are the perspectives of service providers regarding the available services?
10. What is the effect of patients' characteristics on their perspectives concerning the provided services?
11. What is the effect of disease related variables on patients' perspectives concerning the provided services?
12. What recommendations are suggested from this research?

1.7 Context of the study

1.7.1 Demographic context

The GS has a total area of about 365 km^2. It consists of 5 Governorates: North Gaza, Gaza, Deir Al Balah, Khan Yunis and Rafah according to the Palestinian Central Bureau of statistics (PCBS, 2018a). The last census which was performed in December 2017 indicates that the GS total population is 1,899,291 persons contributing in 40% of Palestine population (PCBS, 2018a). The GS is an area with a very high population density of about 5,203 inhabitants per Km^2 (PCBS, 2018b), with an average annual growth rate of 3.0% (PCBS, 2020). Regarding age structure in the GS, 48% of its population are under 18 years old and only 4.3% of the total population are aged 60 years and older, so the local society is still young (PCBS, 2019a). The classification of localities indicates that there are no rural areas in the GS; it only contains urban areas and camps. Inhabitants' distribution represents that 1,624,782 persons live in urban areas and 250,535 persons live in refugee camps representing 86.6% and 13.4% of the total population living in the GS respectively (PCBS, 2019b). In the GS, 1,239,112 persons are registered as refugees indicating 66.2% from the total population (PCBS, 2019a).

1.7.2 Socio-economic context

The long-standing blockade in the GS affects the socioeconomic context deeply and resulted in a protracted humanitarian crisis and a fragile context. The existing stuffy blockade applied on Gaza puts several restrictions on both importing and exporting processes and led to the reduction of fishing area from six to three nautical miles from Gaza's coast. Restrictions also are extended to import including food, medicine entry, fuel, cooking gas and a long list of other goods which is prevented from its normal flow. In the same time, living conditions in the GS continue to deteriorate as a result of the severe shortage of electricity and intermittent outbreaks of hostilities due to the recurrent escalations combined with the absence of investment and the vulnerability of the population. All these factors react together leading to negative impacts affecting all aspects of civilian life, particularly women and children (OCHA, 2018, 2019).

Nearly half of the population in the GS live below the poverty line ($5.50 per day or less) and 62% of the households are estimated to live lacking food security (OCHA, 2019). The highest unemployment rate in Palestine exists in the GS (PCBS, 2019c), the unemployment rate in the GS is 52% (43.5% for males compared with 74.5% for females) and the unemployment rate among youth aged between 15-24 years was 71.8% (65.3% for males compared to 92.2% for females) (PCBS, 2019b). The highest rate of unemployment exists in Rafah governorate (58.3%), followed by Khan Yunis with 53.3%, then Deir al Balah with 51.6%, North Gaza 44.6% and the lowest exists in Gaza with 42.7% (PCBS, 2018a). Regarding illiteracy rates, it is noticed that the GS rate is like that in Jerusalem, have the lowest illiteracy rate in Palestine of about 2.0% (PCBS, 2018a). The latest census 2017 showed that the total number of illiterates in the GS aged 15 years and over was 32,714, it was more prevalent among females than males; as 9,509 males were found illiterate versus 23,205 females (PCSB, 2019a).

1.7.3 Health status

The health sector in the GS faces the three burdens of disease (communicable diseases, NCD's and the burden of injuries) added to that the deteriorated political, security, and economic situations, all these factors are conjugated together leading to multiple challenges affecting service delivery, health outcomes and detaining the efficient planning and health sector management (World Bank, 2016). According to the same source, Palestinian people in the GS as well as in West Bank are experiencing an epidemiological transition from communicable diseases into non-communicable diseases (NCDs). In the

same time that the burden of NCDs is rising, injuries and health consequences resulted from the occupation and recurrent conflicts are also increasing (WHO, 2017b). Regarding the leading causes of death in the GS in 2020, it is reported by the Ministry of Health (MoH) that heart diseases have the highest percent; they were responsible for 49.3% of deaths, after that cancer (9.4%), then cerebrovascular diseases with the percent of 6.1%, COVID-19 was the following leading cause of death in 5.2% of cases, followed by respiratory diseases (4.8%), renal failure (4.5%), conditions in the perinatal period (3.9%), hypertension (3.5%), infectious diseases (3.1%), congenital anomalies (2.3%), accidents (1.6%), Diabetes mellitus (1.5%), cerebral plasy (1.2%), liver diseases (1.1%) and other minor causes representing 3.7% (MoH, 2021a).

The health care system in the GS suffers from severe shortage of essential spare parts for sophisticated equipment. This leads to a greater need for patients' referral outside the GS. According to the maintenance department of health authority in the GS, the main reasons for this shortage are insufficient allocated budget and the current siege imposed on the GS (WHO, 2016a). As a part of the Palestinian health system, health care services in the GS are delivered by a complex network of service providers. These providers are: The MoH and the Palestinian Military Medical Services (PMMS), together considered as public healthcare facilities and they are considered as the main service providers, United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA), non-governmental organizations (NGOs) and the private sector (World Bank, 2016).

Ministry of health facilities

The MoH has 51 PHC centers and 13 hospitals in the GS. MoH facilities provide 2,240 beds (from total 2,943beds in the GS) representing 76% of bed capacity in the GS (MoH, 2019). The MoH is the governing body of all functions of the health system including financing, coordination, licensing, regulation and service provision (WHO, 2019). The referral system was created due to the unavailability of particular medical staff specialties, treatments, medications, equipment and infrastructure within the public system, so a large number of patients are referred to not-for-profit or commercial providers to obtain tertiary care. The access to referral medical centers in Jerusalem, West Bank or the Israeli medical centers is only possible after obtaining a permit from the Israeli authorities, which is a complex process that can result in delays and denial of care (WHO, 2017b).

The Palestinian Military Medical Services facilities

PMMS facilities provide mainly PHC services through 5 health care centers, they provide also secondary and tertiary health care services in 2 hospitals. The PMMS provides 177 beds representing 6% of bed capacity in the GS (MoH, 2019).

United Nations Relief and Works Agency for Palestine Reugees in the Near East

UNRWA plays a critical role in providing PHC services through its 22 clinics distributing across the GS (MoH, 2019). The provided services through these clinics include outpatient care, NCDs, communicable diseases, maternal care including contraceptive care, antenatal care, safer delivery care with referrals and subsidies for hospital delivery, post-natal care and child health care including infant and child care (0-5 years old), immunization, growth monitoring and school health. UNRWA clinics also provide the services of oral health, physical rehabilitation, disability care and radiology (UNRWA, 2019).

Non-governmental organizations

In the GS, there are 80 PHC centers and 16 hospitals operated by NGOs, these hospitals provide 526 beds representing 22% of the total beds in the GS (MoH, 2019). NGOs play an important role in service delivery (World Bank, 2016), they provide PHC services, maternal health services, rehabilitation and specialized care in referral hospitals. They are a mixture of traditional charities, Islamic charitable committees, Christian charities and non-profit organizations and they are supported mainly by the Palestinian diaspora (WHO, 2017b).

1.8 Operational definitions

Ulcerative colitis patient

Is a patient who was diagnosed with UC disease and receives health care services related to the disease from governmental PHC centers or hospitals.

Satisfaction

Satisfaction is calculated in this study using the performance part of the Quality of Care Through the Patient's Eyes for IBD patients (QUOTE-IBD) questionnaire. Patients answers are scored by putting the value 1 for each "no" and "not really" answers and

putting the value 0 for the answers “on the whole, yes” and “yes”, then the mean of each domain is calculated. Average performance scores range from 0 which represents the best performance to 1 that represents the worst performance (Van der Eijk et al., 2001).

Health-related quality of life (HRQoL)

It is defined by the Centers for Disease Control and Prevention (CDC) in 2000 as “an individual’s or a group’s perceived physical and mental health over time”. To measure it, the 4 domains’ short inflammatory bowel disease questionnaire (SIBDQ) is used. Each question is rated from 7 and the average for each domain is calculated by adding its items’ responses divided by their number. The mean of total dimensions is the sum of responses for all the 10 questions dividing the result by 10. The resultant value ranges from 1 to 7. The higher the score, the higher the HRQoL with less IBD’s impact (Irvine et al., 1996).

Chapter Two

Conceptual framework and literature review

2.1 Conceptual framework

In this study, Donabedian's model is used as a framework to evaluate the provided health care services for UC patients in the GS. These services are evaluated in terms of the three Donabedian's model components including input (structure), process and output/outcome. This evaluation is carried out in order to explore the effectiveness of the provided services and to explore if they attain the desired needs of both patients and the working staff. Each component of the Donabedian's model is analyzed into its sub-components to be evaluated within the GS context.

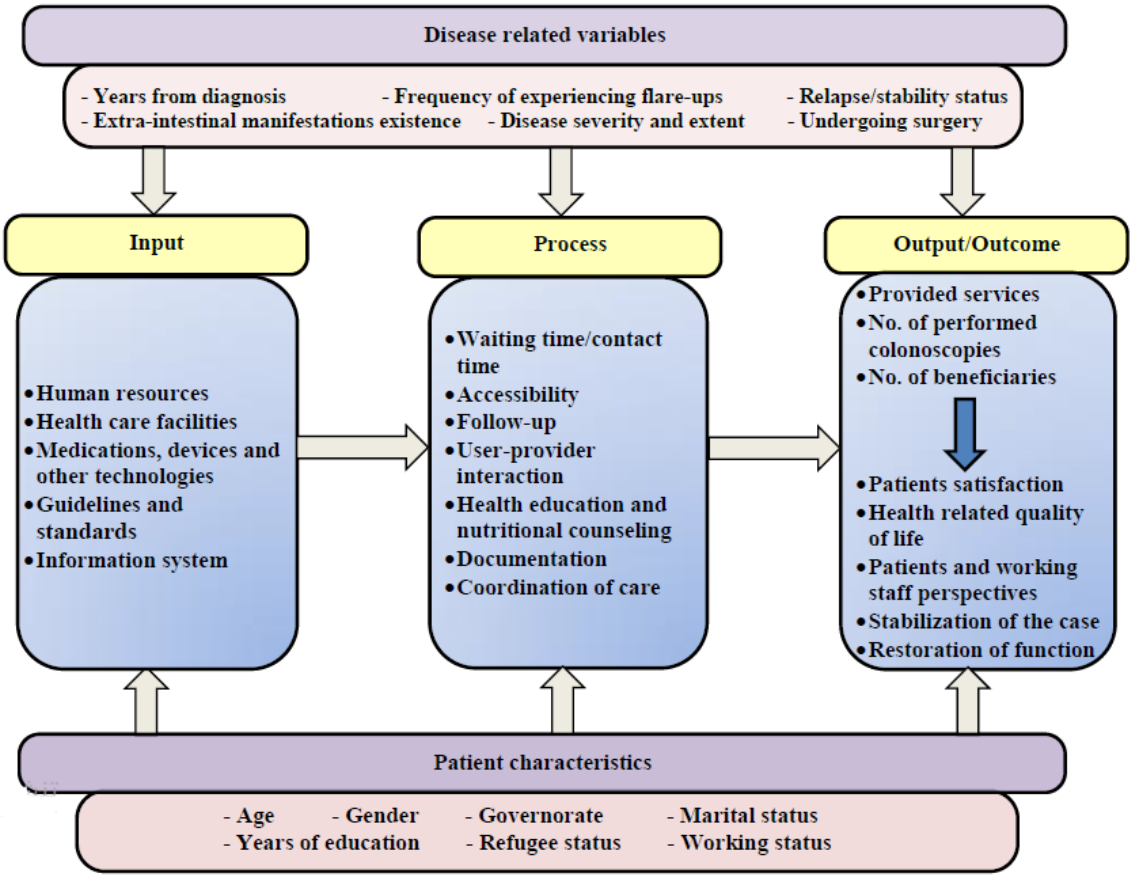

Figure (2.1) The conceptual framework

2.1.1 Input (structure)

According to Donabedian, the structure is the settings in which the process takes place and the instrumentalities of which the process is the product and it is expected that the proper settings and instrumentalities, the good medical care that can be followed. The structure domain includes the adequacy of qualified medical staff, equipment, facilities, medications (Milbank Memorial Fund, 2005)**.** Input domain contains the items human resources (HR), medications, materials, equipment, medical facilities, policies and protocols and information system. Inputs have influence on both process and output domains.

2.1.1.1 Human resources

The study explores the availability of adequate numbers of qualified HR who deal with UC patients as well as their suitable distribution. Health care staff personnel who are needed to deal with UC patients include gastroenterologists, pharmacists, nutritionists, nurses, surgeons and psychosocial specialists. The availability/unavailability status of those HR may affect process items like waiting and contact times and output/outcomes like stabilization of case, satisfaction and QoL.

2.1.1.2 Health care facilities/physical conditions

This research examines the existence of suitable places for the provision of services regarding UC patients, facilities should contain areas for diagnosis, treatment, counseling and medication dispensing.

2.1.1.3 Medications, devices and other technologies

The research identifies the degree to which UC medications are available in both the variety in types and adequacy in quantities. The study identifies the number of colonoscopy devices that are present and whether their number meet the current needs or not as well as the existence of needed laboratory (lab) tests. The availability of these components may affect process items as waiting time for colonoscopy and may affect outputs/outcomes as well. These outputs like number of beneficiaries from medications dispensing, beneficiaries from colonoscopy performance and lab tests performance. Outcomes that may be affected by the availability of these inputs are health improvement/restoration of function, patients' perspectives about the provided services, patient satisfaction and QoL.

2.1.1.4 Guidelines and standards

The study assesses the presence of suitable policies and guidelines that determine proper way of health care provision for UC patients and enhance its application. Guidelines availability as an input may affect the process domain, it may define for example the form of coordination between different levels, also, standards availability for the way of dealing with patients may affect outputs/outcomes.

2.1.1.5 Information system

The study explores the existence of efficient health information system (HIS) and investigates its characteristics from the perspectives of health care staff. It may have an influence on processes like documentation and it affects outputs/outcomes.

2.1.2 Process

Process domain includes waiting time, contact time, accessibility, follow-up, user-provider interaction, health education, documentation and coordination subdomains. Process items are affected by input domain and affects output/outcome domain.

2.1.2.1 Waiting and contact time

The study determines the suitability of waiting and contact times in governmental facilities. It is determined from both patients and health care staff point of view. The study focuses on the waiting time of follow-up, lab tests performance, colonoscopy performance and medications dispensing from governmental facilities pharmacies. Contact time with doctor is identified also. Waiting and contact times may affect outputs like the number of beneficiaries from the provided services in governmental facilities like beneficiaries from follow-up visits and colonoscopy performance and it may affect outcomes like patients' satisfaction and QoL.

2.1.2.2 Accessibility

Accessibility includes the ease of patients to reach governmental health facilities and the of patient's flow through treatment journey. Accessibility is explored through the steps from diagnosis to drug dispensing whether they are smooth or having obstacles. Accessibility is affected by the availability of inputs like medications and colonoscopy devices and it may affect outputs/outcomes like number of beneficiaries and health outcomes.

2.1.2.3 Follow-up

Follow-up is a very important step in controlling the progression of UC. Periodic follow-up visits help to notice any discomfort, complications or health hazards facing the UC patient. Adherence of patients to regular follow-ups is explored. Follow-up may be affected by the presence of adequate HR and may impact outputs/outcomes.

2.1.2.4 User-provider interaction

The research investigates the presence of suitable user-provider interaction, this includes careful listening to UC patients' questions and complaints, giving patients the needed information in understandable language and replying to all their concerns. Moreover, the study explores the existence of respect between clients and health care providers. The study identifies how this domain interacts with demographic and medical information.

2.1.2.5 Health education and nutritional counseling

The existence of health education and nutritional counseling is explored in this study from the perspectives of UC patients and health care providers. It may be affected by the presence of adequate number of HR like GIT specialists and nutritionists and may affect the outputs/outcomes as stabilization of the UC case, satisfaction and QoL.

2.1.2.6 Documentation

Documentation is considered a very important parameter for both the health care system and the UC patient. It ensures proper case management and saving health care system resources. The availability of a record for every patient is investigated as well as medical record completeness for every registered UC patient. The perspectives of health care staff about documentation practices are explored also. Documentation may be affected by the presence of a trained health staff personnel and the presence of an efficient HIS and it may affect the UC patient outcomes as it helps in case management.

2.1.2.7 Coordination

The extent of coordination between the health care staff of the same facility (horizontal coordination) is explored (e.g physicians, nurses, pharmacists, nutritionist, …etc) as well as coordination availability between the different health care providers like primary, secondary/tertiary, NGO's and private health care facilities (vertical coordination). Good coordination and cooperation may affect outcomes.

2.1.3 Output/outcome

Outputs and outcomes are affected by input and process variables. A lot of advantages are gained when outcomes are used to evaluate medical care quality as they are considered as concrete and precise measurements. Outcomes are the ultimate results of outputs.

Outputs

2.1.3.1 Provided services

The study identifies the available services for UC patients and if there are other missing ones and evaluates the quality of the available services. They are affected by the presence of needed inputs and affected by process variables like waiting time.

2.1.3.2 Number of performed colonoscopies

This study identifies the number of performed colonoscopies.

2.1.3.3 Number of beneficiaries from the provided services/ activities

The number of follow-up visits in GIT outpatient clinics is identified.

Outcomes

2.1.3.4 Patients' satisfaction

Satisfaction of patients regarding the quality of care is identified in terms of accessibility, courtesy, cost, accommodation, continuity of care, provided information, competence and autonomy. Patient's satisfaction is affected by inputs availability and processes suitability. Furthermore, the study explores the correlates between demographic variables and UC patients' satisfaction as well as the correlates between patients' medical information and their satisfaction from the provided services.

2.1.3.5 Health-related quality of life

HRQoL is assessed to identify the extent to which UC affects patients' daily life. It may be affected by both input and process variables. The effect of demographic characteristics and medical information on patients' HRQoL is identified.

2.1.3.6 Patients' and working staff's perspectives towards the provided services

Perspectives of patients and working staff towards the provided services are investigated.

2.1.3.7 Stabilization of the case

After receiving health care services, the stabilization of UC patient case is investigated from patients' perspectives.

2.1.3.8 Restoration of function

Patients' perception about restoration of their bowel function, eating habits and normal work after receiving health care services regarding UC is identified through this study.

2.1.4 Intervening factors

2.1.4.1 Patients' characteristics

Patients' characteristics have an influence on domains under study (input, process and output/outcome). It can affect the course of disease and affects its management, so they are considered in the study. Patient characteristics include many aspects like age, gender, living place, marital status, years of education, refugee status and working status. Patients' characteristics are taken into consideration, then their effect on the other variables is identified.

2.1.4.2 Disease related variables

Disease related variables also have an influence on the studied variables in the three domains and may affect disease management decisions. Disease related variables include years of disease from diagnosis, frequency of experiencing flare-ups, relapse/stability status, presence of extra-intestinal manifestations (EIMs), disease severity and extent and undergoing surgery.

2.2 Literature Review

2.2.1 Definition

According to the European Crohn's and Colitis Organization (ECCO), UC is a lifelong disease arising from an interaction between genetic and environmental factors, it is observed predominantly in developed countries and its precise aetiology is still unknown, therefore its cure is not available yet (Dignass et al., 2012).

2.2.2 Epidemiology

Globally, prevalence rates of UC are ranging from 4.9 to 505 per 100,000 in Europe, 37.5 to 248.6 per 100,000 in North America (Friedman & Blumberg, 2018), 286 per 100 000 in the USA (Ng et al., 2017) and 4.9 to 168.3 per 100,000 in the Middle East and Asia. In countries that are becoming more westernized, like China, South Korea, India, Lebanon, Iran, Thailand, and countries in the French West Indies and North Africa, IBD generally and UC specially appears to be emerging, for example, in South Korea, the prevalence of UC has quadrupled from 7.6 per 100,000 in 1997 to 30.9 per 100,000 in 2005. In Hong Kong, the prevalence of UC almost tripled from 2.3 in 1997 to 6.3 per 100,000 over a 9-year period. Urban areas have a higher prevalence of IBD than rural. The incidence peak of UC occurs from the second to fourth decades of age (Friedman & Blumberg, 2018). Regarding female-to-male ratio in the case of UC, it ranges from 0.51 to 1.58 (Friedman & Blumberg, 2018). In Abukhedeir study (2020), which was conducted in the GS, it was found that 42.7% of participants were females and 57% were males.

2.2.3 Ulcerative colitis management

The main goals of treatment are achieving remission, then maintaining it. Achieving remission aims to control UC symptoms, while maintaining remission aims to prevent symptoms from getting back (Peppercorn & Kane, 2019). Individualized therapy is essential in treating each UC case. To get the best possible long-term outcomes of therapeutic management, mucosal healing should be achieved and not merely the clinical symptoms healing (Daperno et al., 2019). In a study that was carried in 2019 by Ljungström et al., they found that 23.3% of the participants experienced a flare-up in the last 6 months, while 34.2% had a relapse in the last 6 to 12 months and 42.5% of the participants did not experience relapses during the last 12 months. Some studies like Carpio et al. (2016), found that 25.8% of the participants were experiencing a disease flare-

up, 22.2% experienced their last flare or sustained worsening of UC symptoms from less than 6 months, 13.9% experienced them before 6 to 12 months, 34.4% experienced these symptoms from a period of more than 12 months and 3.8% of their study participants mentioned that they are not sure about the last time to experience a flare-up.

2.2.3.1 Diagnosis and clinical manifestations of ulcerative colitis

Based on physical examination and the pre-existing clinical symptoms, the diagnosis of UC is confirmed using a combination of methods including endoscopy, radiography, serologic tests and pathological studies (Bruining, 2015).

Regarding clinical manifestations, UC onset may be noticed suddenly or gradually over time. Increased bowel movements and bloody diarrhea may be experienced accompanied by fecal urgency, abdominal pain and cramps. Fever may be noticed also through exacerbation periods. Exacerbation periods appear to alternate with improvement or remission periods. All these manifestations occur with or without the use of medical therapy (Bruining, 2015). In Carpio et al. study (2016), it was found that 60.2% of participants, suffered from diarrhea, 57.1% noticed rectal bleeding, 54.5% suffered from flatulence, 52.5% from fatigue and tiredness, 47.5% had abdominal pain and/or stinging and 38.8% experienced joint pain. In another study, it is found that 78% of the UC patients were in remission and 22%were in relapse according to patients' perspectives (Molander & Ylänne, 2019). Nausea, anorexia and weight loss are uncommon when the disease severity is mild to moderate or when the inflammation is only left sided, while these manifestations may appear in the case of severe active disease (Bruining, 2015). According to Panés et al. (2017), 22.6% of UC patients have a history of EIMs.

Lab tests findings may be normal in mild cases, iron deficiency anemia may occur due to blood loss from gastrointestinal tract (GIT) and may be increased due to the effect of cytokines on the bone marrow, while in severe cases, hypoalbuminemia, hypokalemia, and metabolic acidosis may be found due to the loss of potassium and bicarbonate with diarrhea with increased leukocyte count (Bruining, 2015). Active UC can be associated with a rise in C-reactive protein (CRP) test, erythrocyte sedimentation rate (ESR), platelet count and a decrease in hemoglobin. Lactoferrin is a glycoprotein which present in activated neutrophils, while calprotectin is present in neutrophils and monocytes, so, the presence of fecal lactoferrin, is a specific and highly sensitive marker for detecting intestinal inflammation. Fecal calprotectin levels correlate well with inflammation, predict relapses, and detect pouchitis. Recently the last two tests become integral parts of IBD

management as they are frequently used to differentiate active inflammation from symptoms of irritable bowel syndrome or bacterial overgrowth (Friedman & Blumberg, 2018). The perinuclear antineutrophil cytoplasmic antibody (pANCA) test is found to be positive in about two thirds of UC patients, while anti–Saccharomyces cerevisiae antibody (ASCA) test is found to be positive nearly in one third of them (Bruining, 2015).

Flexible proctosigmoidoscopy or colonoscopy can be used to identify UC and determine its extent, while in severe active disease, only a limited rectosigmoid colon examination should be performed due to the increased risk of perforation (Bruining, 2015). Colonoscopy is used also to perform biopsies, and evaluate strictures and it is indicated to differentiate between crohn's disease and UC when their manifestations are overlapped. Colonoscopy is also indicated in surveillance biopsies for the exclusion of dysplasia development or cancer in patients with UC for more than 8 years (Loftus, 2016). Specimens from mucosal biopsy of the inflamed areas of the GIT are useful to exclude infections or noninfectious colitis causes, like ischemia or drug side effects as non-steroidal anti-inflammatory drugs (Bruining, 2015). The same source indicates that in severe active UC, plain abdominal films with supine and upright views should be performed to exclude the existence of complications, like toxic dilatation or the presence of free air due to perforation.

2.2.3.2 Ulcerative colitis medications

UC as other types of IBD, is characterized by periods of flare-ups followed by remission periods, so it difficult to distinguish between favorable responses to medications from remission episodes (Gelber et al., 2019), but generally, UC treatment depends on the severity of the disease. In case of mild to moderate symptoms (including rectal pain and bleeding) and mild diarrhea, topical medications can be directly applied to the rectum. The mostly used medication as first line treatment is 5-amino salicylic acid (5-ASA) agents. These agents are effective for induction and maintaining remission in UC while in the case of severe symptoms represented by six or more episodes of bloody diarrhea a day -which mostly accompanied by other symptoms-, an oral glucocorticoid (steroid) or a biologic therapy may be indicated (Peppercorn & Kane, 2019). Medical treatments do not only enhance the stability of the disease, but it also normalizes the physical and mental health status (Yarlas et al., 2018). Panés et al. (2017) found that 82.4% of participants were taking aminosalicylates, 36.7% of the participants were on thiopurines (immunosupressors), while

16.5% were taking corticosteroids and 23.6% were taking tumor necrosis factor alpha inhibitors (anti-TNFα drugs. To assess patients adherence to medications, Min Ho et al. (2019) used Medication Adherence Report Scale (MARS) and found that 88.3% of UC patients were adherent to their medications, where 11.7% of them were non-adherents.

5-Amino salicylic acid agents

This group of medications includes sulfasalazine, mesalazine (Pentasa, Asacol HD). Sulfasalazine is effective for mild to moderate cases, its high rate of side effects limits its use, these include allergic reactions, headache, anorexia, nausea and vomiting. It also impairs the absorption of folate, so patients should be given folic acid supplements. Mesalazine, triggers symptoms relief in most people within 4-6 weeks of its use. When the patient does not experience any improvement after this period, a glucocorticoid (steroid) may be added with or instead of the oral 5-ASA medication (Peppercorn & Kane, 2019).

Glucocorticoids (steroids)

Patients with moderate to severe UC are benefitted from oral or parenteral glucocorticoids and they are used only for specific periods during flare-ups, its cessation is performed with tapering after symptoms improvement, but when the case does not improve, other medicines may be introduced like cyclosporine (CSA) and biological drugs (Peppercorn & Kane, 2019). Glucocorticoids for UC treatment include many types like prednisone, budesonide and hydrocortisone. Budesonide is a new glucocorticoid for UC treatment, it is taken orally and released entirely in the colon and has minimal or no glucocorticoids side effects, while hydrocortisone may be given parenterally (Friedman & Blumberg, 2018).

Biological drugs

Biological agents are a group of medications produced by genetic engineering, they are made from living organisms. These agents work by targeting specific cells in the gut that contribute in the inflammation process (LeBlanc et al., 2015). Thus biologics interfere with inflammation pathways, and promote healing of the inflamed colon, they can be used for remission induction or maintaining it by long-term use (Peppercorn & Kane, 2019). Patients responding to these biological drugs experience an improvement in clinical symptoms, better QoL, less disability, fatigue, depression, fewer hospitalizations and surgeries (Friedman & Blumberg, 2018). This group of drugs include TNF-α inhibitors like

adalimumab (Humira), infliximab, certolizumab and golimumab. Biologics also contain α4-Integrin inhibitors like vedolizumab, natalizumab and interleukin-12/23 (IL-12/23) inhibitors like ustekinumab (Motycka & Khoury, 2019). In spite their large benefits, they have multiple side effects, so they are reserved for cases suffering from moderate to severe UC alone or combined with other medications (Peppercorn & Kane, 2019).

- **Anti-TNF Therapies**

Infliximab is an intravenous biologic therapy used for active UC not responding to glucocorticoids, 6-Mercaptopurine (6-MP), or 5-ASA (Friedman & Blumberg, 2018). Infusion reactions and a decreased response to treatment may be experienced due to development of antibodies to infliximab and skin lesions (Friedman & Blumberg, 2018). Adalimumab is a recombinant human monoclonal immunoglobulin G1 (IgG1) antibody, it is a subcutaneous injection and it is approved for the treatment of moderate to severe cases (Friedman & Blumberg, 2018).

- **Anti integrins**

Integrins are expressed on the cell surface of leukocytes and serve as mediators of leukocyte adhesion to vascular endothelium (Friedman & Blumberg, 2018). Natalizumab is a recombinant humanized IgG4 antibody effective for the induction and maintenance of UC. It was introduced to patients who are intolerant to anti-TNF therapy, but now it is not widely used due to its side effects (Friedman & Blumberg, 2018). Vedolizumab is a monoclonal antibody, it is indicated for UC cases who experience no or inadequate response to TNF-α inhibitors or intolerant to them or to immunomodulators and glucocorticoids (Friedman & Blumberg, 2018).

- **Interleukin-12/23 Inhibitors**

Ustekinumab is an intravenous injection and it consists of fully human IgG1 monoclonal antibody that blocks the biologic activity of IL-12 and IL-23. It is approved recently from the Food and Drug Administration for patients who had failed therapy or were intolerant to immunomodulators or corticosteroids (Friedman & Blumberg, 2018). If the case does not respond to medications or experiences unbearable side effects from their medications, they may choose surgery to remove their colon (Peppercorn & Kane, 2019).

Immunomodulators

Azathioprine and 6-Mercaptopurine are purine analogues, they are immunosuppressants and they are used in the same time with biologic therapy or alone. They are usually well tolerated, but they cause some side effects like fever, rash, nausea, hepatitis and bone marrow suppression (Friedman & Blumberg, 2018). CSA is another immunomodulator, which is a peptide that inhibits cellular and humoral immune systems. It works by blocking the production of IL-2 and it has a more rapid onset of action than azathioprine and 6-MP (Friedman & Blumberg, 2018). CSA is a very effective medication for remission induction but it cannot be used for life because of its serious side effects (Peppercorn & Kane, 2019). CSA is used as an alternative to colectomy. It can cause significant toxicity and kidney damage, so renal function should be monitored from time to time. Other side effects include risk of infection, hypertension, tremors, gingival hyperplasia, hypertrichosis, paresthesias, headache and electrolyte abnormalities. But if creatinine is found to elevate, dose reduction may be introduced or even the drug may be discontinued (Friedman & Blumberg, 2018). Tacrolimus also is a macrolide antibiotic with an immunomodulatory effect similar to that of CSA but 100 times more potent than it. It has shown efficacy in the treatment of both children and adults who show glucocorticoid dependency or for patients with refractory UC (Friedman & Blumberg, 2018).

Methotrexate

Methotrexate has anti-inflammatory effect as it inhibits dihydrofolate reductase and decrease the production of IL-1. Most of the time, it is used with biological therapy to decrease the formation of antibodies and improve response of disease. It is applied either by intramuscular or a subcutaneous injection. It is not recommended in maintenance therapy for UC. Its common side effects are headache, abdominal discomfort, nausea, vomiting, serum aminotransferase elevations and rash (Motycka & Khoury, 2019).

2.2.4 Ulcerative colitis and the risk of developing colorectal cancer

UC patients have an increased risk of developing colonic epithelial dysplasia and carcinoma. This risk increases with disease duration and with extent to which the colon area is involved. During the initial 10 years of disease, the risk of colorectal cancer is relatively low, but after that it appears to increase by 0.5–1% each year. The development of colorectal cancer usually occurs due to slow precancerous changes in the colon which

can be detected with a screening test like colonoscopy. So, colonoscopy with multiple biopsies is recommended after eight years of the first diagnosis of UC, if results appear to be normal, it is recommended to be repeated every one to three years (Peppercorn & Kane, 2019) (Mayer, 2018).

2.2.5 Indications for colectomy in ulcerative colitis

Surgery (colectomy) is indicated when the UC patient does not respond to medications or when experiencing unbearable severe side effects from medications, or having a life threatening disease complications including colonic perforation, acute GIT hemorrhage or toxic megacolon (Loftus, 2016). Megacolon is a thin-walled, dilated and poorly motile area of the colon susceptible to rupture (Gelber et al., 2019). Surgery is indicated also in the case of continuous disease leading to corticosteroid dependency or the inability to taper steroid medication to low doses or if the disease is thought to cause growth retardation in pediatrics, as well as in cases of dysplasia occurring with or without colon cancer and when colon cancer is documented or suspected (Andersson & Sŏderholm, 2009, Loftus, 2016). When the colon is surgically removed, this can reduce the risk of colon cancer significantly and eliminate the target organ for the underlying chronic gastrointestinal disorder (Mayer, 2018). In a study carried by Gonczi et al., 2019, it is found that 9.3% of the UC patients had undergone surgery.

2.2.6 Diet and ulcerative colitis

A diverse well-balanced diet has an important role in maintaining health and normal body weight. It is not proven that any specific type of nutrient or diet can relieve symptoms in UC patients, but some particular foods are noticed to make UC symptoms worsened, these foods include milk, yogurt, cheese and others (Peppercorn & Kane, 2019).

2.2.7 Ulcerative colitis burdens

Because UC is a lifelong diseases, it has a significant impact on QoL, it also has personal economic burden as it causes reduction in work ability, long or short-term work interruptions, and out-of-pocket expenses (Kawalec, 2016). Patients with active disease also experience burdens affecting physical, emotional, and social functioning and wellbeing (Yarlas et al., 2018). UC burdens increases when it is accompanied by other chronic diseases. Ljungström et al. (2019) results revealed that 30% of the participants have another chronic disease and 70% without concomitant chronic diseases.

Concerning economic burden of UC, is considered a costy disease, it has direct medical costs represented mainly by hospitalization expenses and indirect costs which are considerable but underestimated (Cohen et al., 2010). Indirect costs of UC are expected to have a significant role in the burden of disease. Indirect costs may be resulted from the lost productivity and earnings for both, patients and their family members. The main components of indirect costs are absenteeism, presenteeism and loss of leisure. Absenteeism which is the absence of the person from the paid work or leaving work earlier because of the disease as in the case of sick leave, early retirement, reduced employment or unemployment. Presenteeism indicating the reduced productivity of paid work due to the disease. Loss of leisure due to reduced opportunities for unpaid activities (Kawalec, 2016).

It was found that work disability occurs within the first 4 weeks of active UC diagnosis, it was a common serious problem among UC population, as Moon et al. (2019) found that the prevalence of severe disability occurred in the form of 28.2% absenteeism, 40.6% presenteeism and 53.5% social activity impairment and they found that patients with severe disease were more likely to have high levels of work disability. Also, UC health care expenditures are converted currently from costs related to hospitalization and surgery to costs driven by medication use and most of the IBD-related therapy costs are shifted towards anti-TNF therapy in an increasing manner (Van der Valk et al., 2016).

In regard to UC psycho-social burdens, it is found that its effects protrude to have an impact on interpersonal relationships, social participation and leisure activities of patients as well as their families (Becker et al., 2015, Argyriou, 2017). Moreover, persons with UC who have high levels of perceived stress and coping behavior as a reaction to stressors are found to have poor QoL and poor prognosis (Luo et al., 2018). Patients who undergo ostomy, seem to be primarily impacted by depression. Amongst the items of depression, they showed high scores on both changes in appetite and energy loss, these results are noticed also in the clinical field as UC patients who experience diet problems, nutrition imbalance, what leads in turn to low body weight, thus fatigue and tiredness what could enhance depression occurrence (Hwang & Yu, 2019). In Craven et al. study (2019), it is found that 7% of patients were referred to a psychiatrist, 56% of the participants were engaged in cognitive-behavioral therapy including mindfulness and stress management, 25% of them had received supportive therapy and less than 5% of the participants were engaged in psychodynamic, existential/humanistic, biofeedback or hypnotherapy.

2.2.8 Quality health care

High-quality health services involve the right care at the right time in response to the needs and preferences of service users, with minimal harm and resource waste. Quality health care increases the chance of attaining the desired health outcomes and it is consistent with effectiveness, safety, people centeredness, timeliness, equity, integration of care and efficiency (WHO,OECD & World Bank, 2018). The same reference indicates that quality health care improvement is a continuous or dynamic process and different methods are used to improve quality of health care continuously like clinical governance mechanisms, peer review, clinical audit, individual feedback, supervision and training and clinical decision support tools based on guidelines. According to Coenen et al. (2020), entering remission phase of UC, was identified to be a strong predictor of good quality of care.

2.2.9 Human resources

Adequate numbers of health workers with the needed skills and knowledge should be considered to ensure suitable service provision as well as the availability of a variety of skilled health workers including doctors, nurses and other different health care professionals, added to that, the suitable skills mix and the availability of teamwork spirit to manage morbidity and mortality and accessibility of patients to meet and speak with health professionals with the right skills (WHO,OECD & World Bank, 2018). To attain effective management of the health workforce, it should include planning and regulating the stock of health workers, their education, recruitment, employment, performance optimization and retention (Cometto, 2020).

For IBD patients, the needed staff members include service gastroenterologists and colorectal surgeons, they are perceived as being the most necessary specialists in the care provision. Radiologists, lab technicians, pathologists, dermatologists, and rheumatologists are necessary for such workup and care. Nutritionist and psychotherapists also play an important and critical role (Koltun, 2017). Louis et al. in 2015, concluded that it is needed to develop a multidisciplinary team (MDT) with specific expertise to provide proper UC services. In Schoultz et al. study in 2016, participants expressed that there is a need for more gastroenterologists and IBD nurses and sought better access to them. Patients who had dealt with IBD nurse reported more satisfaction from care. In New Zealand, GIT specialists' ratio was found 1.96 per 100,000 population in 2017 (Stamm et al., 2020), while in Canada it was found 2.14 per 100,000 population in 2016 (Leddin et al., 2018).

Concerning pathologists ratios, Canada was found to have 4.81 specialists per 100,000 population and the United States of America was found to have 3.94 specialists per 100,000 population in the year 2017 (Metter et al., 2019).

2.2.10 Health care facilities/physical conditions

The existence of accessible and well equipped health care facilities is essential, also, hospitals and clinics' density is an important issue to attain accessible quality of care (WHO,OECD & World Bank, 2018). In another study, 86% of IBD experts agreed that the IBD unit should have adequate facilities for IBD patients' special needs like adequate number of toilets, washing rooms and preparation rooms as in the case of stoma care (Louis et al., 2015).

2.2.11 Medications, devices and other technologies

The availability of medicines, devices and technologies, is a basic requirement for the provision of quality care services (WHO,OECD & World Bank, 2018). Medical devices have a vital role in health care provision. Without these medical devices, common medical procedures would be impossible (WHO, 2017c).

Medical equipment requires regular maintenance and user training. When spare parts, consumables are unavailable or in case of lack in staff training on this equipment, they may be useless and unsafe (WHO,OECD & World Bank, 2018). Health technology management is used to make sure of the availability, accessibility, affordability, appropriateness, and safe use of medical assets (WHO, 2017d).

Regarding the effect of COVID-19 on the provision of lab tests and endoscopy services for IBD patients, Harris et al. (2020) found that hospital blood tests were cancelled in the case of 4.4% of the study participants, delayed in the case of 18% of participants, not affected in 52.1% and the question was not applicable in 24.5% of the participants, the mentioned study found also that general practitioner (GP) blood tests were cancelled due COVID-19 for 3.9% of the participants, 18.3% of them were delayed, 43.7% were not affected and in 34.1% the question was not applicable. In the same study, endoscopy was found to be cancelled in the case of 5.2% of participants, delayed for 5.2% of participants, not affected in 22.5% of the participants and it was not applicable in 67% of the study participants.

2.2.12 Guidelines/standards

Setting standards, assists in the provision of consistent delivery of quality care across different health systems. Health care standards can be achieved via patient care protocols, clinical pathways and standards. These tools are used to guide evidence based health care (WHO,OECD & World Bank, 2018). If evidence based guidelines are not complied, this indicates either the lack of knowledge of all the staff members or part of them about the guidelines or lack of knowing about their existence. Poor compliance or lack of compliance to these guidelines, leads to poor effectiveness of health care services (WHO,OECD & World Bank, 2018).

In Louis et al. (2015) study, they found that 92% of IBD experts agreed that IBD practice guidelines should be documented clearly and it should include the standardized referral data, diagnosis and baseline assessment, therapeutic algorithms, disease activity monitoring, monitoring for side effects, adherence and care entry points like referral from primary care, transition from pediatric to adult care, hospitalization criteria and referral to surgery. In the same study, is found also that 94% of the IBD experts agreed that the working MDT should receive suitable training on the agreed guidelines of the IBD unit and 96% of the experts agreed that the practice guidelines of the IBD unit should be updated to incorporate the latest local and regional IBD guidelines and to communicate these updates in a structured way to the MDT.

2.2.13 Information system

Good information system means improving quality of care. To contribute in the provision of high quality health care, the information system should have the ability to translate data into information, not merely data collection. From regular data collection, continuous research and development can be conducted to improve the validity, utility and comparability of health care quality indicators (WHO,OECD & World Bank, 2018).

The transformation from paper based records to a unique electronic health record, helps in monitoring health care services performance information (WHO,OECD & World Bank, 2018). Adoption to electronic medical record (EMR) in different levels contributes in boosting the quality of the provided healthcare. To ensure efficiency of the EMR, it is needed to introduce proper training to physicians and nurses during EMR implementation process (Lin et al., 2020).

According to Hamade et al. (2019), there is a need to direct more attention for performing interventions aiming to improve the use of EMRs in PHC and to introduce a generalized method for the evaluation of its use, there is a need also to introduce guidelines for implementing interventions aiming to improve the use of these EMR. It is beneficial to implement other interventions like organizational, professional and financial interventions as investing in add-ons of EMR feature, educational materials and financial incentives to improve EMR use.

2.2.14 Waiting and contact time

Ramos et al. (2018), focused on the effect of waiting time, it was clear that patients' preferences are directed towards shorter waiting time clinics. In a study carried by Silver et al. in 2020, it was found that many factors contributed to increase waiting time, these factors include scheduling too many patients at the first hours of the clinic work within intervals of short time and exceeding the capacity of physician for seeing patients per hour. After applying quality improvement principles including identifying best practices and benchmarking, load-leveling and clinic scheduling standardization, waiting times were reduced to large extent and they conclude that it is better to add the overbooking or (add-ons) at the end of the day, to use realistic times for visits and to add a buffer of 30 – 60 minutes at the middle of working hours without appointments when it is possible. In another study, researchers introduced a series of interventions trying to reduce waiting time in outpatient clinics including procedure changes, supply side changes and demand side changes; as a result, the monthly average waiting time was decreased by 3.49 minutes for consultations after a month of introducing these changes (Sun et al., 2017).

In one study, waiting time was utilized for health education of patients to improve their experience regarding their disease and their health in general, enhance the appointment experience for patients and clinicians and gaining other positive effects on motivation of patients. Health education was carried through a group of educational videos displayed via a tablet (Mcintyre et al., 2020). In another study, waiting time from referral to appointment was found to have an influence in predicting attendance of patients in the outpatient GIT clinic as longer waiting time from referral to scheduled appointment was associated significantly with missed appointments (Shrestha et al., 2017). In Soares et al. study in 2015, they found that 36.4% of the IBD patients were waiting from 0-30 minutes, 45.1% of them were waiting from 31-60 minutes and 18.5% were waiting for more than 60 minutes and they found that the average waiting time in the IBD outpatient clinic had a significant association with overall satisfaction, as the overall satisfaction was lower in patients who

had a high average waiting time, they conclude that it is important to pay more focus on reducing waiting time to improve IBD patients' satisfaction with outpatient care. It was stated by the United Kingdom Government -within the standards' series- that waiting time in outpatient clinics should not exceed 30 minutes (Stocking, 1991).

In the PHC setting, it was found by Anan (2011) that the average waiting time for the physician in PHC centers is 31.7 minutes with 24.4 SD. The same study indicates that 44.9% of participants were found to wait less than 30 minutes for physician's consultation, half of participants were found to wait from 30 to 60 minutes and 5.1% were found to wait more than 60 minutes to see the physician.

In Alarcon-Ruiz et al study (2019), consultation time was directly associated with patient satisfaction. In Molander & Ylänne study (2019), they found that 63.5% of the UC patients wished to have more time with the physician and 44.3% of them felt that their physician most of the time had no time to address all their concerns and question. Elmore et al. (2016) found that the mean length of consultation time in primary care 10 minutes and 22 seconds with SD of 4 minutes and 45 seconds. In another study, it was found that 70.9% of participants agreed that they spent enough time with the health care provider in PHC centers, 23.4% answered that the spent time is enough to some extent, while 5.3% of participants answered that it is not enough (Anan, 2011).

2.2.15 Accessibility

The WHO stated that "all people have equal access to quality health services that are co-produced in a way that meets their life-course needs and respects their preferences" (WHO, 2016b). Policy makers are targeted to seek for achieving the goal of universal health coverage by ensuring all people to have the access to high-quality, people-centered health services. A comprehensive health care system allows the access of people to a continuum of care across their life course including health promotion, disease prevention, right diagnosis, suitable treatment, management of disease, rehabilitation, psychological support as well as the provision of palliative care (WHO,OECD & World Bank, 2018). In Seghieri et al. study (2018), they focused on the effects of travel time on patients' preferences for choosing clinics. Their results revealed that patients prefer nearer clinics and they found that differences in choices of patients depend on socioeconomic conditions and age and they conclude that to support equity in access to health care for elderly patients and those with the lowest economic conditions, improvement in patients' transport can be provided like improving public transportation or the provision of subsidized transport as well as

good planning and improving organizational capacity in service points. Benchimol et al. (2018) found that improving access to health care for IBD patients could reduce their hospitalizations, emergency department visits, and they recommend the introduction of innovative delivery of GIT care to IBD patients in rural areas including telehealth, and remote clinics. In Schoultz et al. study in 2016, participants mentioned that there they have no clear pathway for their health care regarding IBD and expressed that need more explicit and consistent pathways to be able to navigate easily when seeking health care. Lönnfors et al. (2014) found that 88% of the participants had access to a GIT specialist at the clinic where they were treated. Nearly two thirds of them experienced that this access was adequate, while the remaining third felt that their access was inadequate.

2.2.16 Follow-up

Molander & Ylänne found in 2019 that 54.5% of UC patients were currently seeing a GIT specialist to manage their disease, 41.7% were seeing an internist with gastroenterology focus, while 15.9% were seeing a PHC physician or a GP. In Harris et al. study (2020), they found that COVID-19 affected follow-up visits as 18.7% of IBD patients answered that their follow-up appointments in hospitals were cancelled, 15.8% patients' appointments was delayed, 41.6% answered that their appointments in outpatient clinics were not affected and the question was not applicable for 25.4% of the participants. They found also that COVID-19 affected also GPs' follow-up visits, as 6.7% of the participants' appointments with GP were cancelled, 10.2% were delayed, 39.9% were not affected and in 43.1% of participants, the question was not applicable.

2.2.17 User-provider interaction

Shared decision making between health care providers and patients is a useful approach to tailor care for the patient according to his/her own needs and preferences to achieve better health outcomes. Providing patients with information, advice and support helps them to manage their health outcomes and assists in development of treatment and health plans collaboratively (WHO,OECD & World Bank, 2018). Biroulet et al. (2016) found that UC patients were happy to discuss treatment options with their physician, while actually, most of their treatment decisions are made by physicians. It is thought to be beneficial to extend the inclusion of patients in treatment decisions, as patients always are afraid of long term risks of medications and they prefer effective, safe treatments over easier to be administered or cheaper ones.

In Sanford et al. (2020) study, specific qualitative physician-patient factors in outpatient clinic visit were associated with high satisfaction. These factors include paying attention, interest, communication and eye contact and they have more weight in the final assessment with the patients' perspectives than quantitative factors like waiting and contact times with the physician in the outpatient clinic, so, physicians' interpersonal skills plays an important role in countering negative effects associated with other factors like long waiting times or delayed care. In china, a study was carried by recruiting 210 surgical residents for participation in a training program on communication skills. By assessing the effect of this training program, it is found that the doctor-patient communication (DPC) competency of surgical residents was improved and satisfaction level was increased for both patients and surgical residents (Bai et al., 2019). In Lönnfors et al. study (2014), 64% of respondents felt that the GIT specialist did not ask them more probing questions about their disease as their expectations.

Molander & Ylänne (2019) found that 79.6%of UC patients were satisfied with the available communication between them and their health care providers and 74.2%of them felt that raising concerns and fears with their health care providers was comfortable, they found also that 59.6% of participants were wishing their physician to spoke with them more about their UC management goals and 53.3% of them wished that their physician had discussed the available treatment options earlier to had better ideas about their choices.

2.2.18 Health education and nutritional counseling

In Louis et al. study (2015), 87% of the participated IBD experts agreed that the IBD unit should include a structured program for patient support that includes educational materials for patients, patient education delivery and patients' interaction with a MDT to enhance this delivery as well as patient–patient interaction opportunities like patient forums or patient 'open days'. In Tormey et al. study in 2019, there was a significant association between health illiteracy and subjective health status, depression and HRQoL, as IBD patients who had limited health literacy had significantly worse scores in overall health status, had more symptoms of depression and lower HRQoL scores than those who had adequate health literacy. Becker et al. findings in 2015, showed that 69% of the UC participants replied that they get information about their disease from the gastroenterologist, 54% are used to obtain their information from Crohn's and Colitis Canada website (CCC) alone, while 55% of the study participants rely on other online

sources, 34% of their respondents obtain information from other UC patients, 28% of participants rely on information from the family doctor, 10% from events sponsored by CCC and 12% from other health care professionals.

2.2.19 Documentation

The medical record which is kept for each patient by health care practitioners is the most frequently used source of information about the process of care and about the outcomes during and after care provision. To ensure the provision of good care and credible assessments of care quality, good records are critical (Bashshur, 2003). It is important to develop processes that aid in facilitating communication between team members together as well as with patients, to provide clear documentation (Louis et al., 2015). Records many times have deficiencies, incompleteness in information, sometimes may indicate untruthfulness or difficulties of interpretation (Bashshur, 2003).

In a study that was carried in an obstetrics and gynecology department for reviewing medical records using a checklist, it was found that a training workshop was effective in improving the recording status of the general and quantitative data as there were significant differences in their averages before and after education, while it was ineffective in improving the qualitative data as no significant differences were observed in the recording of qualitative status (Sayyah-Melli et al., 2017). In the same study, they found that patient demography was of standard quantity in 46% of the reviewed records and 45% of them were of standard quantity of the lab data, 36% was the percent of family's history documentation, it was found also that past medical history was documented in 51% of the reviewed files and that operative procedures was documented in 43% of the files, while allergies documentation percentage was 46% and the doctor's full name and the signature with job category was documented in 56% of the reviewed files.

In Abu Dagga, 2014 study, it was found that the overall documentation average was 81.5% for discharge sheets. In another study, it was found that 84.1% of participants from the health care staff perceive that the results of requested diagnostic tests are documented, 75.5% of them perceive that allergies and adverse drug events are clearly documented and 81.9% agreed that the entries are legible and that any provider can understand the record note (Alkhaldi, 2017).

2.2.20 Coordination

In Louis et al. study (2015), 80% of IBD experts indicated that the IBD unit should coordinate health care with primary care practitioners, obstetrics/gynecology specialists, pediatric transition team where appropriate and immune-mediated inflammatory diseases specialists like rheumatologists and dermatologists and they indicate that patients should have the capability to access emergency IBD care when required through the IBD unit or intensive care facilities. In Schoultz et al. study in 2016, IBD patients mentioned that they felt gaps in communication between different departments, so the provided care was not well coordinated which lead to be referred to the wrong place or to wait for months to have an appointment with the GIT specialist. The same study identified the need for coordination and working in a holistic manner, what requires all health workers to communicate regularly and work together to offer integrated health care services for IBD patients.

2.2.21 Patients' satisfaction

In a study conducted in 2016 by Biroulet et al., the obtained findings showed that around half of the patients were dissatisfied with the effectiveness of their treatment and that they did not have enough knowledge concerning several disease aspects. Patients with uncontrolled disease, were found to have higher rates of dissatisfaction. From patients' point of view, the most important advantages of medications were effectiveness, long lasting and rapid onset of action, safety and tolerability**.** The disease has a high impact on the life of patients in terms of fears and stress and most of these patients have little involvement and relied on their treating physician. Disease severity estimated by physicians seems to be milder than what reported by patients, physicians also estimated fewer flare-ups than reported by patients (Biroulet et al., 2016).

Soares et al., 2015, found that there was an improvement in IBD patients' satisfaction regarding outpatient care when the average waiting time for their outpatient visit was reduced and they perceived that the second priorities in IBD services are inpatient care and facilities, to improve satisfaction with inpatient care and facilities, the provided services should focus on the privacy protection of patients and the quality of meals, respectively. In Casanova et al. (2020) study, it is found that IBD patients seem are satisfied from the provided services regarding their disease as they have the score of 0.16 in the performance part of the QUOTE-IBD.

2.2.22 Health-related quality of life

Regarding HRQoL, Patients with remission phase have better HRQoL than those with active disease, so induction of remission should be put in focus. Remission is attributed with a greater perception of life, lower emotional and social dysfunction compared to patients suffering from active disease (Kalafateli et al., 2013). Panés et al., 2017, found that increased disease activity is associated with worsening HRQoL. The impact was proportional to disease activity, they found that most problems in HRQoL are present in the dimensions of pain/discomfort and anxiety/depression, what emphasizes the importance of expanding the range of the provided care and not merely the achievement of clinical and endoscopic remission. In a distinct study, it was realized that stress, anxiety and depressive symptoms are important predictors of HRQoL in all evaluated dimensions, so, stress is considered as an important risk factor for HRQoL deterioration (Iglesias-Rey et al., 2014). Christiansen et al. (2019) used the SIBDQ to evaluate the HRQoL for UC patients and they found that their SIBDQ total score is 55.6 (from 70), and its domains scores is 16.6 (from 21) for bowel domain, 9.8 for bowel domain (from 14), 16.8 (from 21) for emotional domain and 12.5 (from 14) for social domain.

2.2.23 Patients' characteristics

The age of UC onset play an important role in the severity of the disease, it is found that early onset of UC in childhood is associated with more severe and progressive cases (Van Limbergen et al., 2008). In the same study, it is found that nearly 82% of the children who have a childhood onset of UC, was accompanied by the involvement of most or all of the colon ulceration compared to nearly 48% of patients with adult onset of the disease, the opposite was found, as the rate of the mildest cases with localized ulceration on the rectum only, was found in 1.4% of the children compared to 17% of the adult patients. In the childhood onset of UC, also, surgical decisions may be taken in children earlier than cases with adult onset of the disease (Van Limbergen et al., 2008). Also, determining induction and maintenance treatments in patients with adult onset UC is carried out according to disease severity and extent, while in children, disease activity is a priority over treatment strategies as disease extent is not very useful in managing UC in children, because it is less common to find limited disease among them (Ruemmele & Turner, 2014).

The metabolism of drugs in pediatrics is different, so different dosing and interval schedules are needed when dealing with them. In general, children with IBD suffer from

growth impairment and delay of puberty, this problem does not exist in the case of adults. Added to that, some UC medications are associated with a failure of returning patients to their normal patterns of growth. Due to the early onset of UC in children and young adults, they are exposed to medications for long time. As a result, issues like cumulative dosing, monitoring, long term risks and cost are considered of high concern in these cases (Carroll et al., 2019). Another difference regarding age is that the endoscopic evaluation of UC requires the use of general anesthesia in pediatrics, this is considered very stressful for the children and their caregivers and leads to limit the feasibility of repeated tests and increase relying on clinical assessments more than what happened in the case of adult patients (Ruemmele & Turner, 2014).

Regarding the influence of gender on UC, it is found that around the puberty period, the rates of males and females diagnosed with UC are approximately equal. In the case of younger females, they are found to be diagnosed with UC more slightly than males (Carroll et al., 2019). Diagnosis of UC in men aged 40 years or older is more often than that found in women and it was realized that although there was no difference found in the number of flare-ups between both genders, it was found that EIMs like skin and joint manifestations are more common in females (Severs et al., 2018). Van der Eijk et al. (2001), found that males were satisfied more than females from the provided services. In another study, it was found that there were statistically significant differences between employment status groups using univariate analysis as unemployed IBD patients showed higher mean for overall satisfaction than other groups and it was found that employed IBD patients had the lowest overall satisfaction mean (Soares et al., 2015). Tormey et al. findings in 2019, demonstrated that higher educational levels is associated with better outcomes than lower levels of education.

2.2.24 Disease related variables

Coenen et al. (2020) found that being in remission was significantly associated with improved satisfaction from provided quality of care (P value= 0.001). In Soares et al. (2015) study, they found that patients who experienced their last flare-up attack within the last 3 months had lower overall satisfaction than those who had no relapses in the last year. Also they found that patients who experienced relapses during the last 3 months had lower overall satisfaction than patients who experienced relapses within the period of 4 to 12 months ago (71.6 and 76.2 respectively).

Chapter Three
Methodology

3.1 Study design

This study is performed with a triangulated cross-sectional design that includes both quantitative and qualitative approaches. Cross-sectional study design is a snapshot that measures both the exposure and outcome for a specific population at the same time, so it is basically assesses the association between health-related events and other variables or factors of interest in a defined population at a particular time (Holmes, 2018).

The quantitative part deals with structured data collection methods that fit diverse experiences into predetermined response categories. The quantitative part is conducted through a census study. Quantitative data collection methods generate results which are comparable, generalizable and easy to summarize. From such data, hypotheses testing can be performed, then findings can be generalized, while the qualitative part deals with qualitative data collection methods that play an essential role in the evaluation process, it provides useful information for deeper understanding (Holmes, 2018). Triangulation combines theories and methods in a research study to help in overcoming fundamental biases arising from the use of a single method or a single observer, it enables the validation of data (Noble & Heale, 2019), also triangulation helps in transcending the limitations of each method by comparing findings from different perspectives, ensuring a sophisticated rigor (Williamson, 2005).

3.2 Study population

The study population was grouped into:

1. UC patients who utilize health care services related to UC in the public sector (hospitals and PHC centers).

2. KIs who were selected purposively from health care providers who are in contact with UC patients or influence their services provision including health managers, physicians, nurses, pharmacists.

3. Records pertaining to people with UC that were found in governmental PHC centers.

3.3 Study setting

Governmental PHC centers and hospitals providing health care services to UC patients in the GS.

3.4 Study period

The study took about 18 months; it was started in May 2020 and completed by October 2021. The study duration and activities are described in Annex (1)

3.5 Eligibility criteria

3.5.1 Inclusion

Registered UC patients in governmental hospitals or PHC centers in the GS who receive health care services related to UC from these facilities.

3.5.2 Exclusion

UC patients who do not meet the inclusion criteria.

3.6 Study participants

3.6.1 Quantitative participants

First, all registered UC patients who were found in the governmental hospitals or PHC centers were asked to contribute in the study through an interviewed questionnaire (Census study). The number of participants is 157 patients, they were served at 32 PHC centers. Other governmental PHC centers were found to have no UC cases, closed during data collection period due to COVID-19 or have non-respondent UC patients. Second, the researcher looked for the file of each patient to review its completeness. The number of medical records that was found and reviewed is 145 files, for the rest, no files were found as some of the PHC centers were found to have no files for UC patients, they said that they dispense medications for them according to their report that is put in the PHC center's pharmacy. Other files were not found because they are paper files and they cannot be found using the patient's name, ID number, the insurer name in the case of a family record or insurance number. The file number was difficult to obtain especially in PHC centers that have no computers or connection to the unified system of MoH.

3.6.2 Qualitative sample

A non-probability purposive sample of 10 KIs were selected through a non-probability sample to be interviewed and asked about the provided services to UC patients from their point of view as well as a non-probability purposive sample of 10 UC patients or their family members to conduct in-depth interviews about their perspectives regarding the provided services, missed services and to know more about their suffering while living with the disease.

3.7 Study instruments

Different instruments were used within this study. These include a questionnaire for people with UC regarding their demographics, medical history and the provided services including input, process and output/outcome domains. Another used instrument is a checklist for assessing files' completeness in PHC centers and in-depth interviews for a number of people with UC and KI. Table 3.1 shows a summary of tools used, participants and the focus of each of each.

Table (3.1) Study instruments

Tool	Number	Focus
Patients		
Questionnaire (Annex 7 and 8 for English and Arabic versions respectively)	157	Interviewed questionnaire through mobile calls for all reached patients utilizing governmental health care services provided for UC patients. The questionnaire focuses on their socio-demographic, economic variables, medical information, items describing access status, user-provider interaction, appropriateness of service delivery system, clients' views about the availability of needed services in the public sector, satisfaction from the provided services using QUOTE-IBD which consists of 8 domains and measuring HRQoL using SIBDQ that consists of 4 domains (QUOTE-IBD and HRQoL are calculated as previously mentioned in operational definitions). The used questionnaire focuses also on the effect of COVID-19 on the provided services.
Records checklist (Annex 9)	145	Record checklist for assessing patients' files in PHC centers to assess their completeness average.

Table (3.1a): Continued

Interview (Annex 11)	10	In-depth interviews with UC patients or their family members to ask them about the provided services and to know more about their suffering while living with disease.
Health care providers/Key informants		
KI interview (Annex 10)	10	In-depth interviews with a KI from the general administration of Hospitals, a head of an internal medicine department, an internist, a gastroenterologist, a medical manager of a PHC center, a nurse in a hospital and another nurse from a PHC center, a senior pharmacy manager, a regional pharmacy manager and a pharmacist in a PHC center. They were asked about HR set-up including numbers, qualifications and training. They were asked also about guidelines/protocols, criteria for admission, limitations, planning for the future, coordination between providers, referral system, reporting/ monitoring and evaluation.

3.8 Ethical considerations

- Academic approval from the School of Public Health at Al-Quds University was taken (Annex 3).
- Ethical approval was taken from Helsinki Committee (Annex 4).
- Administrative approval from HR department in the MoH as well as hospitals and PHC centers' directors was obtained (Annex 5).
- Approval for the use of registered tools that was used in the study (approval from the Netherlands Institute of Health Services Research (NIVEL) for the use of performance part of the QUOTE-IBD and the approval of McMaster University for the use of SIBDQ).
- To protect participants' rights and ensure the performance of ethical questionnaires, a covering letter was added to indicate that participation is voluntary and to confirm that confidentiality will be ensured.
- Permissions were requested from KIs and UC patients for recording their in-depth interviews with explaining the recording mechanism.

- The concept of doing no harm was taken in consideration, so interviews were carried out in a confidential setting by preparing a place supporting confidentiality and doing no harm.
- Patients, who were requested to be interviewed, were assured that all provided information as well as their cited comments would not be attributed to their real names.

3.9 Data collection

3.9.1 Quantitative data

This step took 4 months of time. The questionnaire data were collected from governmental hospitals and PHC centers disseminated across the GS. The questionnaire was filled with 157 patients via phone calls; participants were obtained from 32 PHC centers. Other PHC centers have no UC cases, closed during data collection period due to COVID-19 or have non-respondent UC patients. Every questionnaire took from 40–60 minutes to be completed with the UC patient. The record checklist data were collected from patients' files in the PHC centers through Emblem Health (2014) adult medical record review tool which is designed for primary care files. This tool was used after modification to be suitable for the study context. Every file that has been found was checked and the checklist was filled to specify the points that were completed in patients' files. Every checklist took 10 to 15 minutes to be filled.

3.9.2 Qualitative data

The qualitative data were collected within 2 months of time. In-depth interviews were carried out with 10 KIs with semi-structured questions that were designed and asked to a KI from the general administration of Hospitals, a head of an internal medicine department, an internist, a gastroenterologist, a medical manager of a PHC center, a nurse in a hospital and another nurse from a PHC center, a senior pharmacy manager, a regional pharmacy manager and a pharmacist working in a PHC center. Most of the interviews were recorded concomitantly with note taking. Another 10 in-depth interviews were carried out with patients and members of their family from different governorates. These patients were selected from patients who came to the PHC centers to dispense their medications, admitted UC patients or they were called via phone to participate virtually in interviews because of COVID-19 pandemic. Each interview was conducted within 25 to 45 minutes.

3.10 Response rate

From the 201 patients who were found, 44 were non-respondents and 157 UC patient representing 78.1% agreed to participate through mobile calls and they were included in the study. From the 201 patients, the files of 145 patients were found and reviewed for completeness (72.1%).

3.11 Scientific rigor

3.11.1 Quantitative part (questionnaire)

3.11.1.1 Validity

To enhance the validity of the questionnaire, it was evaluated by 10 experts to assess its relevance, their comments were considered in modifying the questionnaire. In addition, a pilot study was conducted before collecting the actual data to examine the responses of clients to the questionnaire and to test its acceptance and clarity for the UC patients.

3.11.1.2 Reliability

To ensure the reliability of the used instruments, first, data entry was performed in the same day of collection to allow any possible interventions and to check the data quality. Second, to ensure correct data entry and decrease entry errors. Also, re-entry of 5% of the data was performed. Then, to ensure that the reliability of the used scales is accepted, Cronbach's Alpha coefficient is computed for each of them as shown in table 3.2

Table (3.2) Results of Cronbach's Alpha test for the used scales

Scale	Cronbach's Alpha
User-provider interaction	0.871
Patient’s satisfaction using the performance part of QUOTE-IBD	0.854
Health-related quality of life using SIBDQ	0.872

3.11.2 Qualitative part (in-depth interviews)

To ensure the trustworthiness of the qualitative part of this study, a member check was performed to ensure the accuracy of transcripts during interviews, the researcher tried to probe for answers and cover all interview dimensions properly, recording of the interviews was performed to permit re-checking the transcripts accuracy and all the transcripts and recordings are kept for tracking information by others at any time (audit trail).

3.12 Pilot study

To explore the appropriateness of the study instruments, a pilot study was performed with 12 clients, added to that, a pilot interview was performed to allow for further improvement of both validity and reliability of the study.

3.13 Data entry and analysis

3.13.1 Quantitative part

The researcher continuously reviewed the questionnaires during data collection as well as before their entry in order to ensure information validity and to allow immediate correction of them when needed. The Statistical Package of Social Science (SPSS) program was used for the questionnaire data entry and analysis, questions and variables were coded and entered with 5% re-entry of data. Then, to check illogical values, data cleaning was performed. To show sample characteristics and plot differences between various patients' characteristics variables, frequency tables were created. Descriptive statistics were used to analyze numerical data, it helps to describe, depict or summarize data in a meaningful manner and the calculation of mean, median, and standard deviation (SD) was performed. Cross tabulation for main findings and advanced statistical tests such as Independent sample T test and One-way ANOVA test were performed to compare means of numeric variables. The excel program was used for the checklist data entry and analysis and 5% of data were re-entered to check entered items and values.

3.13.2 Qualitative part

To analyze the transcripts of the in-depth interviews, open coding thematic analysis method was used. The main findings were obtained from each interview transcript, after that it was categorized into groups depending on related ideas. A comparison between quantitative and qualitative findings is carried out to provide rich material for further analysis and discussion.

3.14 Limitations of the study

- The use of Donabedian's model as a framework for evaluation in this study, despite its importance, makes it difficult to evaluate some components of the health care

system as they cannot be included under input, process or output alone such as governance and financing.

- It is difficult to reach all the UC patients due to the lack of good reporting and documentation, so, only documented cases were included in this study, while there may be some undocumented cases whom the researcher was not able to reach and include in the study, so, undiagnosed and non-served ones are not included.

- Some UC patients may be not found as some PHC centers were closed due to COVID-19 pandemic. Although, they tend to receive their services from other PHC centers, not all of them may be found and the researcher was not able to review their files.

- It was difficult to obtain the severity and extent of UC for the study participants because these items are not documented in patients' files and it is not applicable to perform a colonoscopy for each patient to determine them.

- The effect of surgery on other variables is not determined, because 6 patients only had been undergone colectomy.

Chapter Four
Results and Discussion

This chapter represents the main findings that were consolidated from participants' responses and patients' files. It includes the results of the quantitative and qualitative parts of the study, beginning with descriptive analysis of the quantitative part summarizing demographic and medical information of the study participants as well as the distribution of the study participants according to service provision related variables, services related to mediations, services related to colonoscopy, services related to lab tests, waiting and contact time, follow-up, perspectives of participants regarding accessibility, health education regarding UC, user-provider interaction, restoration of patients' normal life, perspectives regarding the existing gaps, participants' satisfaction, their QoL and their perspectives about the effect of COVID-19 pandemic on health care services regarding UC. Record checklist summarization is provided for the reviewed files of UC patients to assess documentation practices in the PHC centers that provide health care service to these patients. Main inferential findings were summarized at the end of this chapter.

Main findings of the qualitative part through interviews that was summarized including KIs interviews to assess their perspectives regarding the provided services as well as interviews with patients to verify the quantitative results and to illustrate other perspectives or suffering of these patients.

4.1 Descriptive statistics

4.1.1 Socio-demographic and economic characteristics

The total number of the study participants who completed the questionnaire is 157 with a response rate of 78.1% (44 UC patients are non-respondents). As table 4.1 shows, the mean age of participants is 40.9 years with 14.4 SD. Respondents' age ranges from 16 to77 years. It is consistent with information from references which mention that the incidence peak of UC arises in the second to fourth decades (Friedman & Blumberg, 2018). It is found also that only 5 patients are aged less than 20 years of age. The same table demonstrates that nearly one quarter of the study participants ages (26.8%) are less than 30 years, 24.8% of the participants are aged between 30 and 40 years old, while 20.4% of the are in the age group between 41 and 50 years and 28% of the study participants ages are above 50 years.

Table (4.1) Distribution of the study participants according to their socio-demographic and socioeconomic characteristics

Items	N	%
Age in years		
Less than 30 years	42	26.8
30 to 40 years	39	24.8
41 to 50 years	32	20.4
Above 50 years	44	28.0
Total	**157**	**100.0**
	Mean = 40.9, MD= 40.0, SD= 14.4	
Gender		
Male	91	58.0
Female	66	42.0
Total	**157**	**100.0**
Governorate		
North Gaza	23	14.6
Gaza	57	36.3
Middle zone	36	22.9
Khan Yunis	20	12.7
Rafah	21	13.4
Total	**157**	**100.0**
Marital status		
Married	117	76.0
Unmarried	37	24.0
Total	**154**	**100.0**
Years of education		
< Secondary	28	18.0
Secondary	48	31.0
Postgraduate	79	51.0
Total	**155**	**100.0**
	Mean = 12.77, MD= 13.0, SD= 4.0	
Refugee status		
Refugee	91	58.0
Non-refugee	66	42.0
Total	**157**	**100.0**
Working status		
Working	59	37.6
Not-working	82	52.2
Retired	16	10.2
Total	**157**	**100.0**
Work type		
Employee	54	72
Technicians/workers	8	10.7
Owns a private business	7	9.3
Taxi driver	6	8.0
Total	**75**	**100.0**

Regarding the gender of the participants, 66 of them are females representing 42% and 91 are males representing 58% of participants. It is consistent with what aforementioned by Friedman & Blumberg (2018), they indicate that the female-to-male ratio for UC patients ranges from 0.51 to 1.58. It is also consistent with Abukhedeir study findings in 2020 as he found that 42.7% of participants were females and 57% were males. Also table 4.1 shows that 14.6% of participants are residing in North Gaza, 36.3% in Gaza, 22.9% in the Middle zone, 12.7% in Khan Yunis and 13.4% in Rafah governorate.

Around three quadrants of the study participants are married (76%), while the last unmarried quadrant (24%) is composed of those participants who are single, divorced or widowed. Regarding years of schooling for the study participants, the mean is found 12.77 years with SD of 4. A round half of the participants (51%) have studied for more than 12 years (postgraduates), followed by participants who reached secondary schooling (10-12 years) with the percent of 31%, while the rest (18%) of participants have studied for less than secondary schooling (9 years or less). These results are consistent with Abukhedeir in 2020 that found 20.7% of the study participants have an educational level of less than secondary school and 79.3% of the study participants have secondary school level or more

It is found that 58% of the study participants are refugees and 42% are non-refugees. These results are near to what found by Abukhedeir (2020), as he found that 64% of UC cases are refugees and 36% are non-refugees.

More than half of the study participants (52.2%) are found to be not-working, 37.6% are working, while the remaining 10.2% are retired. This unemployment percent is nearly identical to that found by the PCBS, as it was found 52% in the GS (PCBS, 2019b). This is also consistent with the results of Abukhedeir (2020), who found that 48% of the study participants were not working, 20% were unemployed, 28% for homemakers, 38.7% were employed and 9.3% were retired. It is worth to say that this high percent of unemployment among participants represents their bad economic status that is accompanied by their chronic complex disease, what may add an additional economic burden on them as they need expensive medications and special diets, this alerts to the importance of providing affordable health care services for them like lab tests, medications and colonoscopy and to work for their protection by facilitating their work in suitable places or providing financial support for those with severe cases who are unable to work.

Regarding the type of work, the majority of the working/retired study participants are employees representing 72% of the study participants, where 10.7% are technicians and workers, 9.3% owns their private business and 8% are taxi drivers.

4.1.2 Medical history

As shown in table 4.2, the mean of disease years from diagnosis for the study participants is found 8.54 years with a median of 6 years and 8 SD, their range is from 0 to 40 years. It is lower than the disease duration mean that was found by Ljungström et al. (2019), as they found it 12.6 years with 12.9 SD and lower than the median duration of UC diseased participants in Vasudevan et al. (2013) study, which was found 7 years with duration range from 0 to 57 years. The highest percent was 28% for those who were diagnosed for more than ten years, followed by the group of participants who were diagnosed 6 to 10 years ago with a percent of 26.1%, while 25.5% of the study participants were diagnosed with UC from three years or less and 20.4% were diagnosed from 4 to 5 years.

Regarding the frequency of experiencing flare-up attacks, 35% of study participants experience attacks every 1 to 11 months, while 26.1% experience these flare-ups every 12 months or more. It is found also that 19.1% of participants suffer from recurrent flare-ups during a period of less than a month, while 11.5% of them answered that they experience flare-ups irregularly and only 8.3% of the study participants have not experience any flare-up since starting to take their medications. Comparing these results with Ljungström et al. (2019) findings, they found that 23.3% of the participants experienced relapse in the last 6 months, 34.2% had a relapse in the last 6 to 12 months and 42.5% of them experienced no relapses in the last 12 months.

Responses of the study participants about the last time to experience flare-ups are distributed through: 1month or less for 47.1% of them, 30.6% of them experienced their last flare-up symptoms before 2-10 months and 22.3% of them have experienced it before more a period of more than 10 months. Comparing with the study findings of Carpio et al. (2016), they found that 25.8% of their study participants were experiencing a disease, 22.2% experienced their last flare-up or sustained worsening of UC symptoms from less than 6 months, 13.9% experienced them in the period between 6 to 12 months ago, 34.4% of their study participants experience these symptoms from more than 12 months and 3.8% mentioned that they were not sure about the time of their last flare-up symptoms.

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

Items	N	%
Years since diagnosis with UC		
3 Years and less	40	25.5
From 4 to 5 Years	32	20.4
From 6 to 10 Years	41	26.1
More than 10 Years	44	28.0
Total	**157**	**100.0**
	Mean = 8.54, MD= 6.00, SD=8.0	
Frequency of experiencing flare-ups as reported by clients		
Does not occur after starting to take medications	13	8.3
>1 month	30	19.1
1to 11 Months	55	35.0
12 Months and more	41	26.1
Irregularly	18	11.5
Total	**157**	**100.0**
The last time to experience attack symptoms		
Up to one month	74	47.1
From 2 to 10 Months	48	30.6
Above 10 Months	35	22.3
Total	**157**	**100.0**
	Mean = 9.8, MD= 2.0, SD= 20.7	
End of the last UC attack symptom		
Yes	100	63.7
No	57	36.3
Total	**157**	**100.0**
Flare-up symptoms		
Diarrhea	135	86.0
Abdominal pain or cramps	129	82.2
Mucous or pus in stool	99	63.1
Blood in stool	96	61.1
Others	53	33.76
Presence of extra-intestinal manifestation		
Yes	143	91.1
No	14	8.9
Total	**157**	**100.0**
Extra-intestinal manifestations that patients suffer from		
Joint manifestations	103	72.0
Hematological effects	56	39.2
Weight loss	52	36.4
Dermatological manifestations	44	30.8
Ocular manifestations	34	23.8
Respiratory manifestations	32	22.4
Fever	22	15.4
Headache	9	6.3
Effects on liver	7	4.9
Muscles pain	5	3.5
Others	12	8.4
Suffering from other chronic disease/s		
Yes	55	35.0
No	102	65.0
Total	**157**	**100.0**
Other existing diseases		
High blood pressure	30	54.5
Diabetes mellitus	18	32.7
Heart disease	9	16.4
Kidney disease	4	7.3
Others	25	45.4

When the study participants were asked if their last flare-up was finished, almost two thirds (63.7%) agreed, while 36.3% of them answered that they were suffering from flare-up symptoms during the time of the questionnaire filling. These results are consistent with a previous study in 2019, as Molander & Ylänne found that 78% of the UC patients considered themselves in remission phase and 22% considered themselves in relapse.

Regarding the experienced flare-up symptoms, 86% of the study participants answered that they suffer from diarrhea during flare-ups, 82.2% of the participants experience abdominal pain or cramps, 63.1% of them have mucous or pus in stool and 61.1% of them have blood in stool during flare-ups. Some of the study participants experience other symptoms like flatulence, constipation, vomiting, tiredness, stress, headache, stomachache and shortness of breath. Carpio et al. (2016) found that 60.2% of their study participants, suffer from diarrhea during flare-ups, 57.1% experience rectal bleeding, 54.5% suffer from flatulence, 52.5% from fatigue and tiredness, 47.5% suffers from abdominal pain and/or stinging and 38.8% have joint pain. These findings indicate the importance of providing immediate health care services for UC during flare-ups to improve their health status, prevent complications and to improve their QoL.

The vast majority of the study participants (91.1%) suffer from EIMs, while only 8.9% of the participants have no EIMs. These results seems different from the results of Panés et al. (2017), as they found that 22.6% of UC patients only had a history of EIMs. Concerning EIMs, joint manifestations are found the most predominant with 72%, followed by hematological effects with 39.2%, then weight loss with 36.4%, after that dermatological manifestations, as 30.8% of the study participants suffer from, followed by 23.8% of participants who suffer from ocular manifestations, 22.4% suffer from respiratory manifestations, 15.4% experience fever, 6.3% have headache, 4.9% have effects on liver and 3.5% have muscle pain. Other manifestations that are mentioned by 8.4% participants include nerves manifestations, dizziness, nervousness, loss of appetite, swelling, weight gain and tendonitis. These findings imply the importance of providing comprehensive health care services as providing a MDT that can deal with the disease and its EIMs.

In regard to suffering from other chronic disease/s, 35% of study participants answered with yes, while 65% of them answered with no. This is consistent with the results of Ljungström et al. in 2019 as they found that 30% of the UC study participants were with other chronic disease and 70% were without concomitant chronic diseases. Table 4.2

shows that responses of participants about their other existing chronic disease/s are distributed as follows: 54.5% have high blood pressure, 32.7% have diabetes mellitus, 16.4% have a heart disease, 7.3% of them have a kidney disease and other patients suffer from other chronic diseases/conditions with lesser frequencies like disability, rheumatoid arthritis, spinal disc herniation, respiratory disease, thyroid disease, syndromes, liver diseases, varicose veins, brain disease, ankylosing spondylitis, breast cancer, celiac disease, hernia in the diaphragm, retinal detachment, benign prostate hypertrophy.

Figure (4.1) indicates that 6 participants representing 3.8% have undergone a surgery in colon due to UC, while the rest (96.2%) have no colon surgeries due to UC before. This result is consistent with a previous study which found that 9.3% of the UC patients had undergone a previous surgery/colectomy (Gonczi et al., 2019). Figure (4.2) shows that from those participants who have undergone surgery, 5 participants have undergone surgery for once and 1 participant have undergone surgery twice.

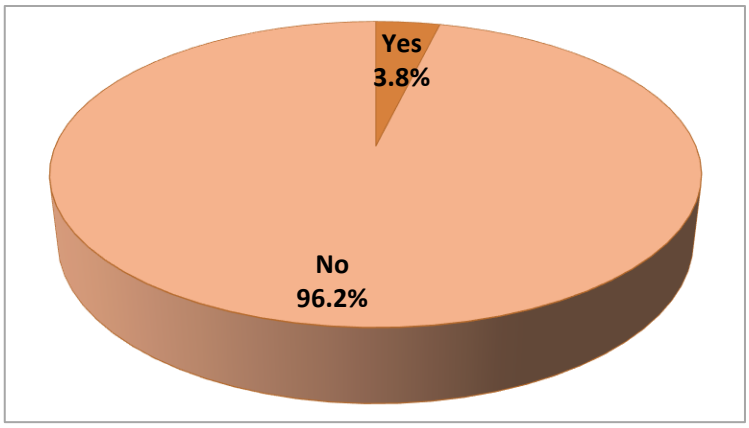

Figure (4.1) Undergoing surgery

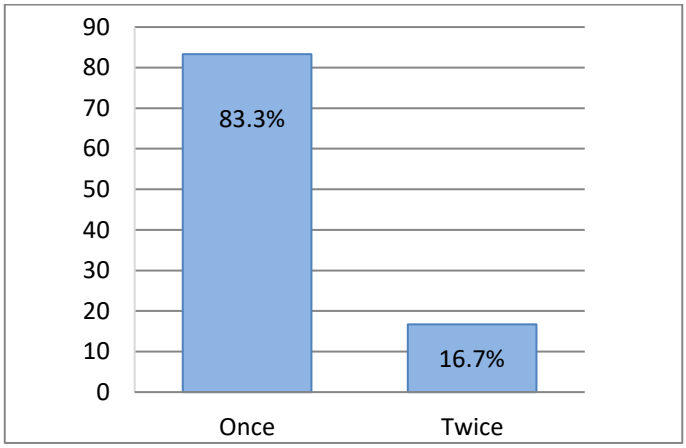

Figure (4.2) Number of colon surgeries

4.1.3 Received services

As indicated in table 4.3, most of the study participants (99.4%) get health care services pertaining to UC from governmental PHC centers, followed by beneficiaries from UC related services provided by governmental hospital (82.2%), after that, 72% for study participants getting UC related health care services from NGOs facilities, while 67.5% of respondents get services from private labs, 52.2% of them get services from a private clinic and 36.9% of the participants tend to get health care services from a community pharmacy. Only 13.4% of the participants get health care services related to UC from an UNRWA clinics and 4.5% get health care services from other places outside the GS. These results indicate the extent to which governmental health care services are important and vital for UC patients, as most of the study participants rely on it.

Regarding the provided health care services related to UC, results indicate that 64.3% of respondents receive follow-up from the GIT outpatient clinic of governmental hospitals, 52.9% of the study participants had performed colonoscopy in governmental hospitals, while 51% of the study participants had performed lab tests, 39.5% of them get health education and 26.8% get nutritional counseling about UC in governmental hospitals. It is found that 14% of the study participants get services from emergency departments related to their disease and 10.8% dispensed medications related to UC from governmental hospitals, 7% of them get inpatient care services and 5.1% get other services from governmental hospitals like surgery or referrals. Concerning qualitative results, a head of a governmental internal medicine department said when interviewed "*UC patients receive services from hospital through two main gates; the first is the outpatient clinic to perform regular follow-ups, where investigation tests are indicated and follow-up of signs is performed. The second gate is for acute or severe cases when they are admitted in the internal medicine department to get their treatment"*. A head nurse in a governmental hospital mentioned that she supervises younger nurses and monitors administrative issues in the internal medicine department. She added that they perform any needed service indicated by doctors for admitted UC patients as monitoring every admitted UC patient in the internal medicine department, giving them intravenous fluids or prescribed medications and said "*Medications are given to patients in time as indicated, we bring these medications from the internal medicine department pharmacy or from the central pharmacy, we also measure patients' vital signs like body temperature, blood pressure, blood glucose levels, identify the number of diarrheas per day, explore if the extent of*

diarrhea is decreased, monitor the compensation of lost fluids during diarrhea, giving blood units or administering sedation in the case of severe abdominal pain. Meals are provided also for admitted UC patients and colonoscopy is performed when needed".

Table (4.3) Distribution of the study participants according services received

Items	N	%
Place of getting health care services regarding UC		
Governmental PHC center	156	99.4
Governmental hospital	129	82.2
NGO facility	113	72.0
Private lab	106	67.5
Private clinic	82	52.2
Community pharmacy	58	36.9
UNRWA clinic	21	13.4
Others (outside the GS)	7	4.5
Receiving health care services regarding UC from a governmental hospital		
Follow-up	101	64.3
Colonoscopy	83	52.9
Lab tests	80	51.0
Health education about UC	62	39.5
Nutritional counseling	42	26.8
Emergency department	22	14.0
Medication dispensing	17	10.8
Inpatient care	11	7.0
Others (surgery, referral)	8	5.1
Receiving health care services regarding UC from a governmental PHC center		
Follow-up	154	98.1
Medication dispensing	152	96.8
Lab tests	32	20.4
Health education about UC	11	7.0
Nutritional counseling	8	5.1
Others	2	1.3
The last time to receive health care services from governmental facilities		
Less than 15 days	47	29.9
From 15 days to one month	73	46.5
More than one month	37	23.6
Total	**157**	**100.0**
	Mean = 1.77, MD = 0.500, SD = 4.78	
Existence of a psychosocial specialist in the governmental health facility where they get their health care services		
Yes	4	2.5
No	31	19.7
I don't know	122	77.7
Total	**157**	**100.0**
Adjustment of UC management plan when participants' case is worsened or passed through complications		
Yes, all the time	108	71.5
Sometimes	13	8.6
No	22	14.6
I don't know	8	5.3
Total	**151**	**100.0**

On the other hand, the study participants' answers about services they get from governmental PHC centers are distributed as follows: The vast majority of study participants (98.1%) have follow-up visits to renew their medications from PHC centers, 96.8% of them dispense their UC medications from these governmental PHC centers, 20.4% perform lab tests in it, while 7% only get health education, 5.1% get nutritional counseling from PHC centers and 1.3% get other services including psychological support and referral to hospital.

According to the General Administration of pharmacy, the monthly average of dispensing Pentasa in PHC centers is 50 0000 tablets, it is dispensed for both UC and crohn's disease patients, so the number of beneficiaries from this service is 280-555 IBD patients monthly.

Through KI interviews, a PHC center's medical manager said "*We work in a fourth level PHC center which provides a variety of health care services. Concerning UC patients, our role in the center is mainly to provide medications like Pentasa and Imuran. PHC centers are also considered as a link between UC patients and governmental hospitals as any suspected UC patient is referred to hospital to be diagnosed, known UC cases also can be referred when needed to the GIT outpatient clinic to perform diagnostics or follow-ups. The PHC center is considered the first option for patients' visits, so we deal with the immediate problem of the patient. Also, if the UC patient needs lab tests like CBC, ESR, we indicate them for him/her. Sometimes, UC patients come after the outpatient visit to ask us about their case or to illustrate their lab test results as we have good relations and trust with our patients".*

An interviewed nurse working in a PHC center illustrated that by working in the chronic diseases department in the PHC center and according to the available patient flow, he deals with chronic disease patients including people with UC. He added that these patients dispense their medications according to special files like UC, crohn's disease and thyroid gland diseases. He said "*The patient first pays for the stamp from the clerk, then comes to the chronic diseases department to deal with nurses as they measure his/her vital signs and take history, then the patient go to the physician and then to the PHC's pharmacy for dispensing medications. The most important service provided in the PHC centers regarding UC is medications dispensing as diagnosis does not occur in PHC centers. The UC patient always comes to the PHC center with his/her diagnosis written on the report*

which is confirmed by the GIT specialist after undergoing colonoscopy and biopsy. In this report, the needed medications are specified".

Regarding the last time to receive health care services from governmental facilities, 29.9% of the study participants answered that they got such services from less than 15 days, while nearly half of them (46.5%) got their last health care services in the period between 15 days to one month ago. The rest of participants (23.6%) got services from governmental health care facilities from more than one month.

The study participants' responses about the existence of a psychological specialist in governmental facilities revealed that most of them (77.7%) did not know if a psychological specialist exists, while 19.7% answered that there is no psychological specialist and only 2.5% of participants agreed that there is a psychological specialist. In other studies like Craven et al. study in 2019, it was found that many patients were benefitted from psychological related services, as they found that 7% of IBD patients were referred to a psychiatrist, more than half of the participants (56%) were engaged in cognitive-behavioral therapy including mindfulness and stress management, 25% of the participants received supportive therapy and less than 5% of the participants for each of psychodynamic, existential/humanistic, biofeedback, and hypnotherapy services.

When interviewed, most of UC patients mentioned that no psychological support is provided for them, a patient's mother said that she hopes that her daughter gets psychological support, and said that this service is missed especially that her daughter has hair loss sometimes due to the use of CSA and because her daughter got depressed due to her recurrent absenteeism from school. Another patient said that psychological support is disappeared completely from specialized persons, but sometimes he mentioned that the doctor supports him and he suggested directing more care regarding psychological support for UC patients as tension and bad psychological conditions have negative effects on UC. From the perspectives of health care working staff, most of interviewed KIs in hospitals said that there are no such specialists. An interviewed KI from the General Administration of Hospitals confirmed that there are no psychological specialists employed in hospitals, but sometimes, they are present in a small scale when there are programs supported from some NGO's and said *"Before a period, a program was implemented for the integration of psychological health inside hospitals, awareness sessions were carried out about how to deal with cases in need to psychological support and small units (one room) was opened in*

some departments like emergency department to be available there once weekly, but this presence was incomplete and was not systematic".

For PHC centers, a medical manager of a PHC center said that they have a psychological support team who performs psychological support for patients. Concerning mental health, the medical manager mentioned that they use the short form general health questionnaire (GHQ-12), which is used for chronically ill patients, they ask the UC patients these 12 questions or patients fill it themselves and using the obtained results, they can diagnose if the patient has any psychological problems and added, "*If the patient seems to have any psychological problems, we have a nurse who performs psychosocial sessions, she performs one session or more for the patient according to his/her case. If the patient is found to be in need to a psychological medication, we prescribe it, especially that UC patients are at high risk of passing through anxiety or depression because of their medications and because of their disease nature especially during relapse periods".*

Regarding the adjustment of UC patients' management plan when their case is worsened or passed through complications, 71.5% answered with "Yes, all the time", 8.6% answered "sometimes", 14.6% for those participants who answered with "No", and the rest (5.3%) answered with "I don't know".

4.1.3.1 Services related to mediations

As table 4.4 shows, the vast majority of the study participant (98.1%) were taking oral 5-ASA (mostly Pentasa or its substitute Rafassal), 45.9% were taking an immunosuppressor like Imuran (azathioprine) or CSA, while 10.2% of them were taking proton pump inhibitors like omeprazole, esomeprazole and pantoprazole, 9.6% of the study participants were taking systemic corticosteroids especially prednisolone tablets and to a lesser extent budesonide tablets or capsules, 6.4% were taking vitamins and minerals like zinc, calcium, vitamin D, vitamin C, vitamin E, vitamin B complex, folic acid and omega 3. It is found also that 5.1% were taking biological agents like Humira (adalimumab) or Infliximab, while 3.2% were taking topical 5-ASA medications like Pentasa suppositories or enemas and 8.9% use other medications like topical corticosteroids (enemas), Flagyl (metronidazole), H1 blockers like ranitidine and famotidine, antiflatulents, ciprofloxacin, Loperamide or herbs. These results are higher than of Panés et al. (2017) findings in participants who were taking aminosalicylates representing 82.4% and those who were on thiopurines (immunosupressors) representing 36.7%, where the study results show lower

values compared to the previously mentioned study concerning the percent of patients taking corticosteroids (6.5%) as well as patients' percent who were taking anti-TNFα drugs (biological medications) representing 23.6%. This is may be because biological agents are not always available in the GS as mentioned by a number of KIs.

According to the same table, 72.6% of the study participants agreed that they are adherent to their prescribed medications all the times, 19.1% answered with sometimes and 8.3% answered that they do not take their medication. The percent of adherent participants to their medications seems to be lower than that found by Min Ho et al. in 2019, as they found that the adherents' percent was 88.3% (using MARS) and the rest of UC patients were non-adherents (11.7%).

Table (4.4) Distribution of the study participants according to services related to mediations

Items	N	%
Medications taken by the participants		
Oral 5-ASA	154	98.1
Immunosuppressor	72	45.9
Proton pump inhibitors	16	10.2
Systemic corticosteroid	15	9.6
Vitamins and minerals	10	6.4
Biological agents	8	5.1
Topical 5-ASA	5	3.2
Others	14	8.9
Participants adherence to the prescribed medication/s		
Yes, all the time	114	72.6
Sometimes	30	19.1
No	13	8.3
Total	**157**	**100.0**
The person who had prescribed medication/s for the participants for the first time		
A physician in MOH	74	47.1
A physician in a private clinic	48	30.6
A physician in an NGO	22	14.0
A physician outside Palestine	9	5.7
Others	4	2.5
Total	**157**	**100.0**
Place of dispensing medications		
Governmental PHC center	155	98.7
Community pharmacy	57	36.3
Governmental hospital	17	10.8
Others (UNRWA clinic, NGO facility)	2	1.3
Availability of their medications in governmental facilities		
Yes, all the time	65	41.4
Sometimes	60	38.2
Some of them are available where others are not	31	19.7
No	1	0.6
Total	**157**	**100.0**

Concerning the person who had prescribed medications for the study participants for the first time, nearly half of the study participants (47.1%) answered that a physician in the MoH had prescribed their medications, while 30.6% of the participants' medications were prescribed by a physician in a private clinic and 14% of the participants' medications were prescribed by an NGO physician. A small portion of participants have their own medication prescription from a physician outside Palestine (5.7%) and 2.5% of the participants have their prescriptions from a physician in Jerusalem, the Jordanian Field Hospital or in UNRWA.

In regard to place of dispensing medications, 98.7% are found to dispense their UC medication/s from governmental PHC centers, while 36.3% of the study participants find themselves have to buy all or some of their medications from community pharmacies, 10.8% of them dispense their UC medications from governmental hospitals and 1.3% dispense medications from UNRWA or from an NGO facility.

When the study participants were asked if they find their medications in governmental facilities all the time, 41.4% answered with yes, 38.2% answered with sometimes, 19.7% answered that some types of their medications are available and others are not and only 0.6% answered that medications are not available at all.

Many of the interviewed patients agreed that they find Pentasa most of the time, a patient's mother said that some medications like Pentasa are always available in the PHC center as well as CSA from hospital, but she added that prednisolone is not always available or it is available sometimes with insufficient amounts and she mentioned that the same thing occurs with Imuran when it is prescribed for her daughter, so they usually tend to buy them from a community pharmacy. Another patient said the contrast about Pentasa as he said *"I have problems in dispensing Pentasa; every month, only half or third of the needed quantity is dispensed for me and if I take my medications as indicated, the dispensed quantities will be adequate only for 10 or 15 days, I cannot buy the remaining quantity from the community pharmacy because it is very expensive, if I tend to buy it, I will sell my house for this purpose as I am not working, so I take only half or third of the needed quantity daily to save the remaining medications' quantity for the rest of the month".*

Many KIs have the same opinion about medications' availability as they mentioned that there are some gaps in medications availability or delay in their arrival especially in the

case of biological therapy, as it is not always available, it pass through many periods of cuts in spite of its urgent need for severe cases. A head of an internal medicine department mentioned when interviewed that there is a gap in the availability of biological medications as they are very important and they transform the disease direction to large extent and it is essential to take these medications in the suitable time and dose and added, *"Biological agents always have periods of cuts and if we find one type, another will be missed because it is not included in the MoH basket, as a result, the patient is obligated to buy it or to have a special permission from the MoH to provide it for him/her".*

A regional pharmacy manager said *"We provide medications with needed types and quantities for each registered patient based on his/her report that is issued by the MoH, we send this report to the MoH central stores to provide us with the needed medications. After receiving the quantity from the MoH drug stores, it is distributed to PHC centers according to the needed quantity of each PHC center. PHC centers after that have the responsibility of dispensing these medications to registered UC patients as indicated. When medications are available in the MoH drug stores, we can provide them easily for patients with the needed quantities, while sometimes as known in our country, there are periods of medications' cuts, in this case, we receive limited quantities of medications, here problems occur, as when I request 200 tablets for example and receive 100 tablet only, then, I should minimize the distributed quantities for PHC centers in my region, this in turn is reflected on quantities received by all patients to give a chance for every patient to have part of his/her medications. PHC pharmacies dispense half or third of the needed quantity for each patient. Sometimes if pharmacists in the PHC centers do not estimate the situation well, then first patients will dispense their complete quantities, while other patients will be not able to dispense any quantity. In this case, pharmacists in PHC centers are responsible for the equity in medications' dispensing. The main obstacle for service provisions occurs only when medications are unavailable in MoH drug stores. Currently there are no problems as medications distribution and dispensing are regular and the needed quantities of medications are available. Medications other than Pentasa and Imuran like Pentasa suppositories or enema are unavailable in the MoH drug stores, so these types cannot be provided, as we can only provide those types of medications that are available in the MoH drug stores. So we cannot provide medications unless it is added to the Palestinian essential drug list (PEDL). In the same time, 50% or more of PEDL's medications are unavailable, so I think it is hard to add new types of medications to it. But it is worth to say*

that sometimes there are some medications that are received out of the PEDL from donations. When these types are available (like budesonide 3mg capsules), we distribute them to the PHC centers to be dispensed to patients, so they are available only few times".

An interviewed senior pharmacy manager said about UC medications and their availability *"UC medications are available including 5-ASA, azathioprine and corticosteroids like prednisolone 5 and 20mg tablets and biological agents. All these medications are included in the PEDL, so they are available with different dosages, this lets doctors to modify doses easily and to change medications from one therapeutic line to another or adding medications according to patient's case. Pentasa and Imuran are available regularly, while we have some problems with prednisolone availability. Around 70% of PEDL's medications are always available. Medications' quantities are sufficient and available regularly in PHC centers in the last 2 years. If some PHC centers have deficiency in Pentasa or Imuran, this occurs because the patient's reports are not monitored as most of the UC patients are prescribed for a loading dose of Pentasa of 2X3 daily, stay on it till their case stabilization. When their flare-up ends, their doctor should reduce their daily dose to 2X2 for example. Because there is no monitoring for reports, patients dispensing average remains at the highest doses, so, some patients dispense more than their monthly need, while others are not able to dispense part or all of their medications. This is because we cannot provide the highest loading dose for all existing patients at the same time, but medications are available to an excellent degree and biological medications are now available in MoH as a donor provided ANERA with financial support to buy Humira for a long period. Some special medications that are not available in the GS for IBD patients can be provided by a special permission after the committee approval especially biological agent and sometimes patients are referred abroad to take their unavailable biological medications like Infliximab. Now, there is nearly no obstacles for providing medications except in the case of medicinal deficit when the MoH cannot provide medications from its sources, then medications quantities will be inadequate".* The senior pharmacy manager suggested setting a committee to modify or update therapeutic protocols according to the international ones, what will lead to modify or change the PEDL also. He added *"The committee is ought to be conducted regularly and produce recommendations like replacing Pentasa with Arava or replacing Imuran by CSA or to change dispensing quantities like dispensing 2g of Pentasa instead of 3g daily, and then to monitor the patients' cases for 1 or 2 months. This means putting complete policies for the follow-up of patients. In my opinion this will lead to the provision of higher quality health care services. It is important to establish a committee for monitoring UC management especially that improper*

management leads the patient to biological treatment which is very costy on the MoH budget, so when UC cases are monitored and managed properly, this will rationalize resources consumption especially that the number of IBD patients is increasing".

4.1.3.2 Services related to colonoscopy

Findings in table 4.5 demonstrate that the mean for the number of times that the study participants had performed colonoscopy is 2.89 times, with 2.67 SD. The same table shows that 38.2% of the study participants had performed colonoscopy for once only since diagnosis. This is because some of them were diagnosed lately, others do not prefer to repeat colonoscopy as it is an annoying process or because they are afraid to enter through flare-up as a result to it, while others wait to repeat it in governmental hospital when their doctor indicate it. It is found that 21% of the participants had performed colonoscopy twice since diagnosis, while 14.6% of them performed it for three times. The rest 26.1% performed colonoscopy four times or more since diagnosis.

Regarding the place of performing colonoscopy, nearly half of the study participants (45.2%) had performed it in a private or an NGO facility only, while 26.8% had performed it in a governmental hospital only. The percent of study participants that had performed colonoscopy in both governmental and NGO hospitals is found to be 28%. The causes for performing colonoscopy outside governmental facilities are illustrated in the same table. The most predominant cause is found long waiting list, as 62.6% of the study participants responded, followed by the unavailability of it in a governmental hospital/break down at the time when it was indicated for them, this occurred with 41.7% of the study participants, while 17.4% of the study participants stated that the cause of performing it outside governmental hospitals was that the physician referred them to do it there, 11.3% had performed it outside governmental hospitals because they perceive that results of it are more accurate than that of the governmental hospital. Another cause for performing colonoscopy outside governmental hospitals is experiencing better care, cleanliness or respect outside governmental hospitals, while 3.5% said that the cause is that the general anesthesia is not given in governmental hospitals during colonoscopy, while 1.7% mention that this is because the governmental facility lacks confidentiality. Equally, 1.7% of the study participants mentioned that the cause lies in that they were living abroad, the same percent (1.7%) had undergone it outside governmental hospitals, because it was indicated for them during the COVID-19 pandemic.

Table (4.5) Distribution of the study participants according to services related to colonoscopy

Items	N	%
Number of performed colonoscopies		
One	60	38.2
Two	33	21.0
Three	23	14.6
Four and more	41	26.1
Total	**157**	**100.0**
	Mean = 2.89, MD = 2.00, SD = 2.67	
Place of performing colonoscopy		
In a private or an NGO hospital	71	45.2
Sometimes in a governmental hospital and sometimes in a private or an NGO hospital	44	28.0
In a governmental hospital	42	26.8
Total	**157**	**100.0**
Causes of performing colonoscopy out of governmental hospitals		
Long waiting list	72	62.6
It was not always available	48	41.7
The physician referred me to it	20	17.4
Results are more accurate	13	11.3
Care/cleanliness/respect are better, than that in the governmental hospital	6	5.2
General anesthesia is not given during colonoscopy	4	3.5
Governmental facilities lack confidentiality	2	1.7
Living abroad	2	1.7
The presence of COVID-19 pandemic	2	1.7
Others	2	1.7
Answers of participants who tried colonoscopy in both governmental and private/ NGO hospital, about which one is more comfortable		
Private/NGO facility	23	52.3
There is no difference	17	38.6
Governmental hospital	4	9.1
Total	**44**	**100.0**
Reasons for perceiving the private/NGO hospital colonoscopy more comfortable		
The use of general anesthesia during colonoscopy in the private/NGO hospitals	14	60.9
Caring for patient is better	6	26.1
Perceiving that it is more accurate	3	13
Total	**23**	**100.0**
Availability of colonoscopy in the governmental hospital when it is indicated		
Yes, all the time	60	44.1
Sometimes	35	25.7
No	41	30.1
Total	**136**	**100.0**
Receiving feedback about colonoscopy result when it was performed in a governmental hospital		
Yes, all the time	67	78.8
Sometimes	5	5.9
No	13	15.3
Total	**85**	**100.0**

When the study participants who had performed colonoscopy in both governmental and private/NGO hospitals were asked about which of them were found to be more comfortable, 52.3% answered that the private/NGO hospital was more comfortable, 38.6% of them said that they did not experience any difference, while 9.1% of them said that they found colonoscopy performance inside governmental hospitals more comfortable. The reasons for patients perceiving the private/NGO hospital is more comfortable are as follows: 60.9% of them said that the cause is the use of general anesthesia during colonoscopy in the private/NGO hospitals, followed by those who said that because caring for patient is better representing 26.1%, the rest 13% answered that the cause is higher accuracy of the private/NGO hospital.

Concerning the availability of colonoscopy in governmental hospitals when it is indicated, 44.1% of the study participants answered with yes, 25.7% of the participants answered with sometimes and 30.1% of them answered with no.

Most of interviewed patients mentioned that, colonoscopy is unavailable in governmental hospitals most of the time when it is indicated for them, a male patient said when interviewed that he performs colonoscopy sometimes in the governmental hospital, when it is not available due to breaking down or when there are long waiting lists which extended to months, he finds himself obligated to perform it in a private/NGO hospital. He added that to specify the date of colonoscopy performance in the governmental hospital, he should first have a follow-up visit, and to have this follow-up visit, he should wait minimally for two weeks, then after seeing the doctor in the governmental hospital, the doctor decides the date of colonoscopy. So, when he has complications or a disease attack, he is unable to wait this long time to have follow-up and colonoscopy, he suggested to perform scheduling for colonoscopy and to define the date of the following colonoscopy for each patient and to remember him/her by a call or message with its date and time. Another patient said *"I perform colonoscopy in the governmental hospital, even I wait for it any period of time, I have no choices except waiting as I cannot perform it outside governmental hospitals because of my hard economic status".*

Regarding the available numbers of colonoscopy devices in the GS, a KI from the General Administration of Hospitals mentioned that the current number of available colonoscopy devices in governmental hospitals in the GS is 5 colonoscopy units and that the 6th device is under preparation in North Gaza governorate, while the existing 5 colonoscopy units are distributed as follows: 1 for children in Rantissi Hospital, 2 in Al-Shifa Hospital, one of them is for the internal medicine department and the other is for the surgery department,

there is also 1 device in Shohadaa Al-Aqsa hospital, it was broken down for a year and currently was returned to work, 1 in Nasser Hospital and 1 in the European Gaza Hospital. He added that colonoscopy devices in the GS have a problem in their maintenance due to the scarcity in their spare parts and their susceptibility to recurrent breakdown due to the high load on it, lack of training or unorganized training on it and lack of washing and disinfecting materials that is used after every patient.

Regarding the number of performed colonoscopies per year, it was found that 632 colonoscopies were performed in internal medicine departments and 249 colonoscopies in surgery departments in the MoH hospitals (MoH, 2021b), while in this year from January to the end of June 2021, 280 colonoscopies were performed in internal medicine departments and 216 colonoscopies in the surgery departments (MoH, 2021c).

An interviewed head of an internal medicine department said regarding colonoscopy "*The most important gap is the unavailability of sufficient number of colonoscopy devices, some hospitals have no colonoscopy devices, so patients may be referred to other hospitals or may sell some of their assets to perform it in a private or an NGO hospital. Because there is no protocols or guidelines, no trust and no coordination between the different health care providers, sometimes the patient performs colonoscopy in one facility, then in the following day he/she repeats it in another facility from another health care provider"*. An internist said that investigation tools (colonoscopy devices) are available, but the available type is only the basic and added "*Advanced international colonoscopy units are missed as the available colonoscopy type is only the routine rigid one, while in some cases there is a need to other different colonoscopy devices types like sigmoidoscope, flexible or capsule colonoscope. These types are needed for cases with severe attack when rigid colonoscope cannot be used".*

In regard to receiving feedback about colonoscopy result when it was performed in a governmental hospital, 78.8% of the study participants answered that they have feedback every time, while 5.9% answered that they receive feedback sometimes and the rest (15.3%) answered with "No".

4.1.3.3 Lab services

As shown in table 4.6, most of the study participants (67.5%) had performed lab tests during the last year, while the rest (32.5%) have not performed any lab test in the previous year. From those who had performed lab tests in the last year, 28.3% answered that it was from the last month or less, 38.7% of the participants answered that they have their last lab

tests from 1.1 to 5 months ago and 33% of them have the last lab tests from more than 5 months. The mean was 1.32 month with SD of 0.47.

Table (4.6) Distribution of the study participants according to services related to lab tests

Items	N	%
Performing lab tests last year		
Yes	106	67.5
No	51	32.5
Total	**157**	**100.0**
Period from performing the last lab test/s		
One month and less	30	28.3
From 1.1 to 5 Months	41	38.7
More than 5 Months	35	33.0
Total	**106**	**100.0**
	Mean = 1.32, MD = 1.00, SD = 0.47	
Place of performing lab Tests		
Private Lab	113	72.0
Governmental hospital	85	54.1
Governmental PHC center	35	22.3
UNRWA clinic	21	13.4
NGO facility	21	13.4
Availability of lab tests in governmental facilities when they were indicated		
Yes, all the time	47	35.3
Sometimes	20	15.0
Some of them are available where others are not	57	42.9
No	9	6.8
Total	**133**	**100.0**
Receiving feedback about lab tests results when they were performed in governmental facilities		
Yes, all the time	90	78.9
Sometimes	15	13.2
No	9	7.9
Total	**114**	**100.0**
Adjustment of UC management plan if lab test results were higher or lower than normal		
Yes, all the time	105	73.9
Sometimes	10	7.0
No	19	13.4
I don't know	8	5.6
Total	**142**	**100.0**

It is worth to mention that most of the study participants (72%) perform their needed lab tests in a private lab and 54.1% of the participants perform them in governmental hospitals labs, followed by those participants who perform their lab tests in governmental PHC centers representing 22.3%, while an equal percent is found for those who perform lab tests in UNRWA clinics labs and NGO's labs with 13.4% for each.

Focusing on the availability of lab tests in governmental facilities when they are indicated, 35.3% of respondents answered that they find the needed lab tests all the time, while 15% of respondents said that they find the lab tests sometimes, 42.9% of respondents answered that some of the lab tests are available in governmental facilities and 6.8% said that the needed lab tests are not available in governmental health care facilities.

Three interviewed patients said that they find lab tests available in governmental health care facilities when they are indicated. One patient said that lab tests are available most of the time either in the PHC center near her home, or she is referred to the central PHC lab to perform the unavailable ones. She rarely does not find them available and performs them in a private lab. Many patients mentioned that they perform lab tests in PHC centers, governmental hospitals or sometimes in private labs, when the indicated tests are not available like vitamin D level, CRP, iron level and vitamin B_{12} level. One patient also said that lab tests are available except the thalassemia test. A different patient said that he tends sometimes to perform lab tests in private labs when he needs to perform them rapidly without having an appointment for follow-up visit and said *"I cannot perform them in hospital as the doctor should indicate them for me in the follow-up visit to be able to perform them there"*. A medical manager of a PHC center said "*Lab tests are available and accessible; lab tests are either present in our PHC center or in the central lab in Shohadaa Al Remal PHC center where we refer patients to perform the unavailable lab tests. The existing lab tests are lab investigations or lab interpretations like CBC, ESR and urinalysis, but if the patient needs advanced tests like colonoscopy, it is not available in any PHC center, so we refer the patient in this case to the GIT outpatient clinic. Patients are satisfied regarding the available lab services".* An interviewed gastroenterologist confirmed that lab tests are available in hospitals also and they can be performed regularly in hospital according to the appointment system or according to the patient's case.

For people who had performed lab tests in governmental facilities, 78.9% of them agreed that they receive feedback about their lab test results all the time, 13.2% of them answered with sometimes, while 7.9% of them answered that they did not receive any feedback about their lab test results. Concerning the adjustment of UC management plan when lab test results are abnormal, 73.9% of the study participants answered with "yes, all the time", 7% of them answered with "sometimes", 13.4% answered with "No" and 5.6% answered with "I don't know". The rest 15 participants, always have normal lab test results.

4.1.4 Status of health care facilities

Regarding the suitability of health care facilities to receive UC patients, an interviewed internist said that the hospital is prepared to deal with UC inpatients as there are no many special requirements for them. An interviewed gastroenterologist has the same opinion and said that this is because the number of UC patients is not too high and they would not need to be admitted at the same time, so they do not need extra requirements inside the internal medicine department, while a head nurse in a governmental hospital said that there is no specialized department for GIT patients to separate them from other patients as UC patients have weak immune system.

4.1.5 Guidelines

All interviewed KIs, confirmed that there are no written guidelines or standards for dealing with UC patients. A head of an internal medicine department said *"Unfortunately, there are no written guidelines to be generalized, applied or supervised. Some certified board doctors can deal with UC cases, while others work according to their experience. Setting up special IBD units and providing sub-specialties or sub-sub-specialties for colon diseases, will enhance the setting of special guidelines that doctors can follow. This will provide better follow-up and patients will have follow-up with any existing doctor as all doctors follow standardized guidelines. Also, to enhance setting up such guidelines, the existence of a colligative body or assembly for gastroenterology or specifically an IBD association can be useful. Putting guidelines is essential to specify work features and technical issues, however, setting guidelines without the availability of teaching facilities is useless, so hospitals are ought to be teaching hospitals and an educational system should be set with clear guidelines and protocols for all diseases especially chronic diseases like UC. This will organize a big part of work, then we have to apply on-job training, auditing and follow-up on these guidelines for the work staff who deals with UC patients".*

4.1.6 Waiting and contact time

From the study participants who had performed colonoscopy in governmental hospitals, around half of them (43%) answered that there was a long waiting list before performing colonoscopy, 26.7% answered with "to some extent", while 30.2% answered that there was not a long waiting list before performing colonoscopy. An interviewed internist said in this regard *"Waiting time in the GS is suitable generally compared to that available abroad,*

but the problem lies in people's mentality as they perceive they should get timely health care services" and added *"Mostly, we give the patient 2 weeks maximally for inpatients to perform colonoscopy which is good compared to other countries. Moreover, if the patient case is urgent, colonoscopy is accelerated".* When the internist was told that about half of the interviewed patients say that they wait long time of nearly two to three months before performing colonoscopy, the comment was that when the case is mild and not admitted, colonoscopy may take longer time to be performed.

Study findings demonstrate that 70.3% from the study participants who have follow-up in governmental hospitals answered that they wait for a long time in the outpatient clinic to see the doctor in the outpatient clinic, 15.8% said that waiting time is long to some extent, while 13.9% said that it is not long.

The average waiting time in outpatient clinics is found 102.8 minutes as 19.8% of participants said that they wait 30 minutes or less, 17.8% said that they wait from 31 to 60 minutes, 12.9% said that they wait from 61 to less than 120 minutes and nearly the half (49.5%) said that they wait for 120 minutes or more. Comparing these results with Soares et al. findings (2015), they found that higher percent of IBD patients (36.4%) were waiting from 0 to 30 minutes, 45.1% were waiting from 31 to 60 minutes and 18.5% were waiting for more than 60 minutes. According to United Kingdom's Governmental standards, waiting time in outpatient clinics should not exceed 30 minutes (Stocking, 1991).

All interviewed patients said that waiting time for follow-up in hospital is too long except one patient who said that it is suitable. One patient said *"Most of the time, I wait for four hours in the outpatient clinic to have a follow-up and when my turn comes, I see the doctor only for few minutes, he looks at lab tests results quickly and does not talk a lot with me or ask about my case or tell me how to deal with UC. The outpatient clinic is always very crowded. One time I asked the doctor about his late coming to the outpatient clinic, he said that he should finish his round for inpatients in the internal medicine department first, then he can come to perform follow-ups for the outpatients".* All patients who have follow-up in the governmental hospital said that they have booking for follow-up every month, some of them see this sufficient, but others say that when they have a flare-up, to have a follow-up visit, they can book for it minimally after 2 weeks, so some of them cannot wait for this appointment and go to a private doctor for follow-up in this case. A gastroenterologist said *"Waiting time for the visits of follow-up is individualized according to the patient's case. For urgent cases, booking for follow-up is often specified after 1 week, while stable cases are given an appointment for follow-up after 1 month or maximally after 6 weeks".*

Table (4.7) Distribution of the study participants according to waiting and contact time

Items	N	%
Existence of long waiting list before participant's turn in colonoscopy performance in governmental hospitals		
Yes	37	43.0
To some extent	23	26.7
No	26	30.2
Total	**86**	**100.0**
Waiting long time for follow-up in outpatient clinic at governmental hospitals		
Yes	71	70.3
To some extent	16	15.8
No	14	13.9
Total	**101**	**100.0**
Average waiting time in the outpatient clinic in the governmental hospital		
30 Min. and less	20	19.8
From 31 to 60 Min.	18	17.8
From 61 to less than 120 Min.	13	12.9
120 Min. and above	50	49.5
Total	**101**	**100.0**
	Mean = 102.8, MD = 90.00, SD = 63.3	
Waiting for long time in follow-up visits in a governmental PHC center		
Yes	4	2.6
To some extent	23	14.9
No	127	82.5
Total	**154**	**100.0**
Average waiting time for the physician in the governmental PHC center		
5 and less	19	12.3
From 6 to 10	80	51.9
From 11 to 15	25	16.2
More than 15	30	19.5
Total	**154**	**100.0**
	Mean = 11.58, MD= 10.00, SD= 9.5	
Waiting for long time before performing lab tests		
Yes	15	13.3
To some extent	21	18.6
No	77	68.1
Total	**113**	**100.0**
Waiting for long time before dispensing medications		
Yes	3	1.9
To some extent	9	5.7
No	145	92.4
Total	**157**	**100.0**
Average contact time with the physician in the governmental hospital		
Less than 10 Min.	29	28.7
10 Min.	33	32.7
More than 10 Min.	39	38.6
Total	**101**	**100.0**
	Mean = 12.3, MD= 10.00, SD= 12.21	
Average contact time with the physician in the governmental PHC center		
Less than 5 Min.	49	31.8
Five Min.	73	47.4
More than 5 Min.	32	20.8
Total	**154**	**100.0**
	Mean = 5.7, MD= 5.00, SD= 3.7	

Table 4.7 illustrates that most of the study participants (82.5%) who have follow-up in governmental PHC centers regarding their UC perceive that they do not wait for long time to see the doctor, 14.9% of them answered that the waiting time was long to some extent and only 2.6% of them said that they wait long time for the doctor to get follow-up.

The average waiting time for the physician in PHC centers is found 11.58 minutes from patients' perspectives with 9.5 SD, it is lower than that found by Anan (2011) study as she found it 31.7 minutes with 24.4 SD and she found that the longest reported waiting time was 62 minutes for dental care and 50 minutes in the case of family planning, while the shortest waiting times were found 20 minutes for nebulizer and dressing. Table 4.7 shows that 12.3% of the study participants wait 5 minutes or less for the doctor in the PHC center, near half of the participants (51.9%) said that they wait for the doctor from 6 to 10 minutes, while 16.2% said that they wait from 11 to 15 minutes and the rest (19.5%) said that they wait for more than 15 minutes. Comparing these results with Anan findings in 2011, she found that 44.9% of participants wait for less than 30 minutes, half of participants wait from 30 to 60 minutes to have consultation with the physician and 5.1% were found to wait more than 60 minutes to see the physician.

A medical manager of a PHC center's opinion about waiting time in the PHC center is found consistent with these results. The medical manager said *"Waiting time is suitable, our PHC center works from 7:30 AM to 2:15 PM and each clinic inside the center deals with 40-50 case daily, so we have no crowdedness in these clinics unlike what occurs in outpatient clinics of hospitals. We can say that we have no waiting time as patients come and get their needed services. If the patient needs to perform lab tests, we indicate its performance, if the case needs psychological support, we perform it and if the patient needs to dispense medications, he/she dispense them simply, so we have no problems with waiting time".*

Furthermore, the same table shows that participants perception about waiting time before performing lab tests is summarized as follows: about two thirds (68.1%) of the participants who perform lab tests in governmental facilities answered that they do not wait for long time, 18.6% answered with "to some extent" and 13.3% answered that they wait for long time to perform lab tests in governmental facilities.

Concerning waiting time before dispensing medications from governmental facilities, the vast majority (92.4%) of the study participants denied waiting for long time, 5.7% of them answered with "to some extent" and only a small portion (1.9%) answered that they wait for long time when they come to dispense their medications from governmental facilities.

The opinion of an interviewed pharmacist working in a PHC center is found consistent with these results as he said that waiting time for medications dispensing is too short as patients dispense their medications quickly without waiting. He added *"In our PHC center, medications are dispensed every 15 days, but a lot of patients adjust their daily doses of Pentasa; if they were taking 3X3 tablets daily, they reduce it to 2X3 daily. In this case, medications will be enough for longer period, in turn they will come after a period of longer than 15 days. Some patients also told the doctor to increase the written doses in the report to dispense the maximal quantity. We dispense medications according to the system of PHC center, so we dispense the written quantities in the report of each patient".*

In regard to contact time with the physician in the governmental hospital, the mean is found to be 12.3 minutes from patients' perspectives. It is found that 38.6% of the study participants who had follow-up visits in governmental hospitals said that the contact time in the hospital is more than 10 minutes, 32.7% said that it is 10 minutes and 28.7% said that the contact time is less than 10 minutes.

Most of the interviewed patients said that the contact time with the doctor is very short, while one patient said that the doctor stays sufficient time with him and that he asks the doctor everything he wants. Another patient said "*The contact time is not adequate in hospital as the UC patient needs more contact time especially in the first follow-ups after diagnosis to illustrate how to take the multiple medications, what to eat and how to deal with acute case".*

A head of an internal medicine department opinion was consistent and he said *"Contact time is not sufficient because there is crowdedness in the GIT outpatient clinic, so the UC patient do not have sufficient contact time, as a result, many patients tend to go to private clinics to have sufficient contact time. High workload prevents reaching integrated health care services, as there is no sufficient number of specialized doctors, so GIT specialists see 200 patients daily instead of 30 as an example, so the patient will not take sufficient contact time with the physician".* The interviewed gastroenterologist has the same opinion and said *"To improve contact time, the number of outpatient clinics should be increased, as well as the number of gastroenterologists and the number of patients per day should be decreased".*

The contact time mean in governmental PHC centers is found 5.73 minutes with 3.7 SD, it is found that 31.8% of the participants answered that it is less than 5 minutes, 47.4% said that the contact time is 5 minutes, while 20.8% said that it is more than 5 minutes. The contact time mean is shorter by nearly the half of what found by Elmore et al. (2016) as

they found the mean length of consultation 10 minutes and 22 seconds with SD of 4 minutes and 45 seconds.

An interviewed medical manager of a PHC center mentioned that UC patients are unique and have special characteristics especially in the case of flare-ups, so, when an UC patient has a problem, the physician will take longer consultation time with him/her depending on his/her case. The medical manager added *"If the patient's case is stable and have no problems and he/she comes for dispensing medications only, the consultation time will be shorter than that when there are health problems' that need taking history or performing physical examination".*

4.1.7 Follow-up

Findings in table 4.8 demonstrate that the vast majority of the study participants (98.1%) receive follow-up from governmental PHC centers that are distributed across the GS, followed by governmental hospitals with the percent of 64.3%, then 54.8% from participants are found to have their follow-up from private clinics, after that 15.9% of the participants indicated that they receive follow-up from NGOs' facilities and only 0.6% indicated that he/she gets follow-up from a community pharmacy.

All interviewed patients had at minimum one follow-up in the governmental hospital, some of them have follow-up in hospital only, while others follow their case with a doctor in a private clinic also. A female patient said that she gets follow-up in the governmental hospital, but it is not always easy to have an additional follow-up visit when an attack occurs while the follow-up appointment is still far, in this case, she tends to have a follow-up in a private clinic.

An interviewed internist said *"The provided health care services in the outpatient clinic may be not with a high quality due to the lack of a pure IBD specialist and because GIT doctors there deal with other GIT patients like patients with hepatic problems and others. This leads to work overload, leading in turn to lower quality services. Currently we start to work on setting up a new department for GIT diseases only within the internal medicine department. By setting it, UC cases can have their follow-up and it is expected to have sufficient number of GIT and IBD specialists at the long term. By separating IBD patients from other internal or GIT departments' patients, this will provide their own nutritionists, surgeons and other needed specialties concerning their case what will affect their health positively".*

Table (4.8) Distribution of the study participants according to follow-up

Items	N	%
Place of receiving follow-up		
Governmental PHC center	154	98.1
Governmental hospital	101	64.3
Private clinic	86	54.8
NGO facility	25	15.9
Community pharmacy	1	0.6
Regularity in follow-up visits		
Yes	101	64.3
No	56	35.7
Total	**157**	**100.0**
Reasons for not conducting regular follow-up visits		
Because of COVID- 19, outpatient clinic is closed and tending not to go out from home	22	39.3
Stabilization of case	15	26.8
Getting bored from follow-up without improvement	15	26.8
I cannot afford transportation cost	6	10.7
Others	12	21.4
Number of follow-up visits per year		
No visits	11	7.0
1-2	12	7.6
≥3	134	85.4
Total	**157**	**100.0**
Adequacy of follow-up visits		
Yes	97	62.2
To some extent	31	19.9
No	28	17.9
Total	**156**	**100.0**
Provider communication with participants in case of participant follow-up absence		
Yes	10	6.5
No	143	93.5
Total	**153**	**100.0**
Physician with the most contact in the last year		
A physician in a governmental hospital	67	42.7
A physician in a private clinic	53	33.8
A physician in a governmental PHC center	26	16.6
A physician in an NGO facility	11	7.0
Total	**157**	**100.0**

In terms of regularity in follow-up visits, 64.3% answered with “Yes”, while 35.7% answered with “No”. Regarding causes for irregular follow-ups, 39.3% of them answered that the cause is the COVID-19 pandemic that led to outpatient clinics’ closure at the time of data collection, followed by 26.8% for both those who said that the cause is the stabilization of their case and those who do not realize improvement in their case and get bored from follow-up, while 10.7% of them answered that the cause is that they are unable to afford the transport cost and 21.4% of responses distributed between long waiting time in outpatient clinic, having sufficient experience to deal with their case, unrespect from the working staff, movement difficulty and untrusting the care provider.

Regarding the number of follow-up visits for the study participants per year, 85.4% answered that they have three or more follow-up visits a year, 7.6% indicated that they get 1-2 visits per year and 7% answered that they have no follow-up visits at all. Concerning participants' perception about the adequacy of these follow-up visits, 62.2% of them feel that they are adequate, 19.9% of participants find them adequate to some extent, while 17.9% of them indicated that their follow-up visits are inadequate. Soares et al. (2015) found that 61% of the IBD participants had 3 or more visits in the outpatient clinic per year, 38.2% have 1-2 visits and 0.8% had no follow-up visits. According to the MoH, the number of follow-up visits in the GS for GIT/liver outpatient clinics is 2390 visits in 2020 (MoH, 2021b), while it is 3549 visits in the first half of the year 2021 (MoH, 2021c). This difference may occur because the outpatient clinics were closed many times during the first period of COVID-19 pandemic in the GS in 2020.

As shown in figure (4.3), the majority of the study participants (93.5%) indicated that the provider did not communicate with them when they were absent for follow-up visits. Only 6.5% indicated that the provider communicates with them in the case of follow-up absence.

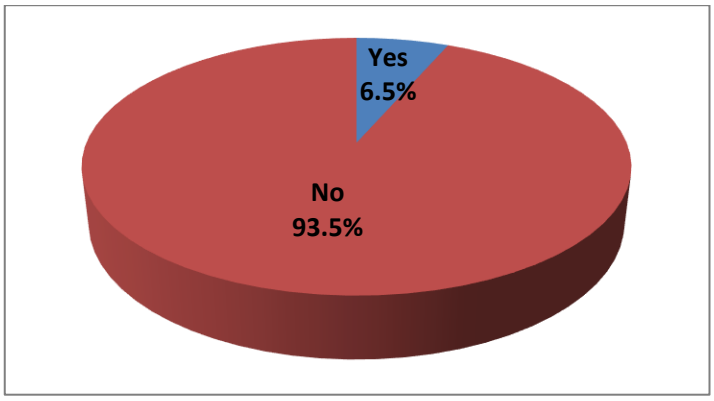

Figure (4.3) Provider communication with participants in the case of participants' follow-up absence

Results reflect that nearly half of the study participants (42.7%) had their most contact with doctors in governmental hospitals in the last year, followed by those who contacted mostly with the doctor in a private clinic with the percent of 33.8%, then 16.6% for those who mostly contacted with a doctor in a governmental PHC centers. The rest (7%) had their most contact last year with a doctor in NGOs facilities. Molander & Ylänne found in 2019 that 54.5% of UC patients were currently seeing a GIT specialist to manage their disease, 41.7% were seeing an internist with gastroenterology focus, while 15.9% were seeing a PHC physician or a GP.

4.1.8 Accessibility

In connection with the ease of reaching governmental health facilities, 84.7% of the study participants answered with "Yes", 10.8% of participants answered by "To some extent" and only 4.5% answered with "No".

An interviewed head of an internal medicine department mentioned that GIT outpatient clinics are not fairly distributed in the GS, as patients who live in eastern areas like Shujaia or other far areas, find difficulties in reaching hospitals and he suggested providing sufficient number of GIT specialists in PHC centers that locate in these areas. He added *"It is important to provide diagnostic services quickly when it is needed like colonoscopy and histology labs for biopsy examination as biopsy analysis is very costy when it is performed in a private histology lab as it costs from 150 to 200 New Israeli Shekels".* A KI from the General Administration of Hospitals said when interviewed that there are 3 histopathology labs in the GS, one in Al-Shifa Hospital, the second in Nasser hospital and the third is available in the European Gaza Hospital.

Table (4.9) Perspectives of participants regarding accessibility

Items	N	%
Ease of reaching governmental health care facilities		
Yes	133	84.7
To some extent	17	10.8
No	7	4.5
Total	**157**	**100.0**
Ease of reaching places inside health care facilities		
Yes	151	96.2
To some extent	3	1.9
No	3	1.9
Total	**157**	**100.0**
Ease of contact with the physician in the health facility when an urgent issue happens to participants regarding UC		
Yes	73	48.3
To some extent	23	15.2
No	55	36.4
Total	**151**	**100.0**
Reactions in case of starting a flare-up attack		
Call the gastroenterologist	78	50.3
Go to the hospital	47	30.3
Go to PHC center	8	5.2
Increase doses/ add medication by him/herself	7	4.5
Others	15	9.5
Total	**155**	**100.0**

Furthermore, study participants' answers concerning the ease of reaching places inside health care facilities are distributed as follows: The vast majority of them (96.2%) answered that it is easy, the rest of answers are distributed equally by 1.9% for those whom answer was "To some extent" and "No".

Nearly half of the participants (48.3%) indicated that it is easy to contact with the physician in the health care facility when an urgent issue happens with them regarding UC, 15.2% indicated that it is easy to some extent and 36.4% indicated that it is not easy to contact with the physician.

An interviewed patient said that he cannot contact with doctors, especially during COVID-19 pandemic as the European Gaza hospital was closed, he added *"I had called the number that the MoH had introduced to obtain my medications in the first period of COVID-19 pandemic, first they reply to my call and said that they will provide it, but they did not do, may be because I live in a far eastern area, after that they did not respond to my following calls. I did not take my medications and my flare-up worsened till the near PHC center opened nearly after one month".* In contrast, an interviewed patients' mother mentioned that they have a good contact with the doctor in the governmental hospital and she calls him when her daughter is admitted and that the doctor attends to see her daughter's case and good care is provided for her.

When the study participants were asked about the thing they do in the case of having an attack, half of them mentioned that they call the gastroenterologist, 30.3% of them tend to go to the hospital, 5.2% of them go to the PHC center, while 4.5% of them increase medication doses or add medication to control the flare-up by themselves. Others tend to search in the internet or do nothing, some of them ask a friend about what to do, follow a special diet or g to the near community pharmacy.

4.1.9 Health education regarding UC

Regarding the main source of information about UC, 67.5% of the study participants indicated that the internal medicine doctor is their main source, 64.3% indicated that internet is the main source, 4.5% indicated that they depend on the physician in the PHC center as their main source of information. To lesser extent, some participants indicated other sources like family, friends, books, patient having the same disease, television, physician in UNRWA. Comparing these results with Becker et al. study findings in 2015, it is found consistent with it in that 69% of the UC participants indicated that they have information about their disease from the gastroenterologist, but 54% of their respondents

were found to obtain their information from CCC alone and 55% of them rely on other online sources, and to a higher extent, they found that 34% of their respondents rely on information they obtain from other people with UC, they found 28% of the respondents rely on information from the family doctor, this is higher than that found by this study, 10% from CCC-sponsored events and 12% from other health care professionals.

Table (4.10) Distribution of study participants' according to health education regarding UC

Items	N	%
Main source/s of information about UC		
Internal medicine doctor	106	67.5
Internet	101	64.3
Physician in PHC center	7	4.5
Others	17	10.8
Receiving health education about UC in governmental PHC center/hospital		
Yes	82	52.2
No	75	47.8
Total	**157**	**100.0**
Time of receiving health education about UC in governmental facilities		
Irregularly, during the follow-up visits	46	56.1
At the time of diagnosis of my UC only	27	32.9
Regularly, every follow-up visit	6	7.3
Others	3	3.7
Total	**82**	**100**
Benefit of the received health education		
Beneficial to large extent	44	53.7
Beneficial- to some extent	37	45.1
Not beneficial	1	1.2
Total	**82**	**100.0**
Receiving educational materials about UC during visits to governmental health care facilities in the last year		
Yes	16	10.2
No	141	89.8
Total	**157**	**100.0**
Areas of need for health education		
Nutrition, what to eat and what not to eat	78	49.7
UC complications	49	31.2
Getting more information about UC generally	48	30.6
Signs and symptoms of the beginning of a flare-up	46	29.3
How to take medication/s	46	29.3
Follow up importance	41	26.1
Other	11	7.0
Perception about disease understanding		
Excellent	80	51.6
Good	59	38.1
Fair/ Poor	16	10.3
Total	**155**	**100.0**

Approximately half of the participants (52.2%) answered that they received health education about UC in the governmental health care facilities before, while the other half (47.8%) denied receiving such health education.

An interviewed patient said *"In the PHC center, there is no health education about UC, doctors in the hospital give us health education, but it is insufficient. Also, not all doctors perceive that diet have really an effect on the disease, but there was a good thing that last year, the doctor invited me with a group of patients with UC and crohn's disease to attend a lecture about special diets and its importance on disease management and a book about suitable diets was distributed for attendants at the end of the lecture. It was conducted by a GIT doctor from the West Bank. It was a good chance to meet other patients with the same disease and exchange experience. Many times I use internet to search for information about dealing with my disease and to know more about suitable food recipes for UC".* The patient suggested to supply health care facilities with nutritionists, conduct continuous workshops, assemble UC patients in one place and to provide facilities that provide suitable foods for them like bakeries, restaurants or supermarkets as that present for celiac patients. Another patient said *"No one neither in the hospital nor in the PHC center had told me how to deal with flare-ups, what to eat or what to avoid. Only the doctor in the private clinic said that to me. Now, I deal with my disease according to my experience".*

The medical manager of a PHC center said *"Health education is one of the most important substrates of medical consultation, so, every patient (including UC patients) should have health education and counseling according to his/her case".* The medical manager added that because there is no specialized department for nutritional counseling and there is no nutritionists, so they give health education and nutritional counseling generally through follow-ups. A head of an internal medicine department said about health education that it is limited according to the available time, he mentioned that the doctor can see every patient for 10 minutes maximally during the follow-up visit, while patients need health education for longer time. He suggested enhancing contact time by providing sufficient number of specialized or semi-specialized doctors in order to provide patients with the needed information about their disease and dealing with it, to put clear guidelines supplied with methods of giving instructions for patients according to their case. He added *"We always have information asymmetry as when I speak with the patient, tell him/her some information and prescribe medications, I expect that he/she knows all things about his/her disease, while in reality, they may hear some words that they do not understand, so there is*

a gap between service providers and patients. This gap leads the patient to search for other source of information, like in the internet, which may not always includes accurate information, what may lead to negative effects on the patient's health. So it is important to provide patients with the right information from the right source and to provide them with posters, brochures, workshops". Regarding nutritional counseling, the head of the internal medicine department said *"Nutritional education is totally missed in internal medicine departments and they are not considered important issues, while patients perceive them their main concern, the most thing that patients are interested with is what to eat during their day, so patients are in urgent need to the existence of a nutritionist to specify suitable meals for them. From abroad experience, it is realized how it is important to provide nutritionists for departments like pediatrics, internal medicine departments, surgery departments, intensive care units and gynecology and obstetrics. Nutritionists have a big role in medical work and they can specify foods that interact with medications".*

Concerning the time of receiving health education in governmental hospitals/PHC centers, patients who had received health education in governmental facilities replied that it was conducted irregularly during follow-up visits (56.1%), 32.9% replied that it was at the time of diagnosis only, 7.3% replied that they had health education regularly, every follow-up visit and 3.7% had health education in other times including the time of renewing report from hospital (nearly every 4 years) or when asking the doctor about a thing only.

The study findings show that 53.7% of participants who received health education in governmental facilities, found it beneficial to large extent, 45.1% found it beneficial to some extent and 1.2% found it not beneficial. About receiving educational materials concerning UC during the last year visits in governmental health care facilities, most of the study participants (89.8%) neglected receiving such materials, while only 10.2% of them affirmed receiving educational materials.

Generally, nearly half of the study participants (49.7%) perceive that they need health education about nutrition to know what to eat and what to avoid to have a stable case, 31.2% prefer to have health education about their disease potential complications, 30.6% want to know more information about their disease in general, while 29.3% need to know about signs and symptoms of flare-up beginning and how to deal with it equally like those who want to take health education about how to take medications, 26.1% prefer to know

about follow-up importance and 7% of answers include other fields like new medications, causes of UC, how to avoid it and about the importance of exercise for UC patients.

In regard to the participants' perception about understanding their disease, 51.6% of the study participants rated it excellent, 38.1% rated it good and the remaining 10.3% perceive their understanding to their disease as fair to poor.

4.1.10 Coordination

An internist said *"Coordination between private and governmental hospitals is not available at all, while it is very weak between primary and secondary health care, this is considered a gap, but currently, there is working on it. I think if the gastroenterologist put a plan for each patient for the next year or 2 years and it is attached to the patient's file in the PHC center, then the physician in the PHC center take it in consideration during UC patient's follow-ups, this will lower workload in outpatient clinics and in the same time, this will facilitate patients' follow-up instead of coming to hospital for routine follow-up only. This is what occurs in some advanced countries and it gives better health outcomes. In these countries, the GP or family doctor takes the role of case management in coordination with the gastroenterologist by producing a renewable management plan for each UC patient according to his/her case. Currently, the role of PHC centers is not activated as needed, patients go to these widely spread centers nearly every month only to dispense their medications, while the GIT outpatient clinics are crowded with stable cases who mostly come for routine check-up investigation that can be performed by physicians in PHC centers".*

A medical manager of a PHC center mentioned that coordination between the health care staff in the same facility is available and essential in all levels and they work as one unit within the PHC level and illustrated that they cooperate and coordinate with other PHC centers in two dimensions; first in referring patients generally and UC patients particularly to the central lab in Sohadaa Al-Remal PHC center to perform unavailable lab tests in their PHC center and they have no problems in this field as patients accept that. The other part of coordination occurs when there is shortage in UC medications, we address this problem by communicating with the near PHC centers to ask if these medications are available. If they are found available, we write a prescription for the UC patient to dispense his/her medications from the other PHC center. Regarding cooperation with hospitals, the medical

manager mentioned that there are 2 forms of coordination between primary and secondary health care facilities; the first is referring UC patients to the GIT outpatient clinic when needed. There they can be referred to the emergency department or admitted. The PHC's medical manager added *"We consider this a faced problem as when we refer the UC patient to hospital, we fill a special referral form, specify a follow-up date in the outpatient clinic and enter this date on the system, then the patient is directed to the administrative manager of the PHC center to specify a number for him/her on the system. The administrative manager communicates then with the outpatient clinic to affirm the follow-up date. If the specified day is too far like after one month or more and the patient's case is urgent and the patient complains, we try to accelerate this referral by writing "urgent" and we direct the patient for going to the GIT outpatient clinic and try to book a nearer date. The other important type of coordination between us and the secondary health care level occurs when we write a referral form for the patient to the gastroenterologist. In this case, we wait for the specialist's feedback which is a missed part. We in PHC centers, believe that respect should be bidirectional; as in the same time that we respect the GIT specialist and write all needed information including patient's data and the cause of referral, the box in the bottom of the referral form remains empty without supplying us with the specialist's feedback about what was happened with the patient in the hospital, while outpatient clinics refuses receiving patients unless they have the mentioned PHC's center referral form with complete data. This issue is considered a big defect that prevents the provision of integrated health care services. This feedback is beneficial for the patient as we can attach it to his/her file what will provide us with the needed information about the patient's case, changes in medications and information about what was performed for the patient in the hospital. It is important to provide us with written material instead of verbal saying by the patient to prove any modifications in the patient's management plan".*

4.1.11 User-provider interaction

This domain includes 18 items reflecting participants' perspectives concerning user-provider interaction. The DPC-13 tool (Sustersic et al., 2018) was used with modifications to be suitable for use in this study. As noticed in table 4.11, the higher the mean score, the better user-provider interaction status. The same table indicates that the total mean for user-provider interaction is 85.7 with 11.9 SD. This mean may be high because answers of patients were taken about the physician with the most contact, most patients tend to have follow-ups with providers they are comfortable to deal with.

Table (4.11) Distribution of the study participants according to user-provider interaction

Items		Strongly disagree	Disagree	Neutral	Agree	Strongly Agree	Weighted Mean
Did the doctor listen to you carefully during consultation?	N	2	8	13	11	123	91.2
	%	1.3	5.1	8.3	7.0	78.3	
Did the doctor allow you to talk without interrupting you?	N	3	5	7	25	117	91.6
	%	1.9	3.2	4.5	15.9	74.5	
Did the doctor encourage you to express yourself / talk?	N	5	4	11	14	123	91.3
	%	3.2	2.5	7.0	8.9	78.3	
Did you feel that the doctor examines you thoroughly?	N	9	5	15	20	108	87.1
	%	5.7	3.2	9.6	12.7	68.8	
Do you feel that the doctor understands you?	N	1	2	10	11	133	94.8
	%	0.6	1.3	6.4	7.0	84.7	
Was it easy to understand what the doctor said?	N	1	0	6	15	135	96.1
	%	0.6	0.0	3.8	9.6	86.0	
Do you feel you were given all the necessary information?	N	5	15	15	32	90	83.8
	%	3.2	9.6	9.6	20.4	57.3	
Did the doctor explain the advantages and disadvantages of the treatment or care strategy?	N	40	13	26	23	55	65.1
	%	25.5	8.3	16.6	14.6	35.0	
In your opinion, did the doctor have a reassuring attitude and way of talking?	N	10	2	16	24	105	87.0
	%	6.4	1.3	10.2	15.3	66.9	
Do the physician deals with you respectfully?	N	2	2	5	7	141	96.1
	%	1.3	1.3	3.2	4.5	89.8	
Did the doctor make sure that you understood his explanations and instructions?	N	8	5	20	24	100	85.9
	%	5.1	3.2	12.7	15.3	63.7	
Did the doctor reply to all your expectations and concerns?	N	4	3	27	26	97	86.6
	%	2.5	1.9	17.2	16.6	61.8	
Do the nurse deals with you respectfully?	N	1	7	13	15	102	90.4
	%	0.7	5.1	9.4	10.9	73.9	
Do the lab technician deals with you respectfully?	N	1	1	9	12	102	94.1
	%	0.8	0.8	7.2	9.6	81.6	
Do the pharmacist deals with you respectfully?	N	1	3	3	15	135	95.7
	%	0.6	1.9	1.9	9.6	86.0	
Do the pharmacist inform you how to take your medications every visit?	N	61	19	12	16	49	56.6
	%	38.9	12.1	7.6	10.2	31.2	
If you want to ask the pharmacist anything about your medication, do you find it easy?	N	1	2	8	18	127	94.4
	%	0.6	1.3	5.1	11.5	81.4	
	Mean = 85.7, MD = 89.4, SD = 11.9						

Findings in table 4.11 show that most of the study participants (95.6%) are agree and strongly agree that it was easy to understand what the doctor said during follow-ups in the past year for the physician with the most contact. Also, with the same percent, the majority of study participants agreed and strongly agreed that the pharmacist deals with them

respectfully. Most of the study participants (94.3%) also agreed and strongly agreed that the physician deals with them respectfully.

Many of the interviewed patients affirm that the working staff deal with them respectfully and listen to them carefully. An admitted patient's mother said when interviewed "*In hospital, health workers pay an excellent attention to my daughter and do not neglect us as well as workers in the PHC center"*. In contrast, another patient mentioned that the health staff in the governmental hospital are always irritated and annoyed and want to finish the follow-up visit quickly because of crowdedness and nurses do not pay attention to patients.

The lowest mean score in this domain is noticed for the item "Do the pharmacist informs you how to take your medications every visit?" as only 41.4% of the study participants agreed and strongly agreed with it. A pharmacist working in a PHC center commented this and said *"I am working here as a pharmacist, my work is only to dispense medications and to give some instructions for taking them like how many times and before or after meals. UC patients take their medications chronically, so, when we dispense their medications for the first time, we tell them how to take these medications, but by time, they became experts more than us and adjust their needed doses, especially that there are patients in our PHC center who take medications for more than 30 years, they have the experience to reduce the number of daily tablets when their case improves and increase the daily dose when their case worsens. As a result, and because they always dispense the maximum daily dose, they have a surplus in medications when they take lower quantities in their stabilization cases, so they do not come to dispense their medications sometimes"*. Regarding contact time with patients, he said that they do not spent a lot of time with them as patients are told by doctors about all needed information concerning medications before arriving pharmacy like taking before or after meals, increasing or decreasing drug doses or any other instructions, so the pharmacist's role from his opinion is to dispense medications only.

The second lowest score in this domain is found for the item "Did the doctor explain the advantages and disadvantages of the treatment or care strategy?" as 49.6% of participants agreed and strongly agreed with it.

4.1.12 Restoration to normal life

Table 4.12 shows patients' perspectives regarding restoration to their normal life after receiving health care services, it consists of 5 items. The average mean for this domain is found to be 71.9 with 17.5 SD. The highest score in this domain is realized for the item of returning to daily normal activities, as 80.9% of the study participants agreed and strongly agreed with the statement. Also, 79% of the study participants are found agree or strongly agree that they realize an improvement in their health status. To a lesser extent, 73.5% of the study participants agreed and strongly agreed that they return to work normally.

Table (4.12) Distribution of the study participants according to restoration to normal life

Items		Strongly disagree	Disagree	Neutral	Agree	Strongly Agree	Weighted Mean
After receiving health care services, to what extent do you realize an improvement in your health status?	N	6	5	22	53	71	82.7
	%	3.8	3.2	14.0	33.8	45.2	
After receiving health care services, to what extent do you realize restoration of your eating habits?	N	5	22	39	42	49	73.8
	%	3.2	14.0	24.8	26.8	31.2	
After receiving health care services, to what extent do you realize restoration of bowel habits?	N	8	21	37	36	55	73.9
	%	5.1	13.4	23.6	22.9	35.0	
After receiving health care services, to what extent do you consider that you have returned to your normal daily activities?	N	6	9	15	37	90	85.0
	%	3.8	5.7	9.6	23.6	57.3	
After receiving health care services, to what extent have you returned to work normally?	N	6	8	9	21	43	80.0
	%	6.9	9.2	10.3	24.1	49.4	
	Mean = 71.9, Median = 72.00, SD = 17.50						

Table 4.12 indicates that 58% of the study participants agreed and strongly agreed that they realize restoration of their eating habits. The least mean score in this domain is observed for restoration of participants' bowel habits, as 57.9% of them answered with agree and strongly agree. Little of interviewed patients said that they returned to their normal life including eating habits, daily activities and work after starting to take their medications, while most of them mentioned that they are trying to cope with their disease, return to their daily life and their new eating habits. An admitted patient said *"Since my diagnosis with UC, I feel tiered by exerting any small effort or while performing home activities. So, I tend to reduce any hard work like preparing hard recipes to prevent being tired, I have not*

returned to my normal life and when I have to go out from home, I tend to think 1000 times before I do". She added that sometimes she misses eating some foods that she avoids them, as during the last 2 years, she was feeling discomfort by eating a lot of food types.

4.1.13 Perspectives about the existing gaps

When the study participants were asked about being returned home without receiving the needed health care services regarding UC in the past year, around two thirds of them (68.6%) answered with yes, while only 31.4% answered that they had not been returned in the past year. From those who had been returned, 33% of them mentioned that they had been retuned 1 or 2 times in the past year, while 36.8% of them had been returned from 3 to 5 times, 19.8% had been returned from 6 to 9 times and 10.4% mentioned that they had been returned 10 times or more. Regarding the reason of their return, the major cause with 85% of responses was the unavailability of medication/s, followed by 20.6% for the unavailability of colonoscopy, then 15.9% because of lab tests unavailability, while 9.3% replied that the cause was the unavailability of the physician in his/her office. The remaining causes distributed between the closure of PHC centers due to COVID-19 and long waiting time in the hospital's outpatient clinic.

More than half of the study participants (54.1%) consider that the unavailability of some medicines is the most annoying thing they face while receiving services related to UC, followed by the unavailability of some lab tests with the percent of 33.8%, while 33.1% mentioned that the most annoying thing is long waiting time followed by participants who mentioned that crowdedness is the most annoying thing (31.2%), 22.9% answered that the inadequate mitigation measures against COVID-19 in the health care facility is the main annoying thing followed by 16.6% for those who answered that the lack in specialized services is the most annoying thing, then 15.9% were annoyed mostly from infrequent colonoscopy performance and 12.7% were mainly annoyed from infrequent appointments. Moreover, 9.6% answered that poor staff communication is the thing annoying most, 7% were annoyed from the short contact time with the care provider, 5.7% were annoyed from the unavailability of colonoscopy in the governmental facility, 4.5% from inadequate care and respect to patients and the rest of participants perspectives about the main annoying things were distributed between bad management of the outpatient clinic, the co-payment's cost, delayed arrival of medications and halving the dispensed medications quantity and the delay in report issuance from hospitals.

Table (4.13) Distribution of participants according to perspectives about the existing gaps

Items	No.	%
Being returned home without receiving services in the past year		
Yes	107	68.6
No	49	31.4
Total	**156**	**100.0**
Times of return in the last year		
2 and less	35	33.0
From 3 to 5	39	36.8
From 6 to 9	21	19.8
10 and more	11	10.4
Total	106	100.0
	Mean = 4.44, MD = 4.00, SD = 3.12	
Reasons for their return		
Medications are unavailable	91	85.0
Colonoscopy was unavailable	22	20.6
Lab tests were unavailable	17	15.9
The physician was unavailable in office	10	9.3
Others	6	5.6
The main annoying thing/s while utilizing services related to UC		
Unavailability of some medicines	85	54.1
Unavailability of some laboratory tests	53	33.8
Long waiting time	52	33.1
Crowdedness	49	31.2
Mitigation measures against COVID-19 are not enough in the health care facility	36	22.9
Lack of specialized services	26	16.6
Infrequent colonoscopies	25	15.9
Infrequent appointments	20	12.7
Poor staff communication	15	9.6
Short contact time with the provider	11	7.0
Unavailability of colonoscopy	9	5.7
Inadequate care and respect to patients	7	4.5
Others	13	8.3
Existence of services that are needed but not available regarding UC		
Yes	61	38.9
No	96	61.1
Total	**157**	**100.0**
Services that are needed but not available		
Availability of medications like Pentasa suppositories, supplements, biological medications, ciprofloxacin	17	27.9
Health counseling and education/ A telephone line for counseling/psychological counseling and support	12	19.7
Promoting service provision	11	18
Availability of colonoscopy when it is indicated with scheduling for the next colonoscopy	10	16.4
Availability of additional human resources	10	16.4

Interviewed patients illustrated some of these annoying things; many patients said that the outpatient clinic is always very crowded, one patient said *"The outpatient clinic is always crowded, and the number of GIT doctors is very small. Also, when the doctor is absent, there is no available substitute, so most of the time I go to a private clinic for follow-up; I go to follow-up in hospital only when I need to perform colonoscopy"*. A mother of a 3 years' patient mentioned that the number pediatrics GIT specialists is insufficient. Another male patient suggested to organize the outpatient clinic and to open the outpatient clinic 3 days instead of 2 days weekly to reduce crowdedness. A patient's wife was annoyed from the co-payment of both medications and lab tests and said that they tried to be exempted from them, but they were told that these medications cannot be exempted from co-payment and said *"When I have the cost of co-payment for only half of medications' quantities, I dispense half of the needed quantities for my husband, to made medications be adequate for the whole of the month, he takes only half of his prescribed quantities daily, so, he is always in relapse. Also, the hospital where he gets follow-up is very far and the transportation for it is very costy, so he tends not to go for follow-up regularly".*

About the existence of services that are needed but not available, 38.9% of the study participants answered with "yes", while 61.1% answered with "No". Regarding these missed services, 27.9% of participants mentioned that the needed service is the availability of some medications like Pentasa suppositories, supplements, biological medications and ciprofloxacin, while 19.7% answered that they need health counseling and education/ a telephone line for counseling/psychological support. Also, 18% answered that they need promoting service provision like paying more care and respect to patients, the availability of lab tests and better management of the outpatient clinic, added to that, 16.4% of participants perceive that the missing service is the availability of colonoscopy when it is indicated with scheduling for the next colonoscopy. Equally, 16.4% of this group said that they feel that there is a need for additional HR like an internist in PHC center, nutritionists, higher number of gastroenterologists and training for the staff.

An interviewed internist spoke about unavailable services and said that comprehensive services are unavailable as well as a special unit for IBD patients including psychological and nutritional services. Another gap was mentioned by the internist which is insufficient number of GIT specialists in outpatient clinics despite numbers seem to be sufficient for the admitted inpatient. The internist added that there is insufficient number of specialized

clinical pharmacists in IBD, nutritionists, nurses and specialized psychological specialists for chronic diseases not psychiatric diseases. The internist added *"Some techniques are unavailable also like embolization technique for patients admitted with severe UC attack, it is considered as an alternative for surgery and it is not available in the GS, also the availability of a specialized gastroenterologist surgeons is missed as there is only one hepato-biliary surgeon in the GS, added to that, there is no sustainability in medications especially in biological therapy, taking in consideration that there are new effective biological agents that are added to the international guidelines that patients in the GS have no access to them".* The internist suggested to support opening of specialized gastroenterology unit, as it will assure continuity of care and a specialized staff will be included, it can be established as a central GIT unit for the whole of the GS, the internist said *"I think it would be sufficient, as the GS is a small area and the central unit can cover all IBD patients and include all the available GIT specialists instead of distributing them in governorates. Unifying the GIT specialists in one place will facilitate service provision and will improve the quality of the provided services".* An interviewed gastroenterologist had a consistent perspectives concerning inadequacy in gastroenterologists and nurses numbers, added that there is miss-distribution for them and mentioned that they have a problem in the narrow space of the outpatient clinic in the hospital where he works as it can accommodate 1 person only and he added that the outpatient clinic's days was diminished from 3 days weekly to once weekly, leading to crowdedness and overload.

A KI from the General Administration of Hospitals said that the number of GIT specialists in the GS is 11, they are distributed as follows: 2 for pediatrics in Rantissi Hospital who have a board certificate, 2 in the Indonesian Hospital, from which one has a board and the other with a diploma degree, 2 gastroenterologists with board in Al-Shifa Hospital, 1 doctor with master degree in gastroenterology in Al-Aqsa Martyrs Hospital, 2 in Nasser Hospital, from which one with a master degree and the other with board certificate and the same with the 2 doctors in the European Gaza Hospital. GIT specialists ratio in the GS which is 0.55 per 100,000 population, seems to be lower than that found in New Zealand in 2017 (1.96 per 100,000 population) according to Stamm et al. (2020) and that found in Canada (2.14 per 100,000 population) in 2016 (Leddin et al., 2018). Regarding the number of histology specialists, the KI from the General Administration of Hospitals mentioned that there are 5 specialists, 3 of them exist in Al-Shifa Hospital, 1 in Nasser Hospital with board certificate and 1 in the European Gaza Hospital. By obtaining the ratio of them per

100,000, it is found 0.25 and it is much less than that found in Canada and the United States of America (4.81 and 3.94 per 100,000 population respectively) in the year 2017 (Metter et al., 2019). About the existence of nutritionists or clinical pharmacists, the same interviewed KI mentioned that in the last year, 22 pharmacists attended a course in clinical nutrition and they are integrated in some services and a policy was conducted for their integration, but this issue stills in its first steps.

4.1.14 Patients' satisfaction

In this section the QUOTE-IBD is used to measure participants' satisfaction. It is a tool that has been developed by the NIVEL. The performance part was used to explore the participants' experiences regarding the functioning of health care workers and medical practices for each health care aspect (Van der Eijk et al., 2001). Concerning the scoring of performance part of the QUOTE-IBD, the response to each statement is chosen from a four-point Likert scale, and then scored as follows: the answers "no" and "not really" are scored with 1, while the answers "on the whole, yes" and "yes" are scored with 0. The average population performance scores range is from 0 which represents the best performance to 1 representing poor performance (Van der Eijk et al., 2001). In this section, findings is compared with Casanova et al. (2020) findings who conducted their study on IBD patients as whole.

As shown in figure (4.4), 85.4% of the study participants were in touch with one or more medical specialists during the past year (52 weeks) because of IBD, while the rest 14.6% of them have no such touch.

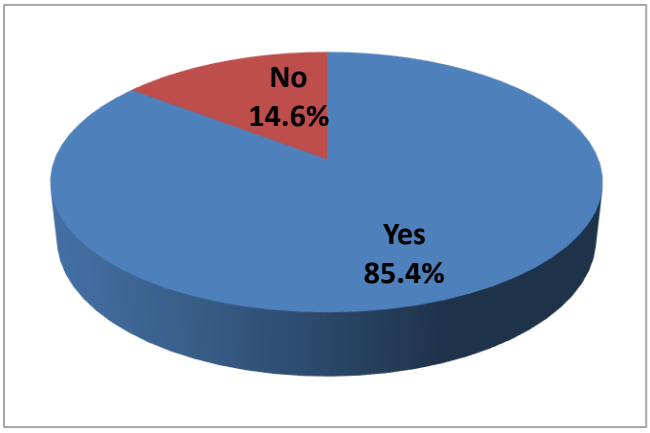

Figure (4.4) Being in touch with one or more medical specialists during the past year because of IBD

As indicated in table 4.14, the average mean of accessibility domain is 0.42 out of 1, the best mean score in this domain is for the promptly availability of the physician in case of acute problems, it if found 0.19, it is found to be better than that of Casanova et al. (2020), as they found it 0.77, the following good statement is found "Is always easy to reach by telephone" with the mean score of 0.34, it is worse than that found by Casanova et al. (2020) as they found it 0.25. The mean score of the item "Makes sure an adequately competent substitute is available if he/she is absent" is 0.42, it is also worse than what found by Casanova et al. (2020) as they found it 0.05. The worst mean score of this domain is 0.47 for the item "Does not keep me in the waiting room for more than 15 minutes", but it is better than that found by Casanova et al. in 2020 (0.77). The previous mean scores are for patients who had a type of contact with a doctor during the past year. For patients who have not been in touch with a medical specialist during the past year, the mean score for the item "The outpatient clinic is easy to reach by telephone" is very bad as it is observed to be 0.68, which is worse than the result of patients with a doctor contact in the past year.

In the same table, the courtesy domain mean is found 0.12. The best mean score in this domain is found for both of the items "Always takes me seriously" and "Gives me confidence in him/her" with 0.07, they are little better than Casanova et al. (2020) findings, who found them 0.09 and 0.1 respectively. The following good result in this domain is for the item "Always keeps appointments punctually" which is found 0.1, it is better than that found by Casanova et al. (2020) who found it 0.54. The worst value in this domain is found for the item "Pays attention to the influence of IBD on my family life and/or work situation" which is found 0.33, but it is better than that found by Casanova et al. (2020) as they found it 0.66.

Table (4.14) Distribution of study participants according to their satisfaction using QUOTE-IBD

	Items	Yes		No		Total		Mean
		N	%	N	%	N	%	
For patients who had a contact with a medical specialist during the past year: The GP/specialist I have seen during the past year, with whom I have had the most contact …...								
Accessibility	Does not keep me in the waiting room for more than 15 minutes	72	53.3	63	46.7	135	100.0	0.47
	is always easy to reach by telephone	89	56.7	45	33.6	134	100.0	0.34
	Makes sure an adequately competent substitute is available if he/she is absent	74	57.8	54	42.2	128	100.0	0.42
	Is promptly available in case of acute problems	110	81.5	25	18.5	135	100.0	0.19
	The outpatient clinic is easy to reach by telephone (Patient with no follow-up during the last year)	7	31.8	15	68.2	22	100.0	0.68
		Mean = 0.42, MD = 0.25, SD = 0.21						

Table (4.14a): Continued

Courtesy	Always takes me seriously	126	93.3	9	6.7	135	100.0	0.07
	Always keeps appointments punctually	122	90.4	13	9.6	135	100.0	0.10
	Pays attention to the influence of my IBD on my family life and/or work situation	90	66.7	45	33.3	135	100.0	0.33
	Gives me confidence in him/her	126	93.3	9	6.7	135	100.0	0.07
		Mean = 0.12, MD = 0.00, SD = 0.20						
Cost	Prescribes medicines which are fully covered by the National Health System or social services	126	93.3	9	6.7	135	100.0	0.07
	Medicines which are fully covered by the National Health System or social services are prescribed to me (Patient with no follow-up during the last year)	21	95.5	1	4.5	22	100.0	0.05
		Mean = 0.06, MD = 0.00, SD = 0.233						
Accommodation	Has a waiting area and consulting room which are clean and orderly	122	90.4	13	9.6	135	100.0	0.10
	Has a waiting area and consulting room with good toilet facilities	90	84.1	17	15.9	107	100.0	0.16
	Waiting areas and consulting rooms in the hospital are clean and orderly (Patient with no follow-ups during the last year)	18	81.8	4	18.2	22	100.0	0.18
	The hospital has good toilet facilities (Patient with no follow-up during the last year)	14	82.4	3	17.6	17	100.0	0.18
		Mean = 0.10, MD = 0.00, SD = 0.25						
Continuity of care	Makes sure that I can see a specialist within 2 weeks after being referred to him/her	75	83.3	15	16.7	90	100.0	0.17
	Always communicates with other health and social care providers about the services I require	60	46.5	69	53.5	129	100.0	0.53
	Is the GP/specialist I usually see	124	91.9	11	8.1	135	100.0	0.08
	Lets me consult him/her regularly	123	91.1	12	8.9	135	100.0	0.09
		Mean = 0.17, MD = 0.00, SD = 0.21						
Information	Informs me, in understandable language, about the medicines that are prescribed for me	126	94.0	8	6.0	134	100.0	0.06
	Informs me clearly about the examinations I am subjected to	120	89.6	14	10.4	134	100.0	0.10
	Informs me clearly about other possible physical problems due to IBD, e.g. joint pain	86	63.7	49	36.3	135	100.0	0.36
	Informs me adequately about nutrition and IBD	78	57.8	57	42.2	135	100.0	0.42
	The hospital provides adequate information about nutrition (Patient with no follow-up during the last year)	11	50.0	11	50.0	22	100.	0.50
		Mean = 0.20, MD = 0.25, SD = 0.24						
Competence	Has a good understanding of my problems	130	96.3	5	3.7	135	100.0	0.04
	Approach my physical complaints, due to IBD, also from a psychological point of view	122	91.0	12	9.0	134	100.0	0.09
	Nurses at the endoscopy department have specific expertise in IBD (Patient with no follow-up during the last year)	14	73.7	5	26.3	19	100.0	0.26
		Mean = 0.05, MD = 0.00, SD = 0.18						
Autonomy	Allows me to have an input into the decisions regarding the treatment or help I receive	87	64.9	47	35.1	134	100.0	0.35
Overall for QUOTE-IBD		**Mean = 0.16, MD = 0.13, SD = 0.15**						

The mean for the domain “cost”, is found 0.06 and it is found that the mean for the item “Prescribes medicines which are fully covered by the National Health System or social services” is found 0.07, which is worse than that found by Casanova et al. (2020) as it was 0.01. The mean score for the item “Medicines which are fully covered by the National Health System or social services are prescribed to me” which is for patient with no follow-up during the last year is found 0.05.

Concerning accommodation domain, its mean is found 0.1. The mean for the item “Has a waiting area and consulting room which are clean and orderly” which is 0.1, is better than that of the item “Has a waiting area and consulting room with good toilet facilities” that have the mean 0.16. Both of them are better than that found by Casanova et al. (2020) as they found it 0.11 and 0.22 respectively. For patient with no follow-ups during the last year, the mean for the items “Waiting areas and consulting rooms in the hospital are clean” and “The hospital has good toilet facilities” is found 0.18 for both of them and they are worse than that for patients who have follow-up during the last year.

In regard to continuity of care domain, its mean is found 0.17. The best mean is found for the item “Is the GP/specialist I usually see”, it is found 0.08 and it is better than that found by Casanova et al. (2020) as they found it 0.14. The item “Lets me consult him/her regularly” has the second best value with 0.09 and it is also better than the result of 0.32 for Casanova et al. study in 2020. The item “Makes sure that I can see a specialist within 2 weeks after being referred to him/her” comes later with the mean of 0.17, it is better than that found by Casanova et al. (2020), as they found it 0.71. The worst mean in this domain is found for the item “Always communicates with other health and social care providers about the services I require” with 0.53 and it is worse than that found by Casanova et al. (2020) as it was 0.42.

For information domain, the mean is found 0.2 and the best mean score in this domain is found for the item “Informs me, in understandable language, about the medicines that are prescribed for me”, it is found 0.06, it is better than the mean found by Casanova et al. (2020), as they found it 0.29. The following best mean in information domain is found for the item “Informs me clearly about the examinations I am subjected to” with 0.1, it is also better than Casanova et al. result (0.2). Then the item “Informs me clearly about other possible physical problems due to IBD, e.g. joint pain” is found to have the mean of 0.36, which is better than Casanova et al. (2020) study findings as they found it (0.49).

The worst score in this domain is found for the item “Informs me adequately about nutrition and IBD” with 0.42, but it also better than 0.59 which was found by Casanova et al. (2020). For patient who had no follow-ups during the last year, the mean for the item “The hospital provides adequate information about nutrition” is found 0.5.

Concerning competence domain, its mean is found 0.05. The mean of the item “Has a good understanding of my problems” is found 0.04 and it is better than that of the item “Approach my physical complaints, due to IBD, also from a psychological point of view” which is found 0.09 and comparing them with Casanova et al. (2020), they seem to be better than their findings, as they were 0.12 and 0.49 respectively.

For patients with no follow-ups during the last year, their answers to the item “Nurses at the endoscopy department have specific expertise in IBD” is found with the mean of 0.26.

Regarding autonomy domain, its item’s mean is found 0.35 and it is nearly the same as found by Casanova et al. study with 0.36.

What noticed from results of this tool is that it is relatively good, this is may be because these answers were taken from participants about the physician with the most contact in the last year from different health care providers in the GS and patients mostly tend to deal with the physician to whom they are reassured.

4.1.15 Total and dimensional satisfaction using QUOTE-IBD

As illustrated in table 4.15, it is noticed that the best mean score is obtained for the competence domain with 0.05, it seems better than that obtained in Ljungström et al. study in 2019 that was found 0.21. Then the following good result is obtained for costs domain which is found 0.06, it seems little higher (worse than) that what found in Ljungström et al. study (2019) as they found costs domain mean 0.05.

Regarding accommodation domain, its mean is found 0.1 which seems worse than Ljungström et al. study results in 2019, as they found it 0.04, while the mean of courtesy domain is found 0.12 which is better than that found by Ljungström et al. (2019), which was found 0.18.

Table (4.15) Distribution of the study participants according to total and dimensional QUOTE-IBD means

Items	Mean	MD	SD
Competence	0.05	0.00	0.18
Costs	0.06	0.00	0.23
Accommodation	0.10	0.00	0.25
Courtesy	0.12	0.00	0.20
Continuity of care	0.17	0.00	0.21
Information	0.20	0.25	0.24
Autonomy	0.30	0.00	0.46
Accessibility	0.42	0.25	0.21
Total care	**0.16**	**0.13**	**0.15**

Continuity of care mean is found 0.17 which is better than Ljungström et al. result in 2019 (0.24). The same thing is found for information domain, its mean is found 0.2, while it was 0.29 in Ljungström et al. study (2019). Autonomy domain mean is found 0.3, it is worse than that found in 2019 by Ljungström et al. (0.09). The worst mean is found 0.42 for accessibility domain. Ljungström et al. results in 2019 seems to be better (0.22). The total care score is found 0.16 and it is typical to what was found by Ljungström et al. (2019).

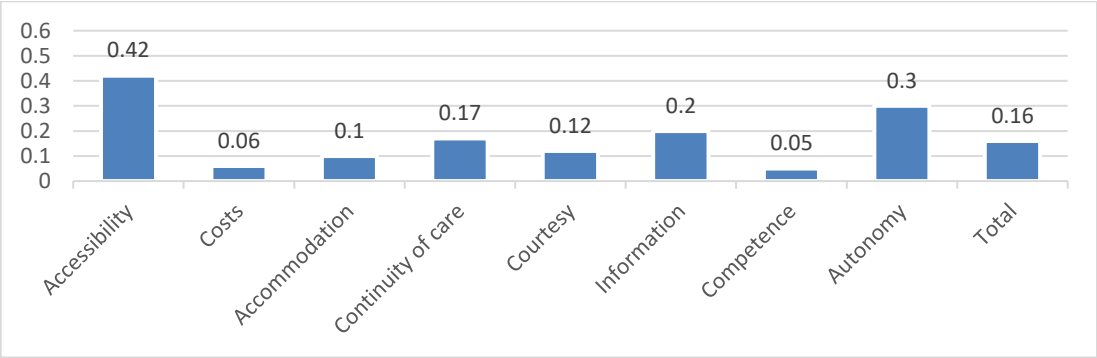

Figure (4.5) Distribution of the study participants according to total and dimensional QUOTE-IBD means

4.1.16 Health-related quality of life using SIBDQ

In this section, the SIBDQ is used, it consists of 10 questions which are derived from the 32-questions Inflammatory Bowel Disease Questionnaire (IBDQ). SIBDQ questions are grouped into 4 domains (bowel, emotional, systemic and social domains). It measures participant's feelings in the past 2 weeks and each question is rated from 7. The mean of total dimensions is the sum of responses for all the 10 questions dividing the result by 10. The resultant value ranges from 1 to 7. Higher scores represent higher HRQoL with less impact from IBD. Each domain score is calculated by adding responses of the items of this domain divided by the number of items of the same domain (Irvine et al., 1996).

4.1.16.1 Systemic dimension of SIBDQ

As table 4.16 shows, the mean of systemic domain is 4.69 (67%), it is lower than that found by Christiansen et al. (2019). Regarding the means of items consisting this domain, the mean of the question "How often has the feeling of fatigue or of being tired and worn out been a problem for you during the last 2 weeks" is found 3.93 (56.1%) and 40.7% of participants agreed that they felt fatigue or tired and worn out and considered it a problem all of the time, most of the time or a good bit of the time over the last 2 weeks due to UC.

Table (4.16) Distribution of the study participants according to their responses to systemic dimension of SIBDQ

Items	**N**	**%**
How often has the feeling of fatigue or of being tired and worn out been a problem for you during the last 2 weeks		
All of the time	20	12.7
Most of the time	28	17.8
A good bit of the time	16	10.2
Some of the time	34	21.7
A little of the time	22	14.0
Hardly any of the time	12	7.6
None of the time	25	15.9
Total	**157**	**100.0**
	Mean = 3.93, Mean percentage = 56.1%, MD = 4.00, SD = 1.96	
Overall, in the last 2 weeks, how much of a problem have you had maintaining or getting to the weight you would like to be		
All of the time	9	5.7
Most of the time	16	10.2
A good bit of the time	6	3.8
Some of the time	14	8.9
A little of the time	15	9.6
Hardly any of the time	12	7.6
None of the time	85	54.1
Total	**157**	**100.0**
	Mean = 5.46, Mean percentage = 78%, MD = 7.00, SD = 2.03	
Systemic mean = 4.69, Mean percentage = 67%, MD = 4.50, SD = 1.64,		

On the other hand, the mean of the question "Overall, in the last 2 weeks, how much of a problem have you had maintaining or getting to the weight you would like to be" is found to be 5.46 (78%), which is better than the previous question, 19.7% of participants agreed that they had a problem in getting or maintaining weight all of the time, most of the time or a good bit of the time during the last two weeks because of UC.

4.1.16.2 Social dimension of SIBDQ

The mean of social dimension is found 4.67 from 7 (66.7%), it is lower than Christiansen et al. result (2019). The mean of the item "How often during the last 2 weeks have you had to delay or cancel a social engagement because of your bowel problem" is 4.59 (65.6%).

Table (4.17) Distribution of the study participants according to their responses to social dimension of SIBDQ

Items	N	%
How often during the last 2 weeks have you had to delay or cancel a social engagement because of your bowel problem		
All of the time	14	8.9
Most of the time	29	18.5
A good bit of the time	10	6.4
Some of the time	22	14.0
A little of the time	19	12.1
Hardly any of the time	6	3.8
None of the time	57	36.3
Total	**157**	**100.0**
	Mean = 4.59, Mean percentage = 65.6%, MD = 5.00, SD = 2.20	
How much difficulty have you had, as a result of your bowel problems, doing leisure or sports activities you would have liked to have done over the last 2 weeks		
A great deal of difficulty, activities made impossible	20	12.7
A lot of difficulty	20	12.7
A fair bit of difficulty	6	3.8
Some difficulty	19	12.1
A little difficulty	22	14.0
Hardly any difficulty	9	5.7
No difficulty; the bowel problems did not limit sports or leisure activities	61	38.9
Total	**157**	**100.0**
	Mean = 4.75, Mean percentage = 67.8%, MD = 5.00, SD = 2.24	
Social Mean = 4.67, Mean percentage = 66.7%, MD = 5.0, SD = 1.97		

Table 4.17 also shows that nearly third of the study participants (33.8%) agreed that they delayed or cancelled a social engagement all of the time, most of the time or a good bit of the time during the last 2 weeks due to their disease, while it is found that the item "How much difficulty have you had, as a result of your bowel problems, doing leisure or sports activities you would have liked to have done over the last 2 weeks" have a higher mean, which is 4.75 (67.8%) and it is noticed that 29.2% of participants agreed that they have difficulty all of the time, most of the time or a good bit of the time to do leisure or sport activities they liked to have done during the last 2 weeks due to UC.

4.1.16.3 Bowel dimension of SIBDQ

As shown in table 4.18, the mean of bowel domain is found 4.25 of 7 (60.7%), it is lower than that found by Christiansen et al. (2019). Bowel dimension consists of 3 questions.

Table (4.18) Distribution of the study participants according to their responses to bowel dimension of SIBDQ

Items	N	%
How often during the last 2 weeks have you been troubled by pain in the abdomen?		
All of the time	18	11.5
Most of the time	24	15.3
A good bit of the time	11	7.0
Some of the time	29	18.5
A little of the time	32	20.4
Hardly any of the time	5	3.2
None of the time	38	24.2
Total	**157**	**100.0**
	Mean = 4.23, Mean percentage = 60.4%, MD = 4.00, SD = 2.03	
How much of the time during the last 2 weeks have you been troubled by a feeling of having to go to the toilet even though your bowels were empty		
All of the time	19	12.1
Most of the time	19	12.1
A good bit of the time	15	9.6
Some of the time	28	17.8
A little of the time	28	17.8
Hardly any of the time	8	5.1
None of the time	40	25.5
Total	**157**	**100.0**
	Mean = 4.34, Mean percentage = 62%, MD = 4.00, SD = 2.06	
Overall, in the last 2 weeks, how much of a problem have you had passing large amounts of gas?		
A major problem	33	21.0
A big problem	17	10.8
A significant problem	5	3.2
Some trouble	23	14.6
A little trouble	31	19.7
Hardly any trouble	16	10.2
No trouble	32	20.4
Total	**157**	**100.0**
	Mean = 4.13, Mean percentage = 59%, MD = 5.00, SD = 2.19	
Bowel Mean = 4.25, Mean percentage = 60.7%, MD = 4.33, SD = 1.69		

The first question, which is “How often during the last 2 weeks have you been troubled by pain in the abdomen?” has the mean of 4.23 (60.4%) and 33.8% of participants were troubled by abdominal pain all of the time, most of the time or a good bit of the time during the last 2 weeks. The second question “How much of the time during the last 2 weeks have you been troubled by a feeling of having to go to the toilet even though your

bowels were empty" has the mean of 4.34 (62%) and 33.8% of participants agreed that this occurred with them all of the time, most of the time or a good bit of the time. The third question "Overall, in the last 2 weeks, how much of a problem have you had passing large amounts of gas?" is found to have the least mean with 4.13 (59%) and it is found that 35% of participants consider this a major problem, a big problem or a significant problem.

4.1.16.4 Emotional dimension of SIBDQ

The emotional domain consists of 3 questions. Its mean is found 4.37 out of 7 (62.4%), it seems lower (worse) than Christiansen et al. (2019) results.

Table (4.19) Distribution of the study participants according to their responses to emotional dimension of SIBDQ

Items	N	%
How often during the last 2 weeks have you felt depressed or discouraged?		
All of the time	17	10.8
Most of the time	15	9.6
A good bit of the time	12	7.6
Some of the time	22	14.0
A little of the time	28	17.8
Hardly any of the time	14	8.9
None of the time	49	31.2
Total	**157**	**100.0**
	Mean = 4.70, Mean percentage = 67.1%, MD = 5.00, SD = 2.08	
How much of the time during the last 2 weeks have you felt angry as a result of your bowel problem		
All of the time	17	10.8
Most of the time	21	13.4
A good bit of the time	5	3.2
Some of the time	25	15.9
A little of the time	30	19.1
Hardly any of the time	16	10.2
None of the time	43	27.4
Total	**157**	**100.0**
	Mean = 4.59, Mean percentage = 65.6%, MD = 5.00, SD = 2.07	
How often during the last 2 weeks have you felt relaxed and free of tension?		
None of the time	19	12.1
A little of the time	33	21.0
Some of the time	30	19.1
A good bit of the time	13	8.3
Most of the time	23	14.6
Almost all of the time	14	8.9
All of the time	25	15.9
Total	**157**	**100.0**
	Mean = 3.83, Mean percentage = 54.7%, MD = 3.00, SD = 2.01	
Emotional Mean = 4.37, Mean percentage = 62.4%, MD = 4.33, SD = 1.58		

The question “How often during the last 2 weeks have you felt depressed or discouraged?” have the mean of 4.7 (67.1%) and 28% of the participants felt depressed or discouraged all of the time, most of the time or a good bit of the time during the last 2 weeks, while the question “How much of the time during the last 2 weeks have you felt angry as a result of your bowel problem” is found to have the mean of 4.59 (65.6%) and 27.4% of the participants felt angry as a result of their disease during the last 2 weeks. The lowest mean of this dimension is found 3.83 (54.7%) for the question “How often during the last 2 weeks have you felt relaxed and free of tension?” and it is found that nearly half of participants (47.7%) were relaxed or free of tension all of the time to a good bit of the time.

4.1.16.5 Total and dimensional HRQoL using SIBDQ

According to table 4.20, the total mean score of SIBDQ is found 4.46 and it is lower than Christiansen et al. (2019) findings as well as all four domains consisting it. The highest mean is found for systemic domain (4.69), followed by social domain mean (4.67), then emotional domain mean (4.37). The lowest mean is found for bowel dimension with 4.25.

Table (4.20) Distribution of participants according to total and dimensional SIBDQ means

Items	Mean	%	MD	SD
Systemic	4.69	67	4.50	1.64
Social	4.67	66.7	5.00	1.97
Bowel	4.25	60.7	4.33	1.69
Emotional	4.37	62.4	4.33	1.58
Total	**4.46**	**63.7**	**4.30**	**1.43**

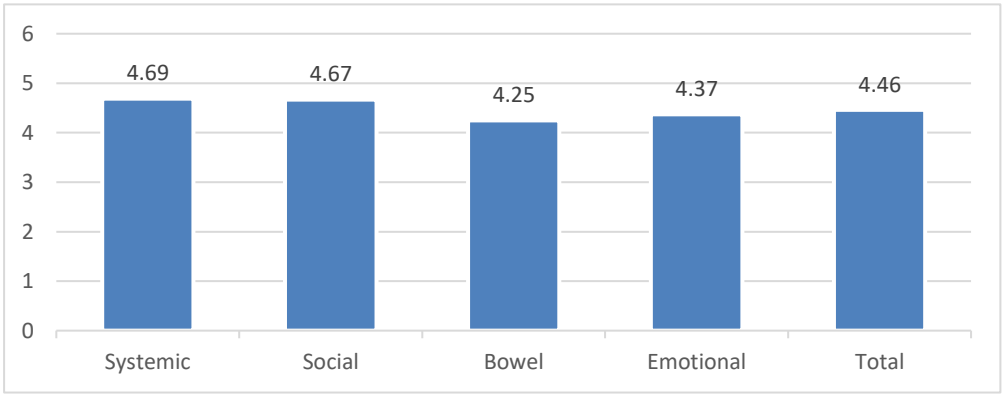

Figure (4.6) Distribution of the study participants according to total and dimensional HRQoL using SIBDQ

A female working mother *said "UC affects my daily life to large extent, I have restricted diet now, so I need more time for preparing special types of foods that I can eat. Also, my young children notice that I do not eat many food types and ask me why I do not eat like them and why I eat rice and potato only!. I tend to eat distributed meals through the day, to prevent the sense of hunger, as it enhances flare-up occurrence, so I find myself have to eat a meal during my wok and it is difficult to eat potato or rice meals in work. Also, my social life is affected, I tend now not to go to feasts or parties to prevent being embarrassed as they ask me, "Why don't you eat?", when I have to go to such events, I tend to say that I follow a regimen for my stomach healing to prevent eating and having complications. My weight is highly affected and it is noticed that I have a severe weight loss since my diagnosis before 2 years, relatives and colleagues surprised when they see me and ask me "Why have you lost all this weight?". Many times I suffer from anemia due to my restricted diet and because of flare-ups that occur sometimes".* Another patient said that UC has affected her daily life largely, especially in the case of flare-ups. When a flare-up occurs, she suffers from severe aches in her legs which affect her walking and affect her work as a teacher. She added *"During flare-ups, I suffer from mouth and tongue sores which affect my speaking during lessons. UC affects my daily life as I cannot eat many of foods that I prepare for my family. Currently, I have a flare-up which is continued from several months. I search always in the internet for new medications or remedies for this disease, one time I had read about stool transplantation which is used in Germany, then I asked the doctor about it, but he mentioned that it is not available in Gaza".*

4.1.17 The effect of COVID-19 pandemic on health care services regarding UC

About case aggravation of participants after the beginning of COVID-19 pandemic in the GS, more than two thirds of the study participants answered with no, 20.4% answered with yes, 5.7% replied that their case was aggravated to some extent and the remaining 1.9% answered that they don't know.

Nearly half of participants (49%) replied that the provided health care services regarding UC have not been affected at all by COVID-19 pandemic, 21.9% perceived that services have been moderately affected, while 14.6% of participants perceived that health care services have been highly affected. The same percent (14.6%) perceived that services have been slightly affected. A medical manager of a PHC center said that health care services provision was affected in the first period after COVID-19 pandemic occurrence in the GS,

as the PHC center was closed for a short period. After that the PHC center was reopened and continue to provide its health care services with considering mitigation measures.

Table (4.21) Distribution of the study participants according to their responses about the effect of COVID-19 pandemic on health care services regarding UC

Items	N	%
Case aggravation after the beginning of COVID-19 pandemic in the GS		
Yes	32	20.4
To some extent	9	5.7
No	113	72.0
I don't know	3	1.9
Total	**157**	**100.0**
Perception about the extent to which COVID-19 has affected the provision of health care services for them		
Highly affected	22	14.6
Moderately affected	33	21.9
Slightly affected	22	14.6
Does not affected at all	74	49.0
Total	**151**	**100.0**
Perception about the extent to which COVID-19 has affected the presence of health care staff when they need them		
Highly affected	22	14.7
Moderately affected	26	17.3
Slightly affected	22	14.7
Does not affected at all	80	53.3
Total	**150**	**100.0**
Perception about the extent to which COVID-19 has affected the dispensing their UC medication/s		
Highly affected	15	9.9
Moderately affected	22	14.6
Slightly affected	15	9.9
Does not affected at all	99	65.6
Total	**151**	**100.0**
Perception about the extent to which COVID-19 has affected their follow-up regarding UC		
Highly affected	35	23.3
Moderately affected	20	13.3
Slightly affected	16	10.7
Does not affected at all	79	52.7
Total	**150**	**100.0**
Need to perform laboratory testing without the ability to perform it in the MoH facilities due to COVID-19		
Yes	36	23.4
No	28	18.2
I have not need it in this period	90	58.4
Total	**154**	**100.0**
Need to perform colonoscopy without the ability to perform it in the MoH facilities due to COVID-19		
Yes	22	14.3
No	4	2.6
I have not need it in this period	128	83.1
Total	**154**	**100.0**

Concerning the participant's perception about the extent to which COVID-19 has affected the presence of health care staff when they need them, around half of the study participants (53.3%) answered that it does not affected at all, while 14.7% answered that it is highly affected. Participants who answered with moderately affected represent 17.3% and the remaining 14.7% of the study participants answered with slightly affected.

An interviewed medical manager of a PHC center said *"In the first period of COVID-19 pandemic in the GS, health care staff presence was highly affected as the PHC center was closed, then the staff capacity returned to their work with full capacity"*.

Regarding affecting medications dispensing, 65.6% of the study participants perceive that COVID-19 does not affect their dispensing of UC medications at all, while 14.6% of participants perceive that it has a moderate effect, 9.9% of the participants perceive that COVID-19 has a slight effect and equal percent is found for participants who perceive that it has a high effect on dispensing of their UC medications.

A medical manager of a PHC center said that dispensing of medications was continued when the PHC center was closed in the first period of COVID-19 pandemic in the GS and the MoH specified the number 103 for telemedicine services, so, patients who find our PHC center closed or cannot leave their homes due to their weak immune system, they called this number and the MoH delivered medications to their homes.

An interviewed pharmacist mentioned that after the start of COVID-19, they tend to dispense medications for UC patients monthly instead of biweekly by doubling the dispensed quantities as the case for all other patients to reduce crowdedness and contribute in decreasing their going out from home as they are immunocompromised patients.

To measure the effect of COVID-19 on the patients' follow-ups regarding UC, the study participants were asked about the extent to which COVID-19 has affected their follow-up regarding UC, 52.7% answered that it does not affected at all, while 23.3% of the study participants mentioned that this service is highly affected, followed by 13.3% for those who perceived that it is moderately affected. The rest 10.7% answered that it is slightly affected. Comparing these results with Harris et al. study (2020), they found that 18.7% of their IBD participants answered that their follow-up appointments in hospitals were cancelled due to COVID-19, 15.8% appointments of the study participants was delayed, 41.6% answered that their appointments in outpatient clinics were not affected and the

question was not applicable for 25.4% of participants, while they found that 6.7% of the participants' appointments with the GP were cancelled, were delayed for 10.2% of participants, were not affected in 39.9% of them and the question was inapplicable in 43.1% of participants,.

An interviewed patient said *"From the beginning of COVID-19 pandemic in the GS, I had no follow-up visits because the outpatient clinic was closed,* lately *it is opened, but I don't go for follow-up because of crowdedness as I have a weak immune system".*

About their need to perform laboratory testing without the ability to perform it in the MoH facilities due to COVID-19, it is found that 23.4% of the study participants agreed, 18.2% of them disagreed and 58.4% mentioned that they did not need to perform lab tests during the COVID-19 pandemic period. In Harris et al. study (2020), they found that hospital blood tests were cancelled in 4.4% of the study participants (IBD patients), delayed for 18% of them, not affected in 52.1% and the question was not applicable for 24.5% of the participated IBD patients, the mentioned study found also that 3.9% of participants' GP blood tests were cancelled due COVID-19, 18.3% were delayed, 43.7% were not affected and in 34.1% of participants the question was not applicable.

On the other hand, it is found that 14.3% of the study participants were in need to perform colonoscopy without the ability to perform it in the MoH facilities due to COVID-19, 2.6% answered that they were not affected by COVID-19 and performed it, while the majority (83.1%) were not in need to perform colonoscopy during that period. In Harris et al. study (2020), endoscopy was cancelled in the case of 5.2% of participants, delayed for 5.2% of participants, not affected in 22.5% of participants and it was not applicable in 67% of the study participants.

4.1.18 Documentation practices

As aforementioned, 145 patients' files were found and checked for documentation completeness. Some PHC centers had no files for UC patients, as they dispense UC medications according to patients' reports that are put in the PHC center's pharmacy. Other paper based files were not found because they cannot be found using the patient's name, ID number, the insurer name in the case of a family record or using the insurance number. The file number was difficult to obtain especially in PHC centers that have no computers or connection to the unified electronic system of the MoH.

Table (4.22) Completeness of documentation practices related to UC

Items	Complete		Incomplete	
	N	%	N	%
Identification and biographical data (N = 145)				
Each page inside the medical record contains the patient's name or ID number	59	40.7	86	59.3
Opening date of the file is written	91	62.8	54	37.2
Date of birth is written	144	99.3	1	0.7
Gender is specified	115	79.3	30	20.7
Address is written	99	68.3	46	31.7
Telephone number or mobile number is filled	68	46.9	77	53.1
Educational level is specified	51	35.2	94	64.8
Occupation is specified	55	37.9	90	62.1
Marital status is specified	77	53.1	68	46.9
Documentation average		**58.2**		
Diagnosis, history and treatment (N = 145)				
Diagnosis is clearly written	125	86.2	20	13.8
Severity and extent of the disease is clearly documented	15	10.3	130	89.7
Prescribed medication are clearly written with dosages	136	93.8	9	6.2
Height, weight and BMI are documented	17	11.7	128	88.3
Posture and gait of the UC patient is documented	7	4.8	138	95.2
Attitude is documented	15	10.3	130	89.7
Cardiovascular examination was performed as a base when the file was opened	11	7.6	134	92.4
Chest examination was performed as a base when the file was opened	11	7.6	134	92.4
Abdomen examination was performed as a base when the file was opened	9	6.2	136	93.8
Central nervous system (CNS) examination was performed as a base when the file was opened	9	6.2	136	93.8
Head eye ear nose throat examination was performed as a base when the file was opened	10	6.9	135	93.1
Skin and hair examination was performed as a base when the file was opened	9	6.2	136	93.8
Mental status exam was performed as a base when the file was opened	4	2.8	141	97.2
Physical & psychological examinations are updated annually	2	1.4	143	98.6
Abdomen, eye, joint and skin examinations are performed when there is new complaints	2	1.4	143	98.6
Allergies and adverse reactions are prominently noted in the record	1	0.7	144	99.3
Allergies are updated annually	0	0.0	145	100.0
Medication/s side effects and symptoms are reviewed with the patient or caregiver and documented	0	0.0	145	100.0
Medication adherence review for compliance of maintenance medications with the dates of initial and refill prescriptions	120	82.8	25	17.2
Family history is documented including pertinent medical history of parents and/or sibling(s)	27	18.6	118	81.4

Table (4.22a): Continued

Medical-surgical history is documented including serious accidents, injuries, operations, illnesses/diseases (acute or chronic), and mental health/substance abuse issues and it is updated as appropriate	15	10.3	130	89.7
Smoking status is documented.	8	5.5	137	94.5
Patient's counseling about high-risk behavior(s) including nutrition is documented or the documentation of the patient's referral to appropriate specialists.	10	6.9	135	93.1
Specialist consultation -if needed- is documented. Name/Specialty and recommendations are all written.	9	6.2	136	93.8
Laboratory tests are ordered as appropriate, especially ESR, liver function test, kidney function tests, CRP, CBC, FBG, lipid profile, iron, folic acid and B_{12} levels and results are documented.	33	22.8	112	77.2
Diagnostic Studies and results are documented as colonoscopy, ultrasound, X-ray and CT scans.	2	1.4	143	98.6
Routine or follow-up visits description is documented including presenting complaints, active (acute) medical or psychosocial problems, or management of a chronic, serious or disabling condition	27	18.6	118	81.4
Unresolved problems from previous office visits are determined to be addressed in subsequent visits.	0	0.0	145	100.0
There is notation/s, for further calls or follow-up visits if needed.	2	1.4	143	98.6
Follow-up after an emergency department visit/s or hospitalization/s is performed and the date/s for emergency department and/or hospitalizations are listed.	1	0.7	144	99.3
Documentation average		**14.7**		
General record items (N = 145)				
All entries in the medical record contain the author's identification (handwritten signature, stamp, a unique electronic identifier, ……..etc.)	6	4.1	139	95.9
All entries in the medical record are dated	41	28.3	104	71.7
The record is an Electronic Medical Record (EMR)	37	25.5	108	74.5
Handwriting inside the record is clear and readable	145	100	0	0
Documentation average		**39.5**		
Overall documentation average		**26.1**		

Table 4.22 demonstrates that the overall documentation average is 26.1%. It is very low and it lower than the overall documentation average of discharge sheets in Abu Dagga (2014) study, as she found it 81.5%. Regarding the checklist categories, the documentation average for the identification and biographical data category is found to be 58.2%. It is higher than that found by Sayyah-Melli et al. (2017) as they found that patient demography was of standard quantity in 46% of the reviewed records.

The highest documentation average is found for the item “Date of birth” as it was documented in 99.3% of the files. Patient’s gender was documented in 79.3% of the reviewed files, followed by 68.3% for address documentation and then opening date documentation, as 62.8% of the reviewed files specified the opening date of the file. The least average of documentation in this category is found for the item “Educational level is specified” with 35.2% average of documentation only. A little higher score (37.9%) is found for the occupation specification item. Only 40.7% of the files have the name or ID number of the patient on each page inside the medical record. For more specification, in 2.1% of the reviewed files, the name of patient or his/her ID number completeness average was from 1-25%, 12.4% of the of the same item was 26-50% completed, 31.7% was completed from 51-75%, 13.1% of the mentioned item was 76-99% completed and 40.7% was 100% documented in each page.

The documentation average for the category “Diagnosis, history and treatment” is the lowest within categories with 14.7% of documentation completeness average. The highest completeness average in this domain is found for the item “Prescribed medication are clearly written with dosages” with 93.8%, followed by the item “Diagnosis is clearly written” that was documented in 86.2% of the reviewed files, then it is found that 82.8% of the files provide medication adherence review for compliance of maintenance medications with the dates of initial and refill prescriptions, after that comes the item of ordering and documentation of the needed lab tests and documenting its results with the completeness average of 22.8%. This is lower than Alkhaldi, 2017 findings who found that 84.1% of participants perceive that the results of requested diagnostic tests are documented. This is also lower than Sayyah-Melli et al. (2017) findings as they found that the percentage of standard quantity of the lab data of the reviewed records was 45%. Concerning the documentation of family history, it is found 18.6%, it is lower than that was found by Sayyah-Melli et al. (2017) as they found it 36%. Medical-surgical history is found to be documented in 10.3% of the UC patients’ records only, it lower than that found by Sayyah-Melli et al. (2017), as the past medical history was documented in 51% of the files and the operative procedures history was documented in 43% of patients’ files.

In regard to the lowest average, it is noticed for the items “Unresolved problems from previous office visits are determined to be addressed in subsequent visits”, “Medication/s side effects and symptoms are reviewed with the patient or caregiver and documented” and

updating the patient's allergies. Each of these items has the score of 0% while the completeness score of 0.7% is found for other 2 items which are "Allergies and adverse reactions are prominently noted in the record" and the item "Follow-up after an emergency department visit/s or hospitalization/s is performed and the date/s for emergency department and/or hospitalizations are listed". This result is significantly different from that found by Alkhaldi, 2017 who found that 75.5% of participants from the health care staff in UNRWA perceived that allergies and adverse drug events are clearly documented. In Sayyah-Melli et al. (2017), they found allergies documentation percentage 46%.

The average 1.4% is realized for 4 items in this category. It is noticed for the item "Physical & psychological examinations are updated annually" as well as for the item "Abdomen, eye, joint and skin examinations are performed when there is new complaints", it is found also for the item of documenting diagnostic studies and results and the item of availability of notations for further calls or follow-up visits if needed. Generally, most of the physical and psychological items are poorly documented. Regarding specialist consultation documentation, it is found complete in only 6.2% of the reviewed files. The severity and extent of disease was specified only in in 10.3% of the reviewed files.

The average for the category, "general record items" is found to be 39.5%. The lowest average was 4.1% for the item "All entries in the medical record contain the author's identification like handwritten signature, stamp, a unique electronic identifier", it is higher in Sayyah-Melli et al. (2017) findings, as doctors full name and the signature with job category was completed in 56% of the reviewed files. Only 25.5% of the files were EMR and it is found that only 28.3% of entries in the medical record were dated, while the highest score in this category and all the record checklist is for the readability and clarity of the patients' records. All of the reviewed records handwritings can be read, this result is higher than that found by Alkhaldi, 2017 as he found that 81.9% of participants agreed that the entries are legible and any provider can understand the record note.

An interviewed internist said "*We have a gap in documentation and we should work on it, what hardens this task is the unavailability of an efficient HIS. All patients' available data are paper based and if we need to return to a patient's file, we will find only part of his/her information in the file. In the outpatient clinic, there is no documentation at all. The main characteristics of high quality record are: To be an efficient HIS that supports us with complete data about patients, especially that a lot of UC patients usually have recurrent*

hospital admissions, so we need to be aware of their history including their lab results. Sometimes when the patient is ill or unconscious and being without companions, an efficient HIS ensures obtaining lab tests results in the needed time. Efficient HIS is an informative system that achieves the needed outcome. These advantages are not obtained from the available electronic system leading to fragmentation in health care provision". A nurse in a PHC center said *"Documentation is a very important issue and we know that not documented means not done, we should direct more focus on documentation. I think we have nearly 80% documentation average for patients files, not all data are electronically available, as the electronic system is still newly used, for example, although we fill the GHQ-12 on paper, it is not filled electronically. The electronic system still needs further modifications, auditing and re-auditing. To meet a high quality medical record, we need first to train the working staff on the right way of data entry and to enhance their monitoring, commitment, motivation and emphasizing on the importance of any portion of data, as it later seems to be of a high value and not such a number, it can provide health workers, students and researchers with important information like prevalence, incidence, the needed quantities of medications for any disease, the cost of each disease,…etc. Another important issue is the continuous auditing for the electronic system to overcome existing gaps and to develop it after a continuous evaluation process. A high quality record should be a part of an electronic system that provides a data base and have the capability to save backup. The EMR should include all patients' data like quaternary name, ID number, mobile or telephone number, the right diagnosis, lab tests results with date and time of performance, to schedule lab tests electronically on the system and to give an alarm when the time of performance is reached and to follow the ICD-10".* From a different angle, a senior pharmacy manager said "*We are not satisfied concerning documentation practices, we have a problem in the documentation of patients' medications because their reports are not monitored regularly for many causes; first, because some patients are remissive, if they do not dispense their required medication amount, they tend to reduce their daily dose themselves without consulting the doctor, this is may be because the unclear follow-up system as UC patients get their follow-up in hospitals, while they dispense medications from PHC centers, what leads to gap formation. Some patients also do not go for follow-up. Also, when physicians write the medical report for patients, they should specify the period of this prescription, thus the report should be renewed every 3 to 6 months. Sometimes doctors do not specify the period of the prescribed doses or specify it for long time in order to reduce their work load as they do not want to see the patient every*

3 months in the outpatient clinic to renew his/her report. We can overcome this by providing GIT doctors in PHC centers to review patients' cases and reports regularly".

4.2 Inferential statistics

4.2.1 User-provider interaction and demographic data

To identify the existence of differences between males and females in user-provider interaction, the independent sample t-test was conducted and its results revealed that females have higher mean (4.42) than males group (4.18) and there were statistically significant differences between both genders in user-provider interaction (P value= 0.013).

Table (4.23) Differences in user-provider interaction scores by demographic data

Independent variable	Demographic data	N	Mean	SD	Factor	Value	Sig.
Gender	Male	91	4.18	0.67	T	-2.519	0.013
	Female	66	4.42	0.44			
Age group	Less than 30 years	42	4.37	0.47	F	0.503	0.681
	30 to 40 years	39	4.29	0.56			
	41 to 50 years	32	4.24	0.69			
	Above 50 years	44	4.23	0.66			
	Total	157	4.29	0.60			
Governorate	North Gaza	23	4.05	0.80	F	2.881	0.025
	Gaza	57	4.21	0.55			
	Middle zone	36	4.36	0.56			
	Khan Yunis	20	4.31	0.55			
	Rafah	21	4.60	0.41			
	Total	**157**	4.29	0.60			
Education level	< Secondary	28	4.30	0.72	F	2.164	0.118
	Secondary	48	4.42	0.50			
	Postgraduate	79	4.19	0.60			
	Total	155	4.28	0.60			
Marital status	Not Married	37	4.33	0.52	T	0.612	0.542
	Married	117	4.26	0.62			
Refugee status	Refugee	91	4.27	0.60	T	-0.256	0.798
	Non-refugee	66	4.30	0.60			
Working status	Working	59	4.21	0.64	F	2.452	0.089
	Not Working	82	4.38	0.50			
	Retired	16	4.09	0.81			
	Total	157	4.29	0.60			

Although younger patients have higher means of user-provider interaction, ANOVA test results revealed that there were no statistically significant differences between different age groups in relation to user-provider interaction (P value= 0.681).

In regard to user-provider interaction between governorates, it is pointed out by ANOVA test that Rafah had the highest mean (4.6) and North Gaza had the lowest mean (4.05) and

it is noticed that there were statistically significant differences in the overall user-provider interaction across governorates (P value= 0.025). Post hoc test revealed that the pairs (Middle Zone and North Gaza), (Rafah and North Gaza), (Rafah and Gaza) had a significant differences in user-provider interaction.

According to table 4.23, it is demonstrated that there were no differences in relation to educational level, marital status and refugee status in user-provider interaction.

4.2.2 User-provider interaction and medical variables

To identify if there were statistically significant differences in user-provider interaction between different groups of years of disease from diagnosis, ANOVA test was used. Table 4.24 indicated that patients who have UC from a period of more than 10 years have the lowest mean (4.15), while the other 3 groups have an equal mean (4.34). The ANOVA test results showed no statistically significant differences between different groups of years of disease from diagnosis regarding user-provider interaction (P value =0.361).

Table (4.24) Differences in user-provider interaction by medical variables

Independent variable	Demographic data	N	Mean	SD	Factor	Value	Sig.
Years of disease from diagnosis	3 Years and less	40	4.34	0.46	F	1.077	0.361
	From 4 to 5 Years	32	4.34	0.58			
	From 6 to 10 Years	41	4.34	0.53			
	More than 10 Years	44	4.15	0.75			
	Total	157	4.29	0.60			
Frequency of experiencing flare-ups as reported by clients	Does not occur after starting to take medications	13	4.37	0.40	F	0.572	0.684
	>1 month	30	4.31	0.61			
	1 to 11 Months	55	4.34	0.51			
	12 Months and more	41	4.17	0.66			
	Irregularly	18	4.26	0.79			
	Total	**157**	**4.29**	**0.60**			
The last time to experience attack symptoms	Up to one month	74	4.26	0.62	F	0.229	0.795
	From 2 to 10 Months	48	4.28	0.60			
	Above 10 Months	35	4.34	0.53			
	Total	**157**	**4.29**	**0.60**			
End of the last UC attack symptom	Yes	100	4.26	0.62	T	-0.666	0.506
	No	57	4.33	0.55			
Suffering from other chronic disease/s	Yes	55	4.30	0.62	T	0.188	0.851
	No	102	4.28	0.59			

Also, to explore if there were statistically significant differences among patients experiencing different frequencies of flare-ups in regard to user-provider interaction, the ANOVA test results show higher mean of user-provider interaction for patients' group who

did not experience flare-ups since starting to take their UC medications (4.37), while patients who experience flare-ups every 12 months or more have the lowest user-provider interaction (4.17), but the ANOVA test results show that there were no statistically significant variances among the frequency of experiencing flare-ups groups in regard to user-provider interaction (P value = 0.684).

Although participants with 10 months or more from experiencing the last flare-up symptoms elicited a higher mean score than the other groups (mean = 4.34), the differences in means between them were statistically not significant in terms of user-provider interaction (P value = 0.795).

Regarding the differences between the end of the last UC attack symptom in relation to user-provider interaction, independent sample t-test results, show that patients who were in attack have a higher user-provider interaction mean (4.33) than patients who ended their last UC attack symptoms (4.26) but the independent sample t-test results show no statistically significant differences between them in relation to user-provider interaction (P value = 0.506).

Concerning suffering from other chronic disease/s, t-test pointed out that UC patients who were suffering from other disease/s have a higher user-provider interaction mean (4.3) than patients with no concomitant disease (4.28), but there were no statistically significant variances between participants having a concurrent disease with UC and those who does not have other chronic disease/s regarding user-provider interaction (P value = 0.851).

4.2.3 Patient Satisfaction and demographic data

In regard to males/females satisfaction, the independent sample t-test results show that females have better satisfaction mean (0.13) than males (0.14), but these differences were statistically not significant (P value= 0.623). It is inconsistent with what found by Van der Eijk et al. in 2001, as they found statistically significant differences in the total care (P value <.05) between males and females, females was satisfied less than males from the provided services (males mean=0.09 and females mean = 0.15).

To explore the existence of differences between different age groups in regard to satisfaction, the ANOVA test revealed that the age groups (30 to 40 years and those who are above 50 years) have better satisfaction mean (0.13) than the age groups (less than 30 years and 41 to 50 years) as they have 0.15 satisfaction mean, the differences between different groups were not statistically significant (P value= 0.88).

Table (4.25) Differences in patient satisfaction by demographic data

Independent variable	Demographic data	N	Mean	SD	Factor	Value	Sig.
Gender	Male	91	0.14	0.14	T	0.492	0.623
	Female	66	0.13	0.12			
Age group	Less than 30 years	42	0.15	0.13	F	0.223	0.880
	30 to 40 years	39	0.13	0.13			
	41 to 50 years	32	0.15	0.16			
	Above 50 years	44	0.13	0.11			
	Total	157	0.14	0.13			
Governorate	North Gaza	23	0.12	0.14	F	0.791	0.533
	Gaza	57	0.16	0.14			
	Middle zone	36	0.14	0.12			
	Khan Yunis	20	0.11	0.11			
	Rafah	21	0.12	0.13			
	Total	157	0.14	0.13			
Education level	< Secondary	28	0.14	0.14	F	0.256	0.774
	Secondary	48	0.13	0.11			
	Postgraduate	79	0.14	0.14			
	Total	155	0.14	0.13			
Marital status	Not Married	37	0.10	0.12	t	-1.888	0.061
	Married	117	0.15	0.13			
Refugee status	Refugee	91	0.13	0.13	t	-0.364	0.717
	Non-refugee	66	0.14	0.14			
Working status	Working	59	0.13	0.13	F	0.051	0.950
	Not Working	82	0.14	0.14			
	Retired	16	0.15	0.12			
	Total	157	0.14	0.13			

Using ANOVA test, Khan Yunis is found to have the best satisfaction mean (0.11) and Gaza has the worst satisfaction mean among governorates (0.16), the differences among governorates were not statistically significant (P value= 0.553). Moreover, patients with secondary level of education (12 years) seem to have better mean (0.13) than the means of other educational groups (less than 12 years of education and more than 12 years of education), these two groups have the mean satisfaction of 0.14, but negative association were found between different levels of education and the overall satisfaction when the ANOVA test was used (P value= 0.774).

An independent sample t-test was conducted to examine if there were statistically significant differences between married and not-married participants in their overall satisfaction. Despite that the not-married participants' satisfaction score mean was better (0.1) than that of the married participants (0.15), the test revealed that there were no statistically significant differences between marital status groups in the overall satisfaction (P value= 0.061). Similarly, by using the independent sample t-test, it is revealed that

refugees have better satisfaction mean (0.13) than non-refugees (0.14) with no statistically significant differences between them in overall satisfaction (P value = 0.717).

Using the ANOVA test, it was found that working patients have better satisfaction mean (0.13) among the working status groups and retired persons have the worst satisfaction mean (0.15), results of the ANOVA test do not denote statistically significant variances between working status groups and overall satisfaction (P value= 0.95). In contrast, Soares et al. (2015) found statistically significant differences between different employment status groups using ANOVA test (P value= 0.027), unemployed IBD patients showed higher overall satisfaction mean than the other groups and employed IBD patients showed the lowest overall satisfaction mean.

4.2.4 Patient Satisfaction and medical variables

Table 4.26 demonstrates that the one way ANOVA test results revealed that UC patients with 4-5 years of diagnosis have better satisfaction mean (0.11) than other patients, while patients with more than 10 years of disease have the worst satisfaction mean (0.17), however, the variances in means regarding years of diagnosis and overall satisfaction were not statistically significant (P value= 0.133).

Table (4.26) Differences in patient Satisfaction by medical variables

Independent variable	Demographic data	N	Mean	SD	Factor	Value	Sig.
Years of disease from diagnosis	3 Years and less	40	0.14	0.10	F	1.891	0.133
	From 4 to 5 Years	32	0.11	0.14			
	From 6 to 10 Years	41	0.12	0.12			
	More than 10 Years	44	0.17	0.15			
	Total	157	0.14	0.13			
Frequency of experiencing flare-ups as reported by clients	Does not occur after starting to take medications	13	0.14	0.10	F	1.200	0.313
	>1 month	30	0.12	0.18			
	1 to11 Months	55	0.16	0.15			
	12 Months and more	41	0.20	0.15			
	Irregularly	18	0.17	0.15			
	Total	157	0.16	0.15			
The last time to experience attack symptoms	Up to one Month	74	0.15	0.17	F	1.042	0.355
	From 2 to 10 Months	48	0.19	0.15			
	Above 10 Months	35	0.15	0.11			
	Total	157	0.16	0.15			
End of the last UC attack symptom	Yes	100	0.15	0.15	T	-1.180	0.240
	No	57	0.18	0.16			
Suffering from other chronic disease/s	Yes	55	0.17	0.18	T	0.375	0.708
	No	102	0.16	0.14			

Also, the one way ANOVA test was conducted to explore if there were statistically significant differences between participants according to the frequency of experiencing flare-ups in relation to their satisfaction, results demonstrate no statistically significant differences (P value= 0.313).

One way ANOVA was conducted to explore if there were differences between participants in satisfaction regarding the last time to experience attack symptoms. Results demonstrate that patients who had experienced their last flare-ups from 2 to 10 months ago have the worst satisfaction among other groups (mean=0.19), but the ANOVA test revealed that differences are not statistically significant between participants regarding their last time to experience attack symptoms in relation to their overall satisfaction (P value= 0.355). This is not consistent with Soares et al. (2015) findings as they used ANOVA test and Tukey's HSD post-hoc test as they found differences in the overall satisfaction between patients with different times of experiencing the last flare-up; they found that there were statistically significant differences (P value= 0.015) between patients who experienced relapses during the last 3 months and those who didn't experience them within the last year as patients who experienced their last attack during the last 3 months had lower overall satisfaction (71.6) than those who had no relapses in the last year (79.6). Also they found statistically significant differences (P value= 0.047) between patients who experienced relapses during the last 3 months (had lower overall satisfaction) and those who experienced relapses within the period of 4 to 12 months ago (71.6 and 76.2 respectively).

Results in table 4.26 demonstrates that by conducting independent sample t-test, it was found that participants who had ended their last flare-up symptoms, have better satisfaction mean (0.15) than those who were still in attack (0.18). At the same time, there were no statistically significant differences between these two groups in satisfaction (P value= 0.24). This is not consistent with Coenen et al. (2020) findings as they used a patient satisfaction questionnaire and they found that in multivariate analysis results, being in remission was significantly associated with improved satisfaction from provided quality of care (P value= 0.001).

The independent sample t-test was conducted also to demonstrate if there were differences between UC patients with another chronic disease and those who have no other concomitant chronic disease regarding satisfaction, participants with no other concomitant chronic disease showed better satisfaction mean (0.16) than those with other chronic disease (0.17), results shows no statistically significant differences (P value = 0.708).

4.2.5 Health-related quality of life and demographic data

To explore if there were differences between males and females participants in HRQoL, the independent t-test was applied, results illustrate that despite males have higher overall HRQoL mean (4.56) than females (4.33), there were no statistically significant differences between them in regard to HRQoL (P value= 0.319). This is consistent with Yarlas et al. findings in 2021.

Moreover, by conducting the ANOVA test, it is found that UC patients with the age above 50 years have the highest HRQoL mean (4.89) among other age groups and it was found that the youngest UC of the age less than 30 years have the lowest HRQoL mean (4.2), but there were no statistically significant differences between the different age groups in HRQoL (P value = 0.104). This result is consistent with Yarlas et al. findings (2021) as there were no statistically significant differences between different ages in HRQoL.

Table (4.27) Differences in health-related quality of life by demographic data

Independent variable	Demographic data	N	Mean	SD	Factor	Value	Sig.
Gender	Male	91	4.56	1.47	t	0.999	0.319
	Female	66	4.33	1.36			
Age group	Less than 30 years	42	4.20	1.34	F	2.087	0.104
	30 to 40 years	39	4.44	1.49			
	41 to 50 years	32	4.24	1.17			
	Above 50 years	44	4.89	1.55			
	Total	**157**	**4.46**	**1.43**			
Governorate	North Gaza	23	4.25	1.18	F	0.287	0.886
	Gaza	57	4.59	1.49			
	Middle zone	36	4.36	1.61			
	Khan Yunis	20	4.48	1.39			
	Rafah	21	4.50	1.28			
	Total	**157**	**4.46**	**1.43**			
Educational level	< Secondary	28	4.02	1.41	F	3.256	0.041
	Secondary	48	4.25	1.59			
	Postgraduate	79	4.72	1.28			
	Total	**155**	**4.45**	**1.42**			
Marital status	Not Married	37	4.56	1.40	t	0.450	0.654
	Married	117	4.44	1.42			
Refugee status	Refugee	91	4.55	1.42	t	0.954	0.342
	Non-refugee	66	4.33	1.44			
Working status	Working	59	4.64	1.28	F	9.129	0.000
	Not Working	82	4.10	1.44			
	Retired	16	5.61	1.17			
	Total	157	4.46	1.43			

Regarding governorates, the ANOVA test also was used to test if there were differences among UC patients from different governorates regarding HRQoL, findings pointed out that participants from Gaza have the highest HRQoL mean (4.59), while participants from North Gaza have the lowest HRQoL mean (4.25), but the ANOVA test revealed also that there were no statistically significant differences between different governorates regarding HRQoL (P value = 0.886).

The ANOVA test was used to check if there were differences in HRQoL among different educational groups, results in table 4.27 demonstrate that the higher the education level, the greater the HRQoL mean, differences were statistically significant among educational levels in relation to HRQoL (P value = 0.041). Post hoc test revealed that the differences between the pair postgraduates and those with less than secondary education level were statistically significant in HRQoL (P value =0.024). It is consistent with Tormey et al. findings in 2019, as they found using univariate analysis that educational level is associated with better HRQoL that was measured using SIBDQ; they found that high educational levels is associated with better outcomes than lower levels of education.

Independent sample t-test was used to examine if there were differences between married and not married groups in the overall HRQoL, results show that not married participants have higher HRQoL mean (4.56) than married ones (4.44), but differences were not statistically significant (P value = 0.654).

Also, the independent sample t-test results was conducted to test if there were differences between refugees and non-refugees regarding HRQoL, t-test results showed that refugees have higher HRQoL mean (4.55) than non-refugees (4.33) with no statistically significant differences among them in the overall HRQoL (P value = 0.342).

Table 4.27 demonstrates that by conducting the one way ANOVA, results revealed that retired participants have the highest HRQoL mean (5.61) among working status groups, while non-working participants have the lowest HRQoL mean (4.1). ANOVA test results demonstrate a strong statistically significant differences between working status and the overall HRQoL (F= 9.1729, P value = 0.000). Post hoc test revealed the existence of statistically significant differences between all working status groups as retired participants have statistically significant differences in HRQoL with working group in HRQoL (P value = 0.12) as well as with non-working group (p value = 0.000).

4.2.6 Health-related quality of life and medical variables

To examine differences in relation to years of disease from diagnosis, the ANOVA test was conducted and its results revealed that participants with more than 10 years of diagnosis have a higher HRQoL mean (4.68), while those who have been with UC from about 6 to 10 years have the lowest HRQoL mean (4.13). However the ANOVA test results revealed no statistically significant variances between the different groups of disease years from diagnosis and the overall HRQoL (P value = 0.239).

Table (4.28) Differences in health-related quality of life by medical variables

Independent variable	Demographic data	N	Mean	SD	Factor	Value	Sig.
Years of disease from diagnosis	3 Years and less	40	4.65	1.31	F	1.422	0.239
	From 4 to 5 Years	32	4.33	1.57			
	From 6 to 10 Years	41	4.13	1.39			
	More than 10 Years	44	4.68	1.43			
	Total	157	4.46	1.43			
Frequency of experiencing flare-ups as reported by clients	Does not occur after starting to take medications	13	5.74	1.00	F	8.477	0.000
	>1 Month	30	3.57	1.17			
	1 to 11 Months	55	4.51	1.18			
	12 Months and more	41	4.88	1.53			
	Irregularly	18	3.92	1.49			
	Total	157	4.46	1.43			
The last time to experience attack symptoms	Up to one Month	74	3.86	1.29	F	18.241	0.000
	From 2 to 10 Months	48	4.71	1.26			
	Above 10 Months	35	5.40	1.33			
	Total	157	4.46	1.43			
End of the last UC attack symptom	Yes	100	4.84	1.44	T	4.656	0.000
	No	57	3.80	1.13			
Suffering from other chronic disease/s	Yes	55	4.49	1.46	T	0.192	0.848
	No	102	4.44	1.41			

Table 4.28 demonstrates that the one way ANOVA test results show that participants who do not experience flare-up since starting to take medications have the highest mean (5.74) and those who have a frequency of experiencing flare-ups of less than one month have the lowest HRQoL mean (3.57). The ANOVA test displays a strong relation between participants' frequency of experiencing flare-ups and their overall HRQoL (P value = 0.000). By using Post hoc test, it is found that the difference between those who do not experience flare-up since starting to take medications is statistically significant with all other groups in regard to HRQoL with p values of (0.000, 0.003, 0.04, 0.000 respectively), also participants who have recurrent flare-ups every 1 to 11 months have higher HRQoL

than those who experience recurrent flare-ups within periods of less than 1 month (P value = 0.002). According to Post hoc test, it is found also that participants who experience recurrent flare-ups within periods of 12 months and more have higher HRQoL than both those who experience flare-ups within periods of less than 1 month and those who experience flare-ups irregularly (P value = 0.00 and 0.01 respectively).

The ANOVA test was conducted also to explore if there were differences between participants with different times from experiencing their last flare-up attacks, it was found that the longer the time from the last flare-up attack, the higher the HRQoL mean. A strong relation is noticed between participants regarding the last time to experience flare-ups and the overall HRQoL (P value = 0.000). Post hoc was conducted and its results revealed that patients who have their last flare-up from more than 10 months have higher HRQoL than those who experience their last flare-up from less than one month and those who have their last flare-up from 2 to 10 months ago (P value = 0.000 and 0.017 respectively). It is found also that patients who experienced their last flare-up from 2 to 10 months have higher HRQoL than those who have their last flare-up from a period of less than one month (P value = 0.000).

To explore the existence of differences between participants who had ended their last flare-ups and those who were still on flare-ups, the independent sample t-test was conducted and its results revealed that those who had ended their flare-up have a higher HRQoL mean (4.84) than those who were still on flare-up (mean = 3.8) and it is found that there were statistically significant differences between the two groups in HRQoL (P value = 0.000).

The independent sample t-test was conducted to explore the existence of differences between participants in relation to suffering from other chronic disease/s and the overall HRQoL, its results show that although UC patients without other chronic disease have higher mean (4.49) than those having another chronic disease (mean = 4.44), there were no statistically significant differences between participants with other chronic disease/s and those with UC only in the overall HRQoL (P value = 0.848).

Chapter Five

Conclusion and recommendations

5.1 Conclusion

This study was carried out to evaluate UC management in the GS. The study is a census study and it is a triangulated cross-sectional study, as it contains both quantitative and qualitative parts. The Donabedian model with its three components (input, process and output) was used in this study for the evaluation of health care services provided to UC patients. For the quantitative part, a questionnaire was used to identify participants' perspectives about the provided services regarding UC to specify areas of gaps. The questionnaire results also was used to study the availability of correlations between some variables and participants' demographic and medical information. The second quantitative tool that was used is a checklist for patients' records in PHC centers to check their completeness. For the qualitative part, in-depth interviews were conducted for more probing about some issues, part of these interviews were conducted with KIs from the working staff and the other part of interviews was conducted with patients to focus more on their suffering from both the disease and missed health care services.

The study results indicated that most of the study participants get one or more services regarding UC from governmental PHC centers, followed by those who have UC related health care services from governmental hospitals and then those who get UC related health care services from NGOs facilities. It is found that most of respondents do not know if there is a psychosocial specialist in governmental facilities where they get their health care services regarding UC.

Results reflect that about two-fifths of participants find their medications all the time, the same portion of participants find their medications sometimes and the last fifth of respondents answered that they either find some of their medications or that they do not find their medications. The unavailability of medications is found to be the most frequent cause of return without having the needed health care service. More than half of the study participants answered that colonoscopy was sometimes available or always unavailable in governmental hospitals when it was indicated for them. A bit more than half of the study participants who had tried colonoscopy in both governmental and NGO hospitals answered that it was more comfortable in the NGO hospital than governmental one, followed by

those answered that there was no difference and a small portion of them said that colonoscopy was more comfortable in the governmental hospital. Nearly one third of the study participants agreed that they find their needed lab tests all the time, while the rest answered that they find them available sometimes, some of the lab tests are available or they were always unavailable.

The mean of waiting time in the outpatient GIT clinic is found very long by most of UC patients, while it is found suitable in PHC centers. The contact time of patients with the physician in the outpatient GIT clinic is perceived to be longer than that with physicians in PHC centers. About half of participants receive health education about UC in the governmental health care facilities and nearly half of them found it beneficial to large extent. For user-provider interaction domain, the average mean is found high.

The total satisfaction of patient from the provided services is found to be high. The best domain in satisfaction scale was found for competence, while the worst is found for accessibility domain. The total HRQoL for the participants is found to be relatively high. The study findings elicited that COVID-19 has not affected the provided services for UC patients to large extent. Using a record checklist for reviewing UC patients' files in the PHC centers, it is found that the overall documentation average is very low.

Inferential statistics results revealed that there were statistically significant differences in user-provider interaction between males and females as females showed better user-provider interaction than males. Also, there were statistically significant differences in user provider-interaction between governorates as patients from Rafah scored the highest user-provider interaction mean. The study results showed that there were statistically significant differences in HRQoL between different educational levels, as the higher the educational level, the higher the HRQoL. Retired patients also was found to have the highest HRQoL mean, then working people, while patients who were not working have the worst HRQoL. Patients who do not experience flare-ups since starting to take their medications have the highest HRQoL mean, while those who experience flare-ups in a frequency of less than a month or irregularly have lower mean than others. Patients who had their last attack for longer periods of time elicited better HRQoL as well as those who were in remission state. The study revealed that there were no statistically significant differences between patients' satisfaction neither with the studied demographic nor medical data.

Qualitative results were consistent with quantitative findings in general. Interviewed UC patients talked in-depth about the provided services and about their suffering, while KIs talked about the provided health care services to UC patients from their point of view.

5.2 Recommendations

- It is important to direct more attention to psychosocial support for UC patients and to provide sufficient number of psychosocial specialists and to provide specialized units inside hospitals and PHC centers for psychological support.
- Securing the needed medications is a must, it is ought to provide UC medications in adequate amounts according to the need of each facility and to include the unavailable ones in the PEDL in order to be able to provide these types for UC patients.
- It is recommended to supply internal medicine departments and outpatient clinics with sufficient numbers of GIT specialists and to provide PHC centers of marginalized areas and high population areas with GIT specialty, this will help in reducing waiting time in outpatient clinics as well as decreasing overload on the gastroenterologists, what will increase contact time, this will have positive effects on the provided services and will improve patients' health outcomes.
- It is needed to provide sufficient numbers of colonoscopy units to address the deficit in this field and cover the increasing needs and it is needed to work for providing more advanced ones.
- It is recommended to maintain the existing laboratory services and to introduce further improvement for it by providing the unavailable ones that are needed for UC patients with taking in consideration their fair distribution. The unavailable and lab tests for UC patients in governmental facilities include Vit B_{12} and Vit D_3, serum iron, total binding capacity, ferritin level and fecal calprotectin analyses.
- The unavailability of protocols and guidelines represents a huge gap for suitable and standardized service provision regarding UC, so suitable guidelines/protocols for the Palestinian context should be put to meet staff's and patient's needs.
- Health education and nutritional counseling improve case stability and participate in attaining good health outcomes, so it is important to direct more focus on it and to perform on-job training for the health care staff about its importance and how to perform it. Health education can be enhanced also through the preparation of booklets, brochures and postures that provide a reliable non-expensive sources of information for patients about UC, how to deal with it, what to eat and what to avoid.

- It is ought to direct more attention to documentation practices by enhancing motivation and commitment of the health care staff and performing training courses and workshops for them to illustrate its importance as well as enhancing the transformation of patients records in all health care facilities to EMR and developing systems to obtain an efficient HIS.
- The study revealed that there is good user-provider interaction, so, attention should be paid on maintaining it, policies and actions can be applied for further improvement especially in the part of dispensing medication by pharmacists, as the item of informing the person with UC about how to take medication/s every visit showed the lowest mean among user-provider interaction items, so pharmacists should be more patient and tell patients how to take medications every visit as it is an important step to enhance patients' adherence to medications as indicated by the physician.
- According to study findings, it is important to improve contact with patients in several dimensions; improving means of contact between patients and their health care providers especially with doctors, improving contact between patients and doctors by increasing contact time, making sure that the patient understand what is said, patients' engagement in decision making regarding their preferences in their case management and expressing understanding to their suffering and to the UC influence on their life.
- Cooperation between the health care staff in the same health facility or between the same level like primary health care (horizontal coordination) is found to be good according to the qualitative data, so, it is important to maintain it and to apply efforts for more cooperation in this regard, while it is found that coordination -including communication and contact- and cooperation between different health care providers (vertical coordination) is needed to be improved, especially between primary and secondary/tertiary health care facilities what will boost the provided health care services and participate in improving health outcomes of UC patients.
- Satisfaction of patient is found to be good, so to maintain and improve it by improving its leading causes. It is noticed that accessibility domain has the worst mean among satisfaction domains, so, it is important to improve its components including waiting time, ease of telephone contact with doctors and the availability of competent substituents in case of doctor's absence and providing subsidized transportation or free transportation means for patients residing in far areas or those in need to financial aid.
- HRQoL for the study participants is found accepted, but it is worth to say that there are some groups of patients who need more focus and support to help them having better HRQoL like persons with lower educational level than 12 years, as they were found to have the lowest HRQoL among educational levels as well as those who are

not working, those who have recurrent flare-ups within periods of less than one month, those who are on a flare-up or suffered from a flare-up within the last month, so more focus should be paid on taking steps to prevent or delay flare-ups.

- Paying more attention on preventing flare-ups occurrence as it has clear negative effects on HRQoL of patients and bowel dimension showed the lowest mean among SIBDQ dimensions. Flare-up prevention can be achieved by health education about things that enhance its occurrence to prevent it and supplying patients with the way of dealing with it in the case of its occurrence.
- Support launching of a platform for people with IBD to advocate their rights and needs and provide support to meet their physical and psychological needs.
- The Palestinian health care system needs to incorporate essential services related to IBD within the package of health services.

5.3 Recommendations for further research

- Studying the prevalence of UC s in Palestine generally and in the GS specifically.
- Conducting studies to determine disease severity and extent in the diagnosed patients and then studying their effect on other variables like satisfaction and HRQoL.
- Conducting studies for the evaluation of the provided services for the other part of IBD, which is crohn’s disease.

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Annexes

Annex (1) Study activities time table

Activity	Duration	May 2020	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan 2021	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct 2021
Proposal writing	1 month																		
Proposal discussion and approval	1 month																		
Development of instruments	1 month																		
Tool validation by experts and updating	1 month																		
Pilot study and updating tool	1 month																		
Data collection	6 months																		
Data entry	6 months																		
Data Analysis	6 months																		
Research writing	2 months																		

Annex (2) Estimated budget

Items	**Unit**	**Cost in USD**
MP3 recorder		120
Transportation		700
Stationary and printing	Package	300
SIM card and balance		200
Data entry and analysis	Package	500
Copy of final report	15 copy*15$	225
Total		2045

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:2020/12/8

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

تحية طيبة وبعد،،،

الموضوع: مساعدة الطالبة هناء عزمي مكي

نشكر لكم دعمكم الدائم لمسيرة العلم والتعليم وخصوصاً دعم كلية الصحة العامة وطلابها، ونود أعلامكم بأن الطالبة المذكورة أعلاه تقوم بعمل بحث كمتطلب للحصول على درجة الماجستير في الصحة العامة–مسار إدارة صحية بعنوان:

"Evaluation of Ulcerative Colitis Management in the Gaza Strip"

وعليه نرجو من سيادتكم التكرم بالموافقة على تسهيل مهمة الطالبة في إنجاز هذا البحث حيث أن الفئه المستهدفة هم مرضى القولون التقرحي متلقي الخدمات في مراكز الرعاية الأولية والمستشفيات التابعة لوزارتكم الموقرة، و وأيضاً الكادر الطبي و الإداري الذين لهم دور في تقديم الخدمات الصحية لهؤلاء المرضى.

و اقبلوا فائق التحية و الاحترام،،،

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

نسخة:
- الملف

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Annex (4) Ethical approval from Helsinki Committee

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: 10\08\2020 **Number:** PHRC/HC/752/20

Name: Hanaa Azmi Makki 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 Ulcerative Colitis Management in the Gaza Strip

The committee has decided to approve the above mentioned research. Approval number PHRC/HC/752/20 in its meeting on 10\08\2020

و قد قررت الموافقة على البحث المذكور عاليه بالرقم والتاريخ المذكوران عاليه

Signature

Member **Chairman** **Member**

10/8/2020 10/8/2020

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:-

10/8/2020

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

السيد : رامي عيد العبادله المحترم

التاريخ:15/12/2020
رقم المراسلة 600148

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

السلام عليكم ,,,

الموضوع/ تسهيل مهمة الباحثة// هناء مكي

التفاصيل //
بخصوص الموضوع أعلاه، يرجى تسهيل مهمة الباحثة/ هناء عزمي رشيد مكي
الملتحقة ببرنامج ماجستير الصحة العامة – مسار الإدارة الصحية – كلية الصحة العامة ـ جامعة القدس أبوديس بغزة في إجراء بحث بعنوان:ـ
"Evaluation of Ulcerative Colitis Management in the Gaza Strip"
حيث الباحث بحاجة لتعبئة استبانة والاطلاع على عدد من ملفات المرضى الذين يعانون من التهاب القولون التقرحي المراجعين لمراكز الرعاية الاولية وعيادات الجهاز الهضمي في المستشفيات، اضافة لإجراء مقابلات معمقة مع عدد من المرضى ومقدمي الخدمات الصحية لهم والمسئولين عن تقديم الخدمات الصحية الحكومية.
نأمل توجيهاتكم لذوي الاختصاص بضرورة الحصول على الموفقة المستنيرة من المرضى الذين هم على استعداد للمشاركة في الدراسة ومن ثم تمكين الباحثة 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 /
البحث المذكور حاصل على موافقة لجنة اخلاقيات البحث الصحي (لجنة هلسنكي)
تسهيل المهمة الخاص بالدراسة أعلاه صالح لمدة 9 اشهر من تاريخه.

محمد ابراهيم السرساوي
مدير دائرة/الإدارة العامة لتنمية القوى البشرية

التحويلات

محمد ابراهيم محمد السرساوي(مدير دائرة)	← رامي عيد سليمان العبادله(مدير عام بالوزارة)	إجراءاتكم بالخصوص(15/12/2020)
رامي عيد سليمان العبادله(مدير عام بالوزارة)	← مدحت محمد يوسف محيسن(وكيل وزارة مساعد)	إجراءاتكم بالخصوص(15/12/2020)
رامي عيد سليمان العبادله(مدير عام بالوزارة)	← مدحت محمد يوسف محيسن(وكيل وزارة مساعد)	إجراءاتكم بالخصوص(15/12/2020)
رامي عيد سليمان العبادله(مدير عام بالوزارة)	← عبد السلام محمد عيد صباح(مدير عام بالوزارة)	إجراءاتكم بالخصوص(15/12/2020)
عبد السلام محمد عيد صباح(مدير عام بالوزارة)	← محمد خليل محمد زقوت(مدير)	إجراءاتكم بالخصوص(16/12/2020)

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Annex (6) List of experts

Expert name	Place of work
Prof. Yehia Abed	Al-Quds University
Dr. Khitam Abu Hamad	Al-Quds University
Dr. Raafat Lubbad	Indonesian Hospital
Dr. Eman El Hinnawi	Al-Shifa Hospital
Dr. Alaa Shaer	Nasser Hospital
Dr. Qusay Abdoh	Al Najah Hospital
Dr. Reem Al-Aila	Indonesian Hospital
Dr. Danuta Sukkar	Shohadaa Al-Remal PHC center
Dr. Elena Khella	Shohadaa Al-Daraj PHC center
Dr. Rula El helo	Shohadaa Al-Remal PHC center

Annex (7) UC patients questionnaire- English

Evaluation of Ulcerative Colitis Management in the Gaza Strip

Consent form-Explanation letter

Dear participant,

- I am Hanaa Azmi Makki and I am conducting a study as a part of master degree requirements in public health at Al-Quds University.
- This study is concerned with the evaluation of services provided to you from the governmental hospital/PHC center concerning your ulcerative colitis.
- This study requires your participation in filling questions. Your participation in the study will have no negative implications on you or your family.
- You are invited to participate in this study as well as all registered users of health care services provided regarding UC through governmental hospital and PHC centers and few people will be invited to participate in interviews later.
- Findings will not refer to your name and confidentiality will be provided and maintained.
- The study is self-funded and completely independent and all findings will be used for research purposes only with no connections with official bodies.
- Your participation is highly appreciated and it is optional.
- If you need me to read the question again or it was not clear, please do not hesitate to ask for repetition or further clarification.
- If you are not sure about which answer to select, you can choose the best one describing your feeling, mostly the first one that comes to your mind. Keep in mind that there is no wrong and right answers.
- You may feel that some questions are repeated, please answer them all

Thanks for your participation

Date ……	**Day ……**
Participant serial number …….	**Filled by 1. Patient 2. Patient's caregiver**
PHC center/ hospital serial number ……...…	
Part I	
Section 1: Socio-demographic and economic characteristics	
1.1. Age in years ……	
1.2. Gender 1. Male 2. Female	
1.3. Governorate 1. North Gaza 2. Gaza 3. Middle Zone 4. Khan Yuins 5. Rafah	
1.4. Marital status 1. Single 2. Married 3. Widow 4. Separated 5. Divorced	
1.5. Years of education …….....	
1.6. Refugee status 1. Refugee 2. Non-refugee 3. Others, specify please……..……	
1.7. Occupational Status 1. Working 2. Not working 3. Retired If working or retired, specify the job please ……	
Section 2: Medical information	
2.1. Years of disease from diagnosis ……..	
2.2. How often do you experience attacks (active disease)? 1. Daily 2. Weekly 3. Monthly 4. Every few months 5. Yearly 6. Others, specify please ……..……..	
2.3. When was the last time you experienced these symptoms? Before …… Month/s	
2.4. Do the last attack is finished? 1. Yes 2. No	
2.5. What were these symptoms? **(Could be more than one answer)** 1. Abdominal pain or cramps 2. Diarrhea or increased need to go to the toilet more than usual 3. Mucous or pus in stool 4. Blood in stool 5. Others, specify please ……..……..….	
2.6. Have you undergone a surgery in your colon due to UC 1. Yes 2. No If yes, please specify how many times …..……. Specify the surgery type please ……...…...……...	
2.7. Do you suffer from any extra-intestinal manifestation? 1. Yes 2. No. **Go to question 2.9** 3. I don't know	
2.8. If you suffer from any extra-intestinal manifestation, please specify which of the followings **(Could be more than one answer)** 1. Dermatological manifestations 2. Ocular manifestations 3. Fever 4. Weight loss 5. Respiratory manifestations 6. Joint manifestations 7. Hematological effects 8. Effects on liver 9. Others, specify please ……..…..……..	
2.9. Do you suffer from other chronic diseases? 1. Yes No. **Go to question 3.1**	
2.10. If yes, which diseases do you have **(Could be more than one answer)** 1. High blood pressure 2. Heart disease 3. Diabetes 4. Kidney disease 5.Respiratory disease 6. Others, specify please ……..……..……..…..	
Part II: Input	
Section 3	
3.1. What are the medications you are taking? **(Could be more than one answer)** 1. Oral 5-ASA 2. Topical 5-ASA 3. Systemic corticosteroid 4. Topical corticosteroid 5. Immunosuppressor 6. Biological agents 7. I don't know 8. Others, specify please ……...……..…	
3.2. Do you take your medication/s regularly in time as prescribed by the physician? 1. Yes, all the time 2. Sometimes 3. No	
3.3. Who had prescribed your medication/s for the first time? 1. A physician in MOH 2. A physician in UNRWA 3. A physician in a private clinic 4. NGO's physician 5. Others, specify please ……..…….	

3.4. **For patients with stoma only:** Is there a stoma therapist in the health care facility where you get your UC health care services? 1. Yes 2. No 3. I don't know
3.5. In the governmental health care facility where you get your health care services, is there a psychosocial specialist? 1. Yes 2. No. **Go to question 3.7** 3. I don't know
3.6. If yes, did you visit him/her before? 1. Yes 2. No
3.7. From where do you get health care services regarding your UC? **(Could be more than one answer)** 1. Governmental hospital 2. Governmental PHC center 3. UNRWA clinic 4. Private clinic 5. NGO facility 6. Public pharmacy 7. Private lab 8. Others, specify please ……
3.8. **In case of getting service from a governmental hospital,** what services do you receive from the it? **(Could be more than one answer)** 1. Colonoscopy 2. Laboratory tests 3. Follow-up 4. Medication dispensing 5. Health education about UC 6. Nutritional counseling 7. Surgery 8. Psychological support 9. Others, specify please ……..……...……
3.9. **In case of getting service from a governmental PHC center,** what services do you receive from the it? **(Could be more than one answer)** 1. Colonoscopy 2. Laboratory tests 3. Follow-up 4. Medication dispensing 5. Health education about UC 6. Nutritional counseling 7. Surgery 8. Psychological support 9. Others, specify please ……..……..……
3.10. When was the last time to receive services? Before …… Month/s
3.11. From where do you get your medication/s? **(Could be more than one answer)** 1. Governmental hospital 2. Governmental PHC center 3. UNRWA clinic 4. Private clinic 5. NGO facility 6. Public pharmacy 7. Others, specify please ……..……...……
3.12. If you take your medication/s from a governmental PHC center or hospital, do you find it/them available every time? 1. Yes, all the time 2. Sometimes 3. Some of them are available where others are not 4. No
3.13. How many times have you performed colonoscopy? …… 1. 1-2 2. 3-5 3. >5
3.14. Where did you perform the colonoscopy? 1. In a governmental hospital. **Go to question 3.17** 2. In a private or an NGO facility 3. Sometimes in a governmental hospital and sometimes in a private or an NGO facility
3.15. If you had performed colonoscopy out of the governmental PHC center or hospital, what was the cause? **(Could be more than one answer)** 1. Long waiting list 2. The physician referred me to it 3. It was not always available 4. The governmental facility lacks confidentiality 5. Results are more accurate 6. Others, specify please ……
3.16. If you had performed colonoscopy in both a governmental facility and a private one, which of them which was more comfortable? 1. Governmental hospital 2. Private or NGO facility 3. There is no difference If the private facility colonoscopy was more comfortable, specify why please ……
3.17. When a colonoscopy is indicated, do you find it available all times in the governmental facilities? 1. Yes, all the time 2. Sometimes 3. No
3.18. **In case of performing colonoscopy in the governmental hospital**, have you received a feedback about its result? 1. Yes, all the time 2. Sometimes 3. No
3.19. If your UC state was worsened or passed through complications, did this affect your UC management plan? 1. Yes, all the time 2. Sometimes 3. No 4. I don't know
3.20. Have you done any laboratory tests last year? 1. Yes 2. No If yes, when was it? Before …… Month/s
3.21. Where do you perform laboratory tests? **(Could be more than one answer)** 1. Governmental hospital 2. Governmental PHC center 3. UNRWA clinic 4. Private lab 5. NGO facility 6. Others, specify please ……..……..…….

3.22. When laboratory tests are indicated for you, do you find it available in governmental facilities? 1. Yes, all the time 2. Sometimes 3. Some of them are available while others are not 4. No
3.23. **In case of performing laboratory tests in the governmental hospital or PHC center**, did you receive a feedback about their results? 1. Yes, all the time 2. Sometimes 3. No
3.24. If there were laboratory test results higher or lower than normal, did this affect your UC management plan? 1. Yes, all the time 2. Sometimes 3. No 4. I don't know
Part III: Process
Section 4
4.1. Do you find it easy to reach the governmental health care facilities? 1. Yes. **Go to question 4.3** 2. To some extent 3. No
4.2. If the answer is not yes, what is the cause? **(Could be more than one answer)** 1. I come by public transportation and it is cost money 2. I come on foot and it takes a long time 3. Others, specify please ……..
4.3. When an urgent issue happens with you regarding UC, can you easily contact with your physician in the health care facility? 1. Yes 2. To some extent 3. No
4.4. If you had performed colonoscopy in the governmental hospital, was there a long waiting list before your turn? 1. Yes 2. To some extent 3. No
4.5. Your main source/s of information about UC is/are from: **(Could be more than one answer)** 1. Internist 2. Physician in PHC center 3. Physician in UNRWA 4. Internet 5. Friend 6. Family 7. Others, specify please ……..……
4.6. From where do you receive follow-up? **(Could be more than one answer)** 1. Governmental hospital 2. Governmental PHC center 3. UNRWA clinic 4. Private clinic 5. NGO facility 6. Public pharmacy 7. Others, specify please ……..……
4.7. **In case of governmental hospital visit for a follow-up**, do you wait for a long time to see the doctor? 1. Yes 2. To some extent 3. No
4.8. Average waiting time in the outpatient clinic in the governmental hospital ……. .minutes 1. <30 2. 30–60 3. >60
4.9. Average contact time with the physician in the governmental hospital……. .minutes 1. 0- 5 2. 6-15 3. >15
4.10. **In case of PHC center visit for a follow-up**, do you wait for a long time to see the doctor? 1. Yes 2. To some extent 3. No
4.11. Average waiting time for the physician in the governmental PHC center……. .minutes 1. <30 2. 30–60 3. >60
4.12. Average contact time with the physician in the governmental PHC center …..… minutes 1. 0- 5 2. 6-15 3. >15
4.13. If you had performed lab tests in the governmental hospital/PHC center, did you wait for a long time to get the service? 1. Yes 2. To some extent 3. No
4.14. If you come to the governmental hospital/PHC center to dispense your medications, do you wait for a long time to get the service? 1. Yes 2. To some extent 3. No
4.15. In the health care facility, do you find it easy to reach places that you want? 1. Yes 2. To some extent 3. No
4.16. If the answer is not yes, what do you think the reason? 1. There is no clear and illustrative pathway 2. There is no clear sign or label to clarify right places 3. The needed places are far from each other 4. The health provider does not say to me where to go later on
4.17. Do you conduct follow-up visits regularly? 1. Yes. **Go to question 4.16** 2. No
4.18. If the answer is no, why? **(Could be more than one answer)** 1. I cannot afford transportation cost 2. My movement is uneasy 3. I do not have time-work issues-leave 4. I am not welcomed by staff 5. I do not trust my provider 6. I need someone to come with me to the hospital/PHC center 7. Others, specify please……
4.19. Number of follow-up visits per year 1. 0 2. 1–2 3. ≥3

4.20. Do you think that your follow-up visits are adequate? 1. Yes 2. To some extent 3. No
4.21. If you did not go to follow-up anytime, did the provider contact you? 1. Yes 2. No
4.22 When you have an attack, you often 1. Call the gastroenterologist 2. Go to the hospital 3. Go to PHC center 4. Ask a friend, what to do 5. Search in the internet 6. Others, specify please……..
Section 5: Health education regarding UC
5.1. Have you received health education about UC in this PHC center/hospital before? 1. Yes 2. No. **Go to question 5.4**
5.2. If yes, when was it? **(Could be more than one answer)** 1. At the time of diagnosis of my UC only 2. Regularly, every follow-up visit 3. Irregularly, during the follow-up visits 4. Others, specify please ……..……....
5.3. If yes, to what extent do you consider that the health education you had received was beneficial? 1. Not beneficial 2. Beneficial- to some extent 3. Beneficial to large extent
5.4. Have you received any educational materials about UC during your visits to governmental health facilities in the last year? 1. Yes 2. No
5.5. In which areas regarding UC, do you feel that you need of health education? **(Could be more than one answer)** 1. Signs and symptoms of the beginning of a flare-up 2. UC complications 3. Nutrition, what to eat and what not to eat 4. Follow up importance 5.How to take medication/s 6. Others, specify please …….
5.6. How would you rate your understanding of your disease? 1. Excellent 2. Good 3. Fair 4. Poor
Section 6: User-provider interaction
Note: In case you have been in touch with more than one medical specialist, think of the one you have had the most contact with in the last year. 6.1. Who is the physician that have you had the most contact with in the last year? 1. A physician in a governmental hospital 2. A physician in a governmental PHC center 3. A physician in a private clinic 4. A physician in an NGO facility 5. Others, specify please ……..……

Strongly disagree 1	**Disagree 2**	**Neutral 3**	**Agree 4**	**Strongly agree 5**
6.2. Did the doctor listen to you carefully during the consultation?				
6.3. Did the doctor allow you to talk without interrupting you?				
6.4. Did the doctor encourage you to express yourself / talk?				
6.5. Did you feel that the doctor examine you thoroughly?				
6.6. Do you feel that the doctor understand you?				
6.7. Was it easy to understand what the doctor said?				
6.8. Do you feel you were given all the necessary information?				
6.9. Did the doctor explain the advantages and disadvantages of the treatment or care strategy?				
6.10. In your opinion, did the doctor have a reassuring attitude and way of talking?				
6.11. Do the physician deals with you respectfully?				
6.12. Did the doctor makes sure that you understood his explanations and instructions?				
6.13. Did the doctor reply to all your expectations and concerns?				
6.14. Do the nurse deals with you respectfully?				
6.15. Do the lab technician deals with you respectfully?				
6.16. Do the pharmacist deals with you respectfully?				
6.17. Do the pharmacist informs you how to take your medications every visit?				
6.18. If you want to ask the pharmacist anything about your medication, do you find it easy?				

Part IV: Output/outcome				
Section 7				
Strongly disagree 1	**Disagree 2**	**Neutral 3**	**Agree 4**	**Strongly agree 5**
7.1. After receiving health care services, to what extent do you realize an improvement in your health status?				
7.2. After receiving health care services, to what extent do you realize restoration of your eating habits?				
7.3. After receiving health care services, to what extent do you realize restoration of bowel habits?				
7.4. After receiving health care services, to what extent do you consider that you have returned to your normal daily activities?				
7.5. After receiving health care services, to what extent have you returned to work normally?				
7.6. In the past year, have you been returned home without receiving the services you came to receive? 1. Yes 2. No If yes, how many times were you returned? ……. If yes, indicate why please …….				
7.7. What is/are the main annoying thing/s that you face while receiving services related to UC? 1. Unavailability of some medicines 2. Crowdedness 3. Long waiting time 4. Poor staff communication 5. Infrequent colonoscopies 6. Lack of specialized services 7. Unavailability of some laboratory tests 8. Short contact time with the provider 9. Mitigation measures against COVID-19 are not enough in the health care facility 10. Infrequent appointments 11. Others, specify please …….				
7.8. Is there any service that you need it and not available? 1. Yes 2. No If yes, specify please ……				
Section 8: Patient's satisfaction/perspectives about the quality of care using (QUOTE-IBD)				
8.1. Have you been in touch with one or more medical specialists during the past year (52 weeks) because of IBD? **(This means any kind of contact, including telephone calls)** 1. No. **Go to question 8.24** 2. Yes. **In case you have been in touch with more than one medical specialist, think of the one you have had the most contact with.**				
The GP/specialist I have seen during the past year, with whom I have had the most contact …..	**No 1**	**Not really 2**	**On the whole, yes 3**	**Yes 4**
8.2. has a good understanding of my problems				
8.3. allows me to have an input into the decisions regarding the treatment or help I receive				
8.4. always takes me seriously				
8.5. always keeps appointments punctually				
8.6. does not keep me in the waiting room for more than 15 minutes				
8.7. informs me, in understandable language, about the medicines that are prescribed for me				
8.8. prescribes medicines which are fully covered by the National Health System or social services				
8.9. is always easy to reach by telephone				
8.10. Makes sure that I can see a specialist within 2 weeks after being referred to him/her				
8.11. always communicates with other health and social care providers about the services I require				

The GP/specialist I have seen during the past year, with whom I have had the most contact …...	**No 1**	**Not really 2**	**On the whole, yes 3**	**Yes 4**
8.12. has a waiting area and consulting room which are clean and orderly				
8.13. approach my physical complaints, due to IBD, also from a psychological point of view				
8.14. informs me clearly about the examinations I am subjected to				
8.15. is the GP/specialist I usually see				

The GP/specialist I have seen during the past year, with whom I have had the most contact …...	**No 1**	**Not really 2**	**On the whole, yes 3**	**Yes 4**
8.16. informs me clearly about other possible physical problems due to IBD, e.g. joint pain				
8.17. has a waiting area and consulting room with good toilet facilities				
8.18. Makes sure an adequately competent substitute is available if he/she is absent				
8.19. informs me adequately about nutrition and IBD				
8.20. lets me consult him/her regularly				
8.21. is promptly available in case of acute problems (or an adequately competent substitute is available)				
8.22. pays attention to the influence of my IBD on my family life and/or work situation				
8.23. gives me confidence in him/her				

We would like your opinion on the following specific statements:

In your experience …..	**No 1**	**Not really 2**	**On the whole, yes 3**	**Yes 4**
8.24. medicines which are fully covered by the National Health System or social services are prescribed to me				
8.25. the outpatient clinic is easy to reach by telephone				
8.26. waiting areas and consulting rooms in the hospital are clean and orderly				
8.27. nurses at the endoscopy department have specific expertise in IBD				
8.28. the hospital has good toilet facilities				
8.29. the hospital provides adequate information about nutrition				

Section 9: Quality of life using SIBDQ

This questionnaire is designed to find out how you have been feeling during the last 2 weeks. You will be asked about symptoms you are having as a result of your inflammatory bowel disease, the way you have been feeling in general, and how your mood has been.

All of the time 1	**Most of the time 2**	**A good bit of the time 3**	**Some of the time 4**	**A little of the time 5**	**Hardly any of the time 6**	**None of the time 7**
9.1. How often has the feeling of fatigue or of being tired and worn out been a problem for you during the last 2 weeks? Please indicate how often the feeling of fatigue or tiredness has been a problem for you during the last 2 weeks by picking one option from						
9.2. How often during the last 2 weeks have you had to delay or cancel a social engagement because of your bowel problem? Please choose an option from						
9.3. How often during the last 2 weeks have you been troubled by pain in the abdomen? Please choose an option from						
9.4. How often during the last 2 weeks have you felt depressed or discouraged? Please choose an option from						
9.5. How much of the time during the last 2 weeks have you been troubled by a feeling of having to go to the toilet even though your bowels were empty? Please choose an option from						
9.6. How much of the time during the last 2 weeks have you felt angry as a result of your bowel problem? Please choose an option from						

9.7. How much difficulty have you had, as a result of your bowel problems, doing leisure or sports activities you would have liked to have done over the last 2 weeks? Please choose an option from 1. A great deal of difficulty, activities made impossible 2. A lot of difficulty 3. A fair bit of difficulty 4. Some difficulty 5. A little difficulty 6. Hardly any difficulty 7. No difficulty; the bowel problems did not limit sports or leisure activities						
A major problem 1	**A big problem 2**	**A significant problem 3**	**Some trouble 4**	**A little trouble 5**	**Hardly any trouble 6**	**No trouble 7**
9.8. Overall, in the last 2 weeks, how much of a problem have you had passing large amounts of gas? Please choose an option from						
9.9. Overall, in the last 2 weeks, how much of a problem have you had maintaining or getting to the weight you would like to be? Please choose an option from						
9.10. How often during the last 2 weeks have you felt relaxed and free of tension? Please choose an option from 1. None of the time 2. A little of the time 3. Some of the time 4. A good bit of the time 5. Most of the time 6. Almost all of the time 7. All of the time						
Section 10: The effect of COVID-19 pandemic on health care services regarding UC						
10.1. Has your case been aggravated after the start of COVID-19 pandemic in the Gaza Strip? 1. Yes 2. To some extent 3. No 4. I don't know						
Highly affected 1	**Moderately affected 2**	**Slightly affected 3**	**Does not affected at all 4**			
10.2. To what extent do you consider that COVID-19 affect the provision of health care services regarding your UC?						
10.3. To what extent do you consider that COVID-19 affect the presence of health care staff when you are in need to them?						
10.4. To what extent do you consider that the dispensing your UC medication/s is affected by COVID-19 pandemic?						
11.5. To what extent do you consider that COVID-19 affect your follow-up regarding UC?						
10.6. Have you needed laboratory testing and cannot perform it in the MoH facilities due to COVID-19? 1. Yes 2. No 3. I have not need it in this period						
10.7. Have you needed an colonoscopy and cannot perform it in the MoH facilities due to COVID-19? 1. Yes 2. No 3. I have not need it in this period						

Annex (8) UC patients questionnaire- Arabic

Evaluation of Ulcerative Colitis Management in the Gaza Strip

نموذج الموافقة

الأخ المشارك/ الأخت المشاركة

- أنا هناء عزمي مكي وأقوم حاليا بعمل دراسة لتقييم الخدمات المقدمة في المستشفيات والمراكز الصحية الحكومية لحالات القولون التقرحي, وهي متطلب للحصول على درجة الماجستير في كلية الصحة العامة/جامعة القدس.
- هذه الدراسة تحتاج مشاركتك في بالإجابة على الأسئلة وهذه المشاركة لن يكون لها أي تأثير سلبي عليك أو على عائلتك مع العلم أن هذه الاستبانة لن تشير لاسمك كما هو الحال في نتائج الدراسة.
- أنت مدعو/ة للمشاركة في هذه الدراسة كما هو الحال لجميع متلقي هذه الخدمات.
- هذه الدراسة ممولة ذاتيا وهي دراسة مستقلة، وسيتم الحفاظ على خصوصيتك ونثمن مشاركتك فيها التي تعتبر اختيارية.
- إذا أردت تكرار سماع السؤال، أو كان غير واضحا، فلا تتردد/ي في طلب تكراره أو توضيحا أكثر له.
- إذا لم تتأكد/ي من إجابة ستختار/ين، فيمكنك اختيار الإجابة الأقرب، وهي غالبا الإجابة التي ستخطر ببالك أولا عند سماع السؤال، مع العلم أنه لا يوجد إجابات صحيحة وأخرى خاطئة.
- من الممكن أن تشعر/ي أن هناك أسئلة مكررة، رجاء أجب/ أجيبي عنها جميعها.

شكرا جزيلا لمشاركتك

التاريخ	**اليوم .....**
الرقم التسلسلي للمشارك/ة	**تعبئة الاستبانة بواسطة 1. المريض نفسه 2. المعتني بالمريض**
الرقم التسلسلي للمركز الصحي/ المستشفى	
الجزء الأول	
القسم 1: الخصائص الاجتماعية والاقتصادية	
1.1. العمر بالسنوات	
1.2. الجنس 1. ذكر 2. أنثى	
1.3. المحافظة 1. الشمال 2. غزة 3. الوسطى 4. خانيونس 5. رفح	
1.4. الحالة الاجتماعية 1. أعزب/ عزباء 2. متزوج/ة 3. أرمل/ة 4. منفصل/ة 5. مطلق/ة	
1.5. سنوات التعليم	
1.6. حالة اللجوء 1. لاجئ/ة 2. مواطن/ة 3. أخرى، الرجاء تحديدها	
1.7. الحالة المهنية 1. أعمل 2. لا أعمل 3. متقاعد/ة إذا كنت تعمل/ تعملين أو كنت متقاعد/ة ، فالرجاء تحديد هذا العمل	
القسم 2: المعلومات الطبية	
2.1. سنوات المرض منذ التشخيص	
2.2. كم هي المدة التي تتعرض/ين فيها لهجمات المرض (نشاط المرض)؟ 1. يوميا 2. أسبوعيا 3. شهريا 4. كل عدة أشهر 5. سنويا 6. أخرى، الرجاء تحديدها	
2.3. متى كانت آخر مرة تعرضت خلالها لتلك الأعراض؟ ..... شهر	
2.4. هل انتهت أعراض آخر هجمة للمرض؟ 1. نعم 2. لا	
2.5. ما هي هذه الأعراض؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)** 1. وجع أو تقلصات في البطن 2. إسهال أو الحاجة إلى دخول الحمام بصورة أكبر من المعتاد 3. مخاط في البراز أو صديد 4. دم في البراز 5. أخرى، الرجاء تحديدها	
2.6. هل سبق وأن أجريت عملية جراحية في القولون نتيجة للقولون التقرحي؟ 1. نعم 2. لا إذا كانت الإجابة نعم، فالرجاء تحديد عدد مرات إجراء مثل هذه العمليات ..... الرجاء تحديد نوع هذه العملية/ العمليات	
2.7. هل تعاني من أية مظاهر للمرض خارج الأمعاء؟ 1. نعم 2. لا. **اذهب/ي للسؤال 2.9** 3. لا أعلم	
2.8. إذا كنت تعاني/ تعانين من أية مظاهر للمرض خارج الأمعاء، فالرجاء تحديدها من التالي **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)** 1. مظاهر جلدية 2. مظاهر على العين 3. سخونة 4. فقدان وزن 5. مظاهر تنفسية 6. مظاهر على المفاصل 7. تأثيرات على الدم 8. تأثيرات على الكبد 9. أخرى، الرجاء تحديدها	
2.9. هل تعاني من أية أمراض مزمنة أخرى؟ 1. نعم 2. لا. **اذهب/ي للسؤال 3.1**	
2.10. إذا كانت الإجابة نعم، فالرجاء تحديدها **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)** 1. ضغط الدم المرتفع 2. مرض قلب 3. مرض السكري 4. مرض كلى 5. مرض تنفسي 6. أخرى، الرجاء تحديدها	
الجزء الثاني: المدخلات	
القسم 3	
3.1. ما هي الأدوية التي تأخذها حاليا؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)** 1. 5-أينوساليسيلات عن طريق الفم 2. 5-أينوساليسيلات موضعية 3. كورتيكوستيرويدات جهازية 4. كورتيكوستيرويدات موضعية 5. مثبطات المناعة 6. علاجات بيولوجية 7. لا أعلم 8. أخرى، الرجاء تحديدها	
3.2. هل تأخذ/ين الدواء الخاص بك بانتظام وفي الوقت الذي حدده لك الطبيب؟ 1. نعم، دائما 2. أحيانا 3. لا	
3.3. من الذي وصف لك العلاج أول مرة؟ 1. طبيب في وزارة الصحة 2. طبيب في الأونروا 3. طبيب في عيادته الخاصة 4. طبيب في مؤسسة أهلية 5. أخرى، الرجاء تحديدها	
3.4. **للمرضي الذين لديهم ستوما فقط:** هل يوجد معالج ستوما في المنشأة الصحية التي تتلقى/ تتلقين منها الخدمات الصحية الخاصة بالقولون التقرحي؟ 1. نعم 2. لا 3. لا أعلم	
3.5. هل يوجد أخصائي نفسي في المنشأة الصحية التي تتلقى منها خدمات لرعاية الصحية التي تتلقى/ تتلقين منها الخدمات الصحية الخاصة بالقولون التقرحي؟ 1. نعم 2. لا. **اذهب/ي للسؤال 3.7** 3. لا أعلم	
3.6. إذا كانت الإجابة نعم، فهل فكرت بالذهاب إليهم؟ 1. نعم 2. لا	
3.7. من أين تحصل/ين على خدمات الرعاية الصحية الخاصة بالقولون التقرحي؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)** 1. مستشفى حكومي 2. مركز حكومي 3. عيادة الأونروا 4. عيادة خاصة 5. مؤسسة أهلية 6. صيدلية عامة 7. مختبر خاص 8. أخرى، الرجاء تحديدها	

3.8. **في حالة الحصول على خدمات الرعاية الصحية من المستشفى الحكومي،** ما هي تلك الخدمات؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**

1. منظار القولون 2. التحاليل المخبرية 3. المتابعة الصحية 4. صرف الأدوية 5. التثقيف الصحي عن القولون التقرحي
6. التوعية الغذائية 7. الجراحة 8. الدعم النفسي 9. أخرى، الرجاء تحديدها .....

3.9. **في حالة الحصول على خدمات الرعاية الصحية من المركز الصحي الحكومي،** ما هي تلك الخدمات؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**

1. منظار القولون 2. التحاليل المخبرية 3. المتابعة الصحية 4. صرف الأدوية 5. التثقيف الصحي عن القولون التقرحي
6. التوعية الغذائية 7. الجراحة 8. الدعم النفسي 9. أخرى، الرجاء تحديدها .....

3.10. متى كانت آخر مرة تلقيت فيها تلك الخدمات الصحية؟ قبل ..... شهر

3.11. من أين تحصل على أدويتك الخاصة بالقولون التقرحي؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**

1. مستشفى حكومي 2. مركز صحي حكومي 3. عيادة الأونروا 4. عيادة خاصة 5. مؤسسة أهلية
6. صيدلية عامة 7. أخرى، الرجاء تحديدها .....

3.12. **إذا كنت تحصل على دواءك/أدويتك من مستشفى أو مركز صحي حكومي،** فهل تجده متوفرا دائما هناك؟

1. نعم، دائما 2. أحيانا 3. بعضها متوفر وأصناف أخرى لا 4. لا

3.13. كم مرة أجريت منظار للقولون؟ ..... 1. 1-2 2. 3-5 3. 5<

3.14. أين أجريت منظار القولون؟

1. في مستشفى حكومي. **اذهب/ي إلى السؤال رقم 3.17** 2. في منشأة خاصة أو أهلية
3. أحيانا في المشفى الحكومي وأحيانا في منشأة خاصة أو أهلية

3.15. **إذا أجريت منظار للقولون خارج المنشآت الحكومية،** فما هو السبب؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**

1. وجود قائمة انتظار طويلة 2. الطبيب قام بتحويلي إليها 3. لأنه ليس متوفرا دائما في المنشآت الحكومية
4. لأن المنشآت الصحية الحكومية تفتقد إلى الخصوصية 5. لأن نتائجها أكثر دقة
6. أخرى، الرجاء تحديدها .....

3.16. **إذا قمت بإجراء منظار القولون في منشأة صحية حكومية و منشأة خاصة،** فأي واحدة منها كانت مريحة أكثر؟

1. المستشفى الحكومية 2. المنشأة الخاصة أو الأهلية 3. ليس هناك فرق

إذا كانت الإجابة المنشأة الخاصة أو الأهلية، فما هو السبب برأيك؟ .....

3.17. عندما يتم الطلب منك عمل منظار للقولون، هل تجده متوفرا دائما في المنشآت الحكومية؟

1. نعم، دائما 2. أحيانا 3. لا

3.18. **إذا قمت بإجراء منظار للقولون في المستشفى الحكومي،** هل تلقيت ردة فعل حول نتيجتها في المنشأة الصحية الحكومية؟

1. نعم، دائما 2. أحيانا 3. لا

3.19. إذا ساءت حالة القولون التقرحي لديك أو مررت بمضاعفات، هل أثر ذلك على خطة إدارة الحالة الخاصة بك؟

1. نعم، دائما 2. أحيانا 3. لا 4. لا أعلم

3.20. هل قمت بإجراء أي تحاليل مخبرية خلال عام من الآن؟ 1. نعم 2. لا

إذا كانت الإجابة نعم، فمتى كان ذلك؟ قبل ..... شهر

3.21. أين تقوم/ين عادة بإجراء التحاليل المخبرية؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**

1. مستشفى حكومي 2. مركز صحي حكومي 3. عيادة أونروا 4. مختبر خاص
5. منشأة أهلية 6. أخرى، الرجاء تحديدها .....

3.22. عندما يتم الطلب منك إجراء بعض التحاليل المخبرية، هل تكون موجودة في المنشآت الحكومية؟

1. نعم، دائما 2. أحيانا 3. بعضها موجود وبعضها لا 4. لا

3.23. **إذا قمت بإجراء تحاليل في المستشفى/ المركز الصحي الحكومي،** هل تتلقى ردة فعل حول نتائج هذه التحاليل المخبرية؟

1 . نعم، دائما 2. أحيانا 3. لا

3.24. إذا كانت نتائج التحاليل المخبرية أعلى أو أقل من الطبيعي، هل أثر ذلك على خطة إدارة الحالة الخاصة بك؟

1. نعم، دائما 2. أحيانا 3. لا 4. لا أعلم

الجزء الثالث: العمليات

القسم 4

4.1. هل تجد أنه من السهل عليك الوصول إلى المنشآت الصحية الحكومية؟

1. نعم. **اذهب/ي إلى السؤال رقم 4.3** 2. إلى حد ما 3. لا

4.2. إذا لم تكن الإجابة نعم، فما هو السبب؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**

1. لأنني آتي باستخدام النقل العام وهو مكلف
2. لأنني آتي هنا على الأقدام وهذا يستغرق وقتا طويلا
3. أخرى، الرجاء تحديدها .....

4.3. إذا حدث معك أمر طارئ بخصوص القولون التقرحي، هل يمكنك التواصل بسهولة مع طبيبك في المنشأة الصحية؟

1. نعم 2. إلى حد ما 3. لا

4.4. إذا قمت بإجراء منظار للقولون في مشفى حكومي، هل كان هناك قائمة انتظار طويلة قبل مجيئ دورك؟
1. نعم 2. إلى حد ما 3. لا

4.5. مصدر معلوماتك الأساسي عن القولون التقرحي هو **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**
1. طبيب الباطنة 2. الطبيب في المركز الصحي الحكومي 3. الطبيب في الأونروا
4. الإنترنت 5. صديق 6. العائلة
7. أخرى، الرجاء تحديدها .....

4.6. من أين تحصل على المتابعة الصحية؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**
1. مستشفى حكومي 2. مركز صحي حكومي 3. عيادة الأونروا 4. عيادة خاصة 5. مؤسسة أهلية
6. صيدلية عامة 7. أخرى، الرجاء تحديدها .....

4.7. **في حال كنت تزور/ين المشفى الحكومي لغرض المتابعة الصحية**، فهل تنتظر/ين لوقت طويل لترى الطبيب؟
1. نعم 2. إلى حد ما 3. لا

4.8. معدل الانتظار في العيادة الخارجية في المشفى الحكومي قبل رؤية الطبيب ..... دقيقة
1. 30> 2. 30-60 3. 60>

4.9. معدل وقت التواصل مع الطبيب في المشفى الحكومي ..... دقيقة
1. 0-5 2. 6-15 3. 15>

4.10. **في حال كنت تزور/ين المركز الصحي الحكومي لغرض المتابعة الصحية**، فهل تنتظر/ين لوقت طويل لترى الطبيب؟
1. نعم 2. إلى حد ما 3. لا

4.11. معدل الانتظار في المركز الصحي الحكومي قبل رؤية الطبيب ..... دقيقة
1. 30> 2. 30-60 3. 60>

4.12. معدل وقت التواصل مع الطبيب في المركز الصحي الحكومي ..... دقيقة
1. 0-5 2. 6-15 3. 15>

4.13. إذا قمت بإجراء تحاليل مخبرية في المشفى الحكومي/المركز الصحي الحكومي، هل تنتظر لوقت طويل حتى تتلقى/ تتلقين هذه الخدمة؟ 1. نعم 2. إلى حد ما 3. لا

4.14. إذا جئت إلى المشفى الحكومي/المركز الصحي الحكومي لصرف الأدوية الخاصة بك، هل تنتظر لوقت طويل حتى تتلقى/ تتلقين هذه الخدمة؟ 1. نعم 2. إلى حد ما 3. لا

4.15. وأنت في المنشأة الصحية، هل تجد/ين الأماكن المطلوبة بسهولة؟ 1. نعم 2. إلى حد ما 3. لا

4.16. إذا لم تكن الإجابة نعم، ما هو السبب باعتقادك؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**
1. ليس هناك مسار توضيحي ظاهر 2. ليس هناك إشارة واضحة أو بطاقة لتوضيح الأماكن الصحيحة
3. الأماكن المطلوبة بعيدة عن بعضها البعض 4. مزود الخدمة لا يذكر لي أين سأذهب بعد ذلك

4.17. هل تواظب على الحضور للمتابعة الصحية؟ 1. نعم. **اذهب/ي إلى السؤال 4.16** 2. لا

4.18. إذا كانت الإجابة لا، فما هو السبب؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**
1. لا أستطيع تحمل تكاليف المواصلات 2. حركتي ليست سهلة
3. ليس لدي الوقت حيث لا أستطيع مغادرة العمل 4. أشعر أنني غير مرحب بي من قبل العاملين
5. لا أثق بمزود الخدمة 6. أحتاج شخصا لمرافقتي
7. أخرى، الرجاء تحديدها .....

4.19. عدد زياراتك للعيادة الخارجية/ المركز الصحي الحكومي في السنة
1. 0 2. 1-2 3. 3≤

4.20. هل تعتقد/ين أن زياراتك للمتابعة الصحية في العام كافية؟
1. نعم 2. إلى حد ما 3. لا

4.21. إذا لم تحضر/ي للمتابعة الصحية في أي وقت، فهل تواصل معك مزود الخدمة حينها؟
1. نعم 2. لا

4.22. عندما تتعرضين لهجمة/ نشاط للمرض، فماذا تفعل/ين عادة؟
1. الاتصال بطبيب الجهاز الهضمي 2. الذهاب للمشفى
3. الذهاب للمركز الصحي الحكومي 4. سؤال صديق/ة ماذا تفعل/ين
5. تبحث/ين في الانترنت 6. أخرى، الرجاء تحديدها .....

القسم 5: التثقيف الصحي فيما يتعلق بالقولون التقرحي

5.1. هل تلقيت تثقيفا صحيا حول القولون التقرحي في المستشفى الحكومي/المركز الصحي الحكومي قبل ذلك؟
1. نعم 2. لا. **اذهب/ي إلى السؤال 5.4**

5.2. إذا كانت الإجابة نعم، فمتى كان ذلك؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**
1. عند تشخيص القولون التقرحي لدي فقط 2. بانتظام، عند كل زيارة للمتابعة الصحية
3. بشكل غير منتظم، خلال زيارات المتابعة الصحية 4. أخرى، الرجاء تحديدها .....

5.3. إذا كانت الإجابة نعم، فلأي مدى تعتقد/ين أن هذا التثقيف الصحي الذي تلقيته/تلقيتيه كان مفيدا؟
1. لم يكن مفيدا 2. كان مفيدا إلى حد ما 3. كان مفيدا إلى حد كبير

5.4. هل سبق وأن تلقيت أي مواد تثقيفية عن القولون التقرحي خلال العام السابق عند زيارتك لهذا المركز الصحي؟
1. نعم 2. لا

5.5. فيما يتعلق بالقولون التقرحي، في أي مجال تشعر/ين أنك بحاجة للتثقيف الصحي؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**

1. علامات وأعراض بداية هجمة القولون التقرحي (نشاط المرض) 2. مضاعفات القولون التقرحي
3. التغذية، ماذا تأكل/ين وماذا لا تأكل/ين 4. أهمية المتابعة الصحية
5. كيفية أخذ الدواء/ الأدوية 6. أخرى، الرجاء تحديدها .....

5.6. كيف تقيم/ين فهمك لمرضك؟ 1. ممتاز 2. جيد 3. مقبول 4. ضعيف

القسم 6: تفاعل مستخدم الخدمة مع مقدميها

ملاحظة: في حال كنت على اتصال بأكثر من اختصاصي طبي، فكر في الشخص الذي كنت على اتصال به أكثر خلال العام الماضي.

6.1. من هو الاختصاصي الطبي الذي كنت على اتصال به أكثر خلال العام الماضي
1. طبيب في المشفى الحكومي 2. طبيب في المركز الصحي الحكومي
3. طبيب في عيادته الخاصة 4. طبيب في مؤسسة أهلي 5 . أخرى، الرجاء تحديدها .....

	لا أوافق بشدة 1	لا أوافق 2	محايد 3	أوافق 4	أوافق بشدة 5
6.2. هل استمع لك الطبيب بعناية أثناء الاستشارة؟					
6.3. هل سمح لك الطبيب بالتحدث دون مقاطعتك؟					
6.4. هل شجعك الطبيب على التعبير عن نفسك/التحدث؟					
6.5. هل قام الطبيب بفحصك بدقة؟					
6.6. هل تشعر/ين بأن الطبيب يفهمك؟					
6.7. هل كان من السهل عليك فهم ما قاله الطبيب؟					
6.8. هل تشعر/ين بأنك قد حصلت على كافة المعلومات الضرورية؟					
6.9. هل شرح لك الطبيب مزايا وعيوب استراتيجية العلاج أو الرعاية؟					
6.10. برأيك، هل كان للطبيب سلوك وطريقة مطمئنة في الكلام؟					
6.11. هل يتعامل معك الطبيب باحترام؟					
6.12. هل تأكد الطبيب من فهمك لشروحاته وتعليماته؟					
6.13. هل استجاب الطبيب لكل توقعاتك واهتماماتك؟					
6.14. هل يتعامل معك الممرض/ة باحترام؟					
6.15. هل يتعامل معك فني/ة المختبر باحترام؟					
6.16. هل يتعامل معك الصيدلي/الصيدلانية باحترام؟					
6.17. هل يذكر لك الصيدلي/ الصيدلانية كيفية تناول الدواء في كل زيارة؟					
6.18. إذا أردت سؤال الصيدلي/ الصيدلانية أي شيء عن أدويتك، فهل تجد/ين ذلك سهلا؟					

الجزء الرابع: المخرجات

القسم 7

	لا أوافق بشدة 1	لا أوافق 2	محايد 3	أوافق 4	أوافق بشدة 5
7.1. بعد تلقي خدمات الرعاية الصحية، إلى أي مدى لاحظت تحسنا في حالتك الصحية؟					
7.2. بعد تلقي خدمات الرعاية الصحية، إلى أي مدى لاحظت عودة عاداتك في الأكل؟					
7.3. بعد تلقي خدمات الرعاية الصحية، إلى أي مدى لاحظت عودة عادة الأمعاء لديك؟					
7.4. بعد تلقي خدمات الرعاية الصحية، إلى أي مدى توافق أنك قد عدت إلى نشاطاتك اليومية المعتادة؟					
7.5. بعد تلقي خدمات الرعاية الصحية، إلى أي مدى عدت إلى عملك بشكل طبيعي؟					

7.6. خلال العام الماضي، هل تم إرجاعك من دون تلقي الخدمات التي جئت للحصول عليها؟
1. نعم 2. لا
إذا كانت الإجابة نعم، فكم مرة تم إرجاعك؟ .....
إذا كانت الإجابة نعم، فالرجاء توضيح السبب .....

7.7. ما هو الشيء الأكثر إزعاجا الذي يواجهك عند تلقيك لخدمات الرعاية الصحية الخاصة بالقولون التقرحي؟ **(يمكن أن تتم الإجابة بأكثر من إجابة واحدة)**

1. عدم توفر بعض الأدوية 2. الازدحام 3. قوائم الانتظار الطويلة
4. ضعف التواصل مع طاقم العاملين 5. عدد مرات إجراء منظار القولون غير كافية
6. قلة وجود الخدمات التخصصية 7. عدم توفر بعض التحاليل المخبرية
8. ضيق وقت التواصل مع مزود الخدمة 9. تدابير الحد من انتشار كوفيد-19 ليست كافية في المرفق الصحي
10. قلة تحديد مواعيد للمراجعة والمتابعة 11. أخرى، الرجاء تحديدها .....

7.8. هل يوجد أي خدمات متعلقة بالقولون التقرحي تشعر أنك تحتاجها/تحتاجينها وهي غير موجودة؟ 1.نعم 2. لا إذا كانت الإجابة نعم، فالرجاء تحديدها					
القسم 8: رضا المرضى عن جودة الرعاية باستخدام ترجمة (QUOTE-IBD)					
8.1. هل كنت على اتصال بواحد أو أكثر من الاختصاصيين الطبيين خلال العام الماضي (52 أسبوع) بسبب مرض التهاب الأمعاء؟ (هذا يعني أي نوع من التواصل، بما يشمل المكالمات الهاتفية) 1. لا. **اذهب/ي للسؤال 8.24** 2. نعم. **في حال إن كنت على اتصال بأكثر من اختصاصي طبي، فهنا المقصد أن تفكر بأكثر شخص كنت على تواصل معه.**					
الطبيب العام/الأخصائي الذي التقيته خلال العام الماضي وكان لي أكثر اتصال معه	**لا 1**	**ليس كثيرا 2**	**على العموم، نعم 3**	**نعم 4**	
8.2. لديه فهم جيد لمشاكلي					
8.3. يسمح لي بالمشاركة في القرارات المتعلقة بالعلاج او المساعدة التي أتلقاها					
8.4. يأخذ أموري دائما على محمل الجد					
8.5. يحافظ على المواعيد في وقتها المحدد					
8.6. لا يبقيني في غرفة الانتظار لأكثر من 15 دقيقة					
8.7. يخبرني بلغة مفهومة عن الأدوية الموصوفة لي					
8.8. يصف لي الأدوية التي يغطيها نظام الصحة الوطني أو الخدمات الاجتماعية بالكامل					
8.9. من السهل دائمًا الوصول إليه عبر الهاتف					
8.10. يتأكد من أنه بإمكاني رؤية أخصائي في غضون أسبوعين بعد إحالتي إليه / إليها					
8.11. يتواصل دائمًا مع مقدمي الرعاية الصحية والاجتماعية الآخرين بشأن الخدمات التي أحتاجها					
8.12. منطقة الانتظار وغرفة الاستشارة نظيفة ومنظمة					
8.13. يتعامل مع الشكاوى الجسمية التي سببها مرض التهاب الأمعاء من جهة، وكذلك من وجهة نظر نفسية					
8.14. يُعلمني بشكل واضح بالفحوصات التي أخضع لها					
8.15. هو الطبيب العام/الأخصائي الذي أراه عادة					
8.16. يخبرني بوضوح عن المشاكل الجسدية الأخرى المحتملة بسبب مرض التهاب الأمعاء، مثل ألم المفاصل					
8.17. منطقة الانتظار وغرفة الاستشارة بها دورات مياه جيدة					
8.18. يتأكد من توفر بديل عنه وأن يكون كفؤ بشكل كاف في حالة غيابه					
8.19. يُعلمني بشكل كافٍ عن التغذية ومرض التهاب الأمعاء					
8.20. يتيح لي بأن أستشيره بانتظام					
8.21. متاح على الفور في حالة حدوث مشاكل حادة (أو يتوفر بديل كفؤ بشكل كاف)					
8.22. ينتبه إلى تأثير مرض التهاب الأمعاء على حياتي العائلية و / أو حالة العمل لدي					
8.23. يعطيني الثقة به					
نود أن نسألك عن رأيك حول هذه الجمل المحددة: حسب خبرتك					
8.24. يتم وصف الأدوية التي يغطيها نظام الصحة الوطني أو الخدمات الاجتماعية بالكامل لي					
8.25. من السهل الوصول إلى العيادة الخارجية عبر الهاتف					
8.26. مناطق الانتظار وغرف الاستشارة في المستشفى/المركز الصحي نظيفة ومنظمة					
8.27. الممرضين/الممرضات في قسم المناظير لديهم خبرة خاصة في مرض التهاب الأمعاء					
8.28. يحتوي المستشفى/المركز الصحي على دورات مياه جيدة					
8.29. يقدم المستشفى/المركز الصحي معلومات كافية عن التغذية					
القسم 9: جودة الحياة باستخدام SIBDQ					
صمم هذا الاستبيان لمعرفة كيف كان شعورك خلال الأسبوعين الأخيرين. سوف توجه لك أسئلة حول أعراض كنت تعاني منها نتيجة لمرض التهاب الأمعاء لديك، كيف كان شعورك العام وكيف كان مزاجك.					
كل الوقت 1	**معظم الوقت 2**	**جزء لا بأس به من الوقت 3**	**بعض الوقت 4**	**قليل من الوقت 5**	**بالكاد في أي وقت 6**	**ولا في أي وقت 7**
9.1. كم من الوقت شكّل الإحساس بالتّعب أو الإرهاق والإنهاك مشكلة بالنسبة لك خلال الأسبوعين الأخيرين؟ الرجاء الإشارة إلى كمية الوقت التي شكّل الإحساس بالتّعب و الإرهاق مشكلة بالنسبة لك خلال الأسبوعين الأخيرين وذلك باختيار إحدى الإجابات						
9.2. كم من الوقت، خلال الأسبوعين الأخيرين، كنت مضطرا إلى تأجيل أو إلغاء ارتباط اجتماعي بسبب مشكلة الأمعاء لديك؟						
9.3. كم من الوقت خلال الأسبوعين الأخيرين، عانيت من ألم في البطن؟						
9.4. كم من الوقت، خلال الأسبوعين الأخيرين، شعرت باكتئاب أو إثباط لعزيمتك؟						
9.5. كم من الوقت، خلال الأسبوعين الأخيرين، انزعجت من الشعور بضرورة الذهاب إلى المرحاض بالرغم من أن أمعاءك كانت فارغة؟						
9.6. كم من الوقت، خلال الأسبوعين الأخيرين، شعرت بالغضب نتيجة لمشكلة الأمعاء لديك؟						

9.7. كم من الصعوبة واجهت نتيجة لمشاكل الأمعاء لديك، أثناء ممارسة الأنشطة الترفيهية أو الرياضية، والتي كنت تود ممارستها خلال الأسبوعين الأخيرين؟

1. صعوبة عظيمة تجعل من ممارسة الأنشطة أمرا مستحيل
2. كثير من الصعوبات
3. قدر لا بأس به من الصعوبات
4. بعض الصعوبات
5. قليل من الصعوبات
6. بالكاد واجهت أي صعوبة
7. ليست هناك أية صعوبة، مشاكل الأمعاء لم تُحد من ممارسة الأنشطة الترفيهية أو الرياضية

مشكلة رئيسية 1	مشكلة كبيرة 2	مشكلة بارزة 3	مشكلة إلى حد ما 4	مشكلة صغيرة 5	بالكاد تكون مشكلة 6	لا مشكلة 7
9.8. بشكل عام، في الأسبوعين الأخيرين، إلى أي حد واجهت مشكلة في إخراج كميات من الغاز؟						
9.9. بشكل عام، في الأسبوعين الأخيرين، إلى أي حد واجهت مشكلة في الحفاظ على وزنك أو الوصول إلى الوزن الذي تريد؟						

9.10. كم من الوقت، خلال الأسبوعين الأخيرين، شعرت بالاسترخاء وعدم التوتر؟ الرجاء اختيار إجابة واحدة مما يلي:

1. ولا في أي وقت
2. قليل من الوقت
3. بعض الوقت
4. جزء لا بأس به من الوقت
5. معظم الوقت
6. تقريبا كل الوقت
7. كل الوقت

القسم 10: تأثير جائحة كوفيد-19 على خدمات الرعاية الصحية الخاصة بالقولون التقرحي

10.1. هل تفاقمت حالتك بعد بدء جائحة كوفيد-19 في قطاع غزة؟

1.نعم
2. إلى حد ما
3. لا
4. لا أعلم

تأثير كبير 1	تأثير متوسط 2	تأثير قليل 3	لم تتأثر على الإطلاق 4
10.2. إلى أي مدى تعتبر/ين أن كوفيد-19 أثر على تقديم خدمات الرعاية الصحية لك فيما يتعلق بالقولون التقرحي؟			
10.3. إلى أي مدى تعتبر/ين أن كوفيد-19 أثر على تواجد طاقم الرعاية الصحية عندما كنت بحاجة إليهم؟			
10.4. إلى أي مدى تعتبر/ين أن صرف دواء/أدوية القولون التقرحي قد تأثر بجائحة كوفيد-19؟			
10.5. إلى أي مدى تعتبر/ين أن كوفيد-19 أثر على المتابعة الصحية للقولون التقرحي لديك؟			

10.6. هل احتجت تحاليل مخبرية ، ولم تستطع/تستطيعي القيام بها في المستشفى الحكومي أو المركز الصحي بسبب كوفيد-19؟

1. نعم
2. لا
3. لم أحتجها خلال هذه الفترة

10.7. هل احتجت إجراء منظار للقولون في المرافق الحكومية، ولم تستطع/تستطيعي القيام بها بسبب كوفيد-19؟

1. نعم
2. لا
3. لم أحتجه خلال هذه الفترة

Annex (9) Record Checklist

Patient's serial number ……..….	Clinic's serial number ……..
Reviewer ……..	Date of review ……..

Identification and biographical data	**Yes**	**No**	**N.A.**
1. Each page inside the medical record contains the patient's name or ID number.			
2. Opening date of the file is written.			
3. Date of birth is written.			
4. Gender is specified.			
5. Address is written.			
6. Telephone number or mobile number is filled.			
7. Educational level is specified.			
8. Occupation is specified.			
9. Marital status is specified.			
Diagnosis, history and treatment	**Yes**	**No**	**N.A.**
10. Diagnosis is clearly written.			
11. Severity and extent of the disease is clearly documented.			
12. Prescribed medications are clearly written with dosages.			
13. Height, weight and BMI are documented.			
14. Posture and gait of the UC patient is documented.			
15. Attitude is documented.			
16. Cardiovascular examination was performed as a base when the file was opened.			
17. Chest examination was performed as a base when the file was opened.			
18. Abdomen examination was performed as a base when the file was opened.			
19. Central nervous system (CNS) examination was performed as a base when the file was opened.			
20. Head eye ear nose throat examination was performed as a base when the file was opened.			
21. Skin and hair examination was performed as a base when the file was opened.			
22. Mental status exam was performed as a base when the file was opened.			
23. Physical & psychological examinations are updated annually.			
24. Abdomen, eye, joint and skin examinations are performed when there are new complaints.			
25. Allergies and adverse reactions are prominently noted in the record			
26. Allergies, are updated annually			
27. Medication/s side effects and symptoms are reviewed with the patient or caregiver and documented.			
28. Medication adherence review for compliance of maintenance medications with the dates of initial and refill prescriptions.			
29. Family history is documented including pertinent medical history of parents and/or sibling(s).			

30. Medical-surgical history is documented including serious accidents, injuries, operations, illnesses/diseases (acute or chronic), and mental health/substance abuse issues and it is updated as appropriate.			
31. Smoking status is documented.			
32. Patient's counseling about high-risk behavior(s) including nutrition is documented or the documentation of the patient's referral to appropriate specialists.			
33. Specialist consultation -if needed- is documented. Name/Specialty and recommendations are all written.			
34. Laboratory tests are ordered as appropriate, especially ESR, liver function test, kidney function tests, CRP, CBC, FBG, lipid profile, iron, folic acid and B_{12} levels and results are documented.			
35. Diagnostic Studies and results are documented as colonoscopy, ultrasound, X-ray and CT scans.			
36. Routine or follow-up visits description is documented including presenting complaints, active (acute) medical or psychosocial problems, or management of a chronic, serious or disabling condition.			
37. Unresolved problems from previous office visits are determined to be addressed in subsequent visits.			
38. There is notation/s, for further calls or follow-up visits if needed.			
39. Follow-up after an emergency department visit/s or hospitalization/s is performed and the date/s for emergency department and/or hospitalizations are listed.			
General record items	**Yes**	**No**	**N.A.**
40. All entries in the medical record contain the author's identification (handwritten signature, stamp, a unique electronic identifier, ……..etc.).			
41. All entries in the medical record are dated.			
42. The record is an Electronic Medical Record (EMR).			
43. Handwriting inside the record is clear and readable.			

Annex (10) Key informants' interview

1. Please tell me about your work, how it relates to UC? (Physician) (KI in pharmacy) (Nurse)
2. How do you perceive the provided health care services to people with UC? What are the good things and what are the existing gaps? To probe: Health care facilities, are they suitable for service provision, human resources (specialized GIT or trained physicians, nurses, ….. etc), their numbers and distribution in the Gaza Strip), medications availability in types and quantities, equipment (colonoscopy devices) and diagnostic tests: availability and adequacy in numbers and distribution over governorates, health education and nutritional counseling (educational materials and workshops), follow-up (are follow-up visits enough?) and psychological support (Is there a department for psychological support of UC patients)? (Physician) (KI in pharmacy) (Nurse).
3. What is your opinion in waiting time, is it suitable in the case of colonoscopy booking, follow-up, medications dispensing and lab tests. What could be done to achieve the required waiting time? (Physicians) (Pharmacist)
4. Contact time with the UC patient, is it suitable. What could be done to achieve the required contact time? (Physician) (KI in pharmacy)
5. Are there guidelines and standards that determine the provision of proper health care services (Physician) (Nurse)
6. To what extent are you satisfied with documentation practices? In your opinion, how can we meet a high quality medical record? What are its characteristics? (efficient electronic health information system) (Physician) (KI in pharmacy) (Nurse)
7. How do you perceive the coordination between health care providers (primary health care and secondary health care, public and private health care facilities, doctors and pharmacists, colonoscopy department, labs….etc. (Physician) (KI in pharmacy) (Nurse)
8. What services do you think that they are needed but not available? What are the main obstacles to reach integrated health care services to UC patients? (limited availability of services, limited specialized services, limited diagnostic facilities, high work load of health care workers) (Physician) (KI in pharmacy) (Nurse)
9. What could be done to improve the provided services? (Physician) (KI in pharmacy) (Nurse)

Annex (11) UC patient interview

1. How are you, how is your health in general?
2. How does UC affect your daily life? How does it affect your family life? How much UC affect your wellbeing, in which direction?
3. How can you describe health care services that you receive regarding UC in governmental facilities (hospitals and/or PHC centers)?
4. What are good and not good things that you face when you receive these services? To probe: Health care facilities (are they suitable for service provision), human resources (specialized GIT or trained physicians, nurses, ….. etc), medications availability in types and quantities, equipment (colonoscopy devices) and lab tests: availability, health education and nutritional counseling (adequate information during follow-up, educational materials and workshops), follow-up (are follow-up visits enough?), waiting time and psychological services.
5. To what extent didn't you receive services which you came to receive? Why? (Equipment, staff, medications and lab tests)
6. Do you consider that the health care staff deals with you respectfully and listen to you carefully?
7. What are services you need to have but not available?
8. In your opinion, what could be done to improve the provided services regarding UC?

عنوان الدراسة: تقييم إدارة خدمات القولون التقرحي في قطاع غزة

إعداد: هناء عزمي مكي

إشراف: د. بسام أبو حمد

ملخص الدراسة

نظرة عامة

القولون التقرحي هو أحد أنواع أمراض التهابات الأمعاء، وهو مرض معقد ومتزايد عالميا. تهدف الدراسة لتقييم الخدمات المقدمة لمرضى القولون التقرحي من خلال المرافق الصحية التابعة لوزارة الصحة في قطاع غزة.

المنهجية

تم استخدام الطريقة المختلطة في هذه الدراسة عن طريق التثليث بين المنهج الكمي والنوعي. الطريقة النوعية تم استخدامها في جمع البيانات من جميع مرضى القولون التقرحي الذين تم إيجادهم بواسطة الاستبانة التي تم إكمالها مع 157 مريض وكذلك مراجعة ملفات المرضى التي تم إيجادها في المراكز الصحية الحكومية باستخدام قائمة الفحص (145 ملف). تم جمع البيانات النوعية من خلال إجراء مقابلات معمقة مع 10 مرضى و10 من العاملين في وزارة الصحة ذوي العلاقة بتقديم الخدمات لمرضى القولون التقرحي وذلك للتعرف أكثر على آرائهم فيما يتعلق بخدمات الرعاية الصحية المقدمة. ولقد تم استخدام برنامج الحزمة الإحصائية للعلوم الاجتماعية في إدخال بيانات الاستبانة وتحليلها، كما تم استخدام برنامج الإكسل في إدخال بيانات قائمة الفحص وتحليلها، وتم استخدام تقنية الترميز لتحليل جزئية البيانات النوعية.

أهم النتائج

أظهرت نتائج الدراسة أن متوسط عمر المشاركين كان 40.9 سنة وأن 58% منهم هم من الذكور و 42% هم من الإناث. تم إيجاد أن 63.7% من المشاركين في الدراسة اعتبروا أنهم في مرحلة هدوء للمرض و36.3% اعتبروا أنهم في مرحلة انتكاسة، كما توضح النتائج أن 35% من المشاركين كان لديهم مرض مزمن آخر أو أكثر، بشكل أساسي مرض ضغط الدم المرتفع ويليه مرض السكري. تمثلت الخدمات المقدمة لمرضى القولون التقرحي من المراكز الصحية الحكومية بصرف الدواء، التحاليل المخبرية، التثقيف الصحي، والإرشاد التغذوي. وجد أنه يتم تقديم نفس الخدمات من خلال المستشفيات الحكومية بالإضافة إلى خدمات التنظير وخدمات قسم الطوارئ ورعاية مرضى القولون التقرحي المنومين في المستشفيات. معظم المرضى (77.7%) كانوا لا يعلمون ما إذا كان هناك أخصائي نفسي في المرافق الحكومية أم لا، و 19.7% منهم ذكروا أنه لا يوجد مثل هذا الأخصائي و 2.5% فقط من المشاركين في الدراسة ذكروا أنه يوجد أخصائي اجتماعي في مرافق الرعاية الصحية الحكومية. المكان الرئيسي لصرف العلاج الخاص بالقولون التقرحي للمشاركين في الدراسة كان المراكز الصحية الحكومية بنسبة 98.7%، ويليها نسبة 36.3% لمن يصرفون العلاج من صيدليات المجتمع ثم نسبة 10.8% لمن يقوموا بصرف دوائهم من المستشفيات الحكومية. وافق 41.4% ممن شاركوا في الدراسة على أنهم دائما ما يجدوا الدواء الخاص بهم موجودا لصرفه من المرافق الحكومية و 44.1% من المشاركين يجدون المنظار متوفرا في كل وقت في المستشفيات الحكومية. متوسط وقت الانتظار للمتابعة

كان طويلا في المستشفيات الحكومية (102.8 دقيقة)، بينما كان 11.6 دقيقة في المراكز الصحية الحكومية. متوسط وقت التواصل مع الطبيب في المستشفى كان 12.3 دقيقة وكان 5.7 دقيقة في المركز الصحي الحكومي. تقريبا نصف المشاركين في الدراسة (52.2%) وافقوا على أنهم تلقوا تثقيفا صحيا في المرافق الحكومية حول القولون التقرحي و ثلثي المشاركين في الدراسة تقريبا تم إرجاعهم مرة على الأقل في آخر سنة بدون الحصول على الخدمات التي جاؤوا لتلقيها بخصوص القولون التقرحي من المرافق الحكومية. متوسط التفاعل بين متلقي الخدمة ومزودها كان مرتفعا (85.7%) و متوسط رضا المرضى عن الخدمات المقدمة كان مرتفعا كذلك، أما بخصوص متوسط جودة الحياة الكلي للمرضى الذي تم إيجاده فهو 4.46 من أساس 7. أظهرت النتائج فروقا ذات دلالة إحصائية بين تفاعل متلقي الخدمة ومزودها وبين كل من جنس متلقي الخدمات والمحافظة. حيث وجد أن الإناث حصلوا على متوسط أفضل في التفاعل بين تلقي الخدمة ومزودها، وحصلت مدينة رفح على أفضل متوسط في التفاعل بين تلقي الخدمة ومزودها. كذلك تم إيجاد أن هناك فروقا ذات دلالة إحصائية في جودة الحياة الكلية بين المستويات التعليمية المختلفة وكذلك في حالة عمل الأشخاص وتكرار حدوث هجمات المرض وتوقيت آخر هجمة من هجمات القولون التقرحي و حالة المريض الحالية من حيث الاستقرار أو وجود انتكاسة. حيث أن نتائج الدراسة أشارت إلى أن المستويات العلمية الأعلى حازت على رضاً أعلى حول الخدمات الصحية المقدمة، وأن الأشخاص المتقاعدين كان معدل جودة الحياة المتعلقة بالصحة لهم هو الأعلى، يليه الخاص بالأشخاص العاملين، بينما حصل الأشخاص غير العاملين عل المعدل الأقل فيها. حصل المرضى الذين لم يشعروا بأعراض الانتكاسة منذ بدء أخذهم للدواء على المعدل الأعلى في جودة الحياة المتعلقة بالصحة، بينما حصل أولئك الذين يشعرون بتكرار أعراض الانتكاسة خلال مدة أقل من شهر أو الذين تحدث لديهم الانتكاسة بشكل غير منتظم على معدلات أقل في جودة الحياة المتعلقة بالصحة من المجموعات الأخرى. ووجد أن المرضى الذين كانوا في فترة هجمة للمرض منذ وقت أطول كان لديهم معدل أفضل لجودة الحياة المتعلقة بالصحة كما هو الحال بالنسبة للمرضى الذين هم في حالة هدوء للمرض. معدل اكتمال التوثيق في ملفات مرضى القولون التقرحي في المراكز الصحية الحكومية هو 26.1%، وهو قليل جدا. نتائج الجزئية النوعية كانت بشكل عام متوافقة مع النتائج الكمية ودعمت باتجاه تحسين الخدمات المقدمة.

الخلاصة

استخلصت الدراسة أن خدمات الرعاية الصحية المقدمة الخاصة بالقولون التقرحي لا تزال بحاجة للمزيد من التحسين خاصة في جزئية توفير الدعم النفسي الاجتماعي لمرضى القولون التقرحي وتقليل وقت الانتظار وزيادة وقت التواصل والحاجة لزيادة عدد أطباء الجهاز الهضمي وأخصائيي التغذية وتوفير العدد الكافي من أجهزة المنظار وتحسين التنسيق والتعاون بين المستويات المختلفة لمقدمي خدمات الرعاية الصحية الحكومية وكذلك تحسين التوثيق.