

QATAR UNIVERSITY

COLLEGE OF PHARMACY

EVALUATING PHARMACY HEALTH LITERACY AND ITS BARRIERS AMONG
PATIENTS WITH CARDIOVASCULAR DISEASES IN QATAR

BY

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ABSTRACT

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Title: Evaluating Pharmacy Health Literacy and Its Barriers among Patients with Cardiovascular Diseases in Qatar

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Background: Patients' health literacy, which is their capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions, is a critical determinant of whether they are able to actively participate in their healthcare. The objective of this study was to measure the level of health literacy among patients with acute coronary syndrome (ACS) and/or heart failure (HF) and to explore barriers and facilitators to health literacy among this population.

Methods: The Abbreviated version of the Test of Functional Health Literacy in Adults (S-TOFHLA) and the Three-item Brief Health Literacy Screen (3-item BHLS) were used to assess health literacy levels among patients with ACS and/or HF. A qualitative approach was used to identify facilitators and barriers to health literacy with the use of one-to-one interviews for patients' perspective and focus group discussions for healthcare providers' perspective.

Results: The prevalence of inadequate to marginal health literacy was found to be 36% using S-TOFHLA and 54% using 3-item BHLS. The most prominent factors were found to contribute to health literacy including patient attitudes and attributes, healthcare provider skills and attitudes, healthcare facility attributes, communication-related aspects, care process, and resources.

Conclusions: Limited health literacy is common among patients with ACS and/or HF in Qatar. Many aspects were found to play a role in the patient's health literacy; therefore, combination of interventions may be necessary to yield the most improvement in patient understanding, health literacy, and health outcomes.

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ABBREVIATIONS

3-item BHLS	Three-item Brief Health Literacy Screen
ACS	Acute Coronary Syndrome
AF	Atrial Fibrillation
AHA	American Heart Association
AHRQ	Agency for Healthcare Research and Quality
AMI	Acute Myocardial Infarction
AREALD-30	Arabic Rapid Estimate of Adult Literacy in Dentistry
AUROC	Area Under the Receiver Operating Characteristic Curve
BMI	Body Mass Index
BSAIT	Basic Skills Agency Initial Assessment Test
CAD	Coronary Artery Disease
CCAT	Crowe Critical Appraisal Tool
CHD	Coronary Heart Disease
CICU	Cardiothoracic Intensive Care Unit
Cr α	Cronbach's alpha
CVDs	Cardiovascular Diseases
DBP	Diastolic Blood Pressure
ED	Emergency Department
HbA1c	Hemoglobin A1c
HBP-HLS	High Blood Pressure-Health Literacy Scale
HDU	High-Dependency Unit
HF	Heart Failure
HMC	Hamad Medical Corporation
HR	Heart Rate
ICC	Intraclass Correlation Coefficient
IHD	Ischemic Heart Disease
IOM	Institute of Medicine
IRB	Institutional Review Board

MENA	Middle East and North Africa
METER	Medical Term Recognition Test
MRC	Medical Research Committee
NAAL	National Assessment of Adult Literacy
NCDs	Non-communicable Diseases
NHS	National Health Strategy
NSTEMI	Non-ST Segment Elevation Myocardial Infarction
NVS	Newest Vital Sign
OPD	Outpatient Department
PIAT-R	Peabody Individual Achievement Test – Revised
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QNRS	Qatar National Research Strategy
REALM	Rapid Estimate of Adult Literacy in Medicine
REALM-R	Rapid Estimate of Adult Literacy in Medicine – Revised
REALM-SF	Rapid Estimate of Adult Literacy in Medicine – Short Form
SBP	Systolic Blood Pressure
SILS	Single Item Literacy Screener
SORT-R	Slosson Oral Reading Test – Revised
STEMI	ST-Segment Elevation Myocardial Infarction
S-TOFHLA	Short Test of Functional Health Literacy in Adults
TOFHLA	Test of Functional Health Literacy in Adults
UA	Unstable Angina
USDHHS	US Department of Health and Human Services
WHO	World Health Organization
WHS	World Health Survey
WRAT-R	Wide Range Achievement Test – Revised

CHAPTER 1: INTRODUCTION

1.1. Global Burden of Cardiovascular Diseases

1.1.1. Prevalence of cardiovascular diseases

Non-communicable diseases (NCDs), which are diseases that are non-infectious and non-transmittable among people, have replaced communicable diseases as the main global disease burden worldwide [1]. The principal types of NCDs include cardiovascular diseases (CVDs), cancer, diabetes mellitus, and chronic respiratory diseases. CVDs such as coronary heart disease (CHD), cerebrovascular disease, rheumatic heart disease, and others, are the most common NCDs and account for approximately half of all NCDs. It is estimated that 92.1 million adults (36.6%) have at least one type of CVD in the United States alone and it is projected that 43.9% of the United States' adult population will have some form of CVD by 2030 [2].

There is a wide heterogeneity in the prevalence and patterns of different types of CVDs in various populations globally. Heart failure (HF), stroke, coronary artery disease (CAD), and atrial fibrillation (AF) are the most prevalent forms of CVD [2]. HF is a global public health problem affecting an estimated 26 million people worldwide [3]; it was estimated that 44% of patients with newly diagnosed CVD have HF [2]. In 2013, 25.7 million people had stroke, of which 10.3 million were a first episode of the stroke, and 8.56 million people had acute myocardial infarction (AMI) worldwide [4]. Furthermore, the worldwide prevalence of atrial fibrillation (AF) was estimated at 33.5 million in 2010 [2].

1.1.2. Cardiovascular disease mortality

CVDs are now recognized as the leading cause of mortality worldwide. Out of 54

million deaths globally in 2013, 17.3 million deaths or 32% were due to CVDs [5], and it is expected to increase to more than 23.6 million by 2030 [5, 6]. The majority of these CVD deaths were attributed to either ischemic heart disease (IHD) or cerebrovascular disease. The leading cause of CVD-related deaths was IHD, which caused an estimated 8.2 million deaths in 2013 [2]. The second most common cause of CVD-related deaths in 2013 was cerebrovascular disease, accounting for more than 8 million deaths. Stroke was responsible for 6.5 million of these deaths, of which 3.3 million deaths due to ischemic stroke and 3.2 million deaths due to hemorrhagic stroke [2].

The dominance of CVDs as a major contributor to the total global mortality is increasing despite the advances in their prevention, diagnosis, and treatment [7]. This trend is a result of a combination of factors including the aging population, growth of the population, rapid urbanization, and epidemiologic changes in CVD [7].

1.1.3. Economic burden of cardiovascular diseases

Besides the clinical burden, CVDs cause a significant economic burden as it consumes up to 17% of the overall healthcare expenditures in the United States [8]. The global estimated cost of CVD was more than \$860 billion in 2010, and it is expected to increase to more than \$1040 billion by 2030. As the population ages, the prevalence and costs of CVD are expected to increase substantially [8]. Despite this trend, there are many opportunities to improve cardiovascular health while limiting costs [9].

1.2. The Burden of Cardiovascular Diseases in Qatar

In Qatar, NCDs have been the leading cause of deaths in the past 10 years with

CVDs as the leading cause of mortality, accounting for 17.1 deaths per 100,000 population in 2010 [10]. Little information is available on CVD morbidity indicators in Qatar. Particularly, no objective figures have been published regarding the prevalence of CVDs at the national level in Qatar. However, an epidemiologic study found that a total of 16,750 patients were admitted with acute coronary syndrome (ACS) between 1991 and 2010 in Qatar [11]. Moreover, according to the World Health Survey (WHS) that was conducted by the World Health Organization (WHO) in Qatar in 2006, the prevalence of hypertension was 14.4% and the prevalence of hyperlipidemia was 24.7% [12].

CVD is one of the leading causes of morbidity and mortality in Qatar and worldwide which brings significant health, economic, and social impact. Therefore, patients' contribution is needed to reduce this high CVD burden.

1.3. Communication and Health Literacy in Cardiovascular Diseases

1.3.1. Cardiovascular diseases and self-management

With the shift in predominant disease patterns from acute to chronic diseases, the promotion of self-management among patients with long-term conditions such as CVDs is essential [13]. Self-management is defined as *“the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition”* [14].

To address the clinical and economic burden of CVDs, interventions must target the multilevel barriers to effective management [15]. CVDs including, but not limited to, ACS and HF are complex conditions that require patients to gain special skills and knowledge to manage their disease condition [16, 17]. In comparison to conditions that are

easy to detect and treat, the management of ACS and HF requires a higher level of patient involvement [18-20]. For example, patients with ACS or HF are expected to be able to read, assess, understand, and act on complex medical information as well as to make informed decisions and understand how to access appropriate health care when needed [16, 21]. A lack of skills in these areas, possibly attributed to limited health literacy, hinders many ACS and HF patients from engaging in effective self-care management of their conditions. Therefore, understanding the prevalence of limited health literacy is fundamental to designing effective intervention strategies for improving health communication.

1.3.2. Prevalence of limited health literacy

Patient health literacy is an essential component of effective health communication and self-management of chronic diseases [22]. Patients with limited health literacy tend to use a passive communication style with their healthcare providers, do not participate in decision making, and lack the ability to self-manage their diseases and medications [22]. Therefore, it is important to understand the construct of health literacy and the prevalence of limited health literacy.

There is a lack of shared definition of the term “health literacy” in the literature among researchers, because it is a relatively new construct and its definition is evolving [23]. A widely cited definition of health literacy is developed by the Institute of Medicine (IOM) as “*the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions*” [24]. This definition was later modified by Berkman et al. to “*the degree to*

which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions” [23].

The National Assessment of Adult Literacy (NAAL), which was the first large-scale national literacy assessment with component specifically designed to measure health literacy in United States’ population, estimated that 36% of adults had below basic or basic health literacy and only 12% of adults had proficient health literacy [25]. A pooled analysis of 85 studies reported that the prevalence of low health literacy was 26% and the prevalence of marginal health literacy was 20% [26]. The prevalence of low health literacy among patients with ACS and HF varies across different studies. A systematic review found that the prevalence of low health literacy among HF patients ranges from 17.5% to 97%, and an average of 39% of the study participants had low health literacy [27]. On the other hand, the prevalence of poor health literacy among ACS patients was found to be 34% in one study [28], while another study found the prevalence to be 44% [29]. In general, limited health literacy has negative impact on healthcare outcomes.

1.3.3. The impact of limited health literacy on health outcomes

In the last 20 to 30 years, there has been a substantial increase in the body of literature to document the relationship between health literacy, health status, and health outcomes [23]. Studies have shown that low or inadequate health literacy, compared to adequate health literacy, is associated with poorer knowledge or comprehension of health care services as well as poorer health outcomes [23]. For instance, adequate health literacy has been associated with the use of health care services and access to care. Individuals with limited health literacy have a higher risk of emergency department (ED) visits and

hospitalizations [30, 31] and lower probability of use of preventative services [31-33]. Moreover, health literacy has been associated with healthcare-related skills as evidence shows that low health literacy is related to poorer skills in taking medications [34-37]. In addition, studies found poorer health status [31, 32, 38, 39] and higher all-cause mortality rates [40-42] among persons with low health literacy. Consequently, evidence suggests higher healthcare costs among patients with limited health literacy compared with patients with adequate health literacy [43-46].

Several studies showed similar effects of limited health literacy on health status and health outcomes among patients with ACS and HF. Low health literacy was found to be associated with lower medication adherence [47], increased incidence of hospitalization [48, 49], and higher risk of mortality [50] in patients with HF. Similarly, patients with limited health literacy and ACS were found to have lower medication adherence [51] and higher hospital readmission rate [52, 53]. Therefore, health literacy skills are considered important determinants of health outcomes in CVD patients, with the assessment of health literacy levels emerging as a key issue in this population.

1.4. Health Literacy Assessment Instruments

Educational attainment, the highest level of education completed, is an inconsistent indicator of skill level in healthcare [23]. Thus, it can be an inaccurate measure of individual's literacy skills when evaluating differences in health outcomes or the effectiveness of health interventions [23]. This recognition led to the development of more direct health-related literacy measures.

Although health literacy is a complex construct since it incorporates different

domains and contexts, there are many well-validated instruments that are used to assess health literacy in research and clinical practice settings. Some of the most common types of health literacy assessment instruments include word-recognition tests and tests of functional health literacy. Word-recognition tests measure an individual's ability to recognize and pronounce words in a list and are considered useful predictors of general reading ability. One of the most commonly used word-recognition tests is the Rapid Estimate of Adult Literacy in Medicine (REALM), which is a list of 66 medical terms that can be completed in 3 to 5 minutes [54]. The Rapid Estimate of Adult Literacy in Medicine – Short Form (REALM-SF) [55] and the Rapid Estimate of Adult Literacy in Medicine – Revised (REALM-R) [56] are abbreviated but correlated versions of the REALM that are considered equivalent to the original REALM tool. Tests of functional health literacy include word-recognition, reading comprehension, numeracy skills, and application to real-life situations. The gold standard of functional health literacy assessments is the Test of Functional Health Literacy in Adults (TOFHLA) [57]. This measure takes a relatively long time to complete (22 minutes). The abbreviated version of TOFHLA, Short Test of Functional Health Literacy in Adults (S-TOFHLA), takes about 12 minutes to complete and its results are well correlated with the original TOFHLA [58]. Another tool to measure functional health literacy is the Newest Vital Sign (NVS), which is one of the most recently developed instruments [59]. It encompasses a nutrition label of ice cream and six questions that measure an individual's reading, comprehension, and abstract reasoning skills. In general, health literacy assessment instruments are broadly categorized into generic and disease-specific tools.

1.4.1. Generic health literacy assessment instruments

Generic instruments are for general use to assess health literacy across different patient populations [60]. They can be more suitable for widespread use in routine daily practice [61]. However, these generic instruments are considered to be less sensitive to detect small but clinically important differences in treatment or intervention effects, because they do not focus on specific aspects of the disease [60]. Although generic questionnaires allow cross-condition comparison and comparison with healthy individuals, one of their limitations is that they may be less responsive to detect and quantify subtle changes related to a specific disease [60].

1.4.2. Disease-specific health literacy assessment instruments

Disease-specific instruments focus on specific aspects of a particular disease. They can be more acceptable and less burdensome to patients as these measures are developed with a particular disease condition in mind [60]. Disease-specific instruments can be more sensitive to measure small changes that can be important to clinicians and patients [60]. There are advantages and disadvantages of using either a generic or specific instrument, and the choice of instrument should be based on the aim of the assessment and the availability of the instruments.

1.5. Rationale of the Study

The issue of health literacy has been widely studied in developed countries, with very few studies conducted in Arab countries. The few studies available are restricted to only three Arab countries that may have unique socioeconomic characteristics. These

include the validation of the Arabic Rapid Estimate of Adult Literacy in Dentistry (AREALD-30) in Saudi Arabia [62]; the validation of Arabic versions of three health literacy tools, namely the Single Item Literacy Screener (SILS), the NVS, and the S-TOFHLA in Iraq [63]; and the validation of Arabic versions of three health literacy tools, namely the S-TOFHLA, the REALM-R, and the Three-item Brief Health Literacy Screen (3-item BHLS) in Lebanon [64]. Outside the Arab world, the REALM has been validated in Arabic language in a sample of Moroccan Berber women in the Netherlands [65].

To date, no information is available on the prevalence of low health literacy among Qatar's population. In addition, no studies have investigated pharmacy health literacy in the Middle East region. The high prevalence and burden of CVD, especially ACS and HF, in Qatar make these conditions important in which to start investigating health literacy and its impacts in Qatar. Given that Qatar has not produced any research in the field of health literacy so far, this study would provide new insights that might trigger further research and interventions aimed at increasing the ability to improve health communication and health outcomes among patients with CVD and low health literacy. Therefore, this study is primarily intended to assess health literacy skills among patients with ACS or HF living in Qatar and to explore the barriers and potential facilitators to improve health literacy among this population.

1.6. Aim and Objectives of the Study

The overall aim of this project is to determine the factors associated with limited health literacy among ACS and HF patients in Qatar and to identify potential interventions and tools to improve health literacy skills among this population. The following specific

objectives are set to achieve the aim of this study.

1.6.1. Objectives of Phase 1: Evaluation of health literacy skills among patients with ACS and HF in Qatar

1. To evaluate the existing evidence on the tools/instruments used to measure health literacy among patients with CVD and to adapt tools for the present study.
2. To assess the level of health literacy among patients with ACS or HF using the adapted validated health literacy assessment instrument.
3. To determine the prevalence of limited health literacy among patients with ACS or HF.
4. To compare the characteristics of ACS and HF patients with limited health literacy versus those with adequate health literacy.

1.6.2. Objectives of Phase 2: Identification of the facilitators of and barriers to health literacy skills among patients with ACS and HF from the patients' and their healthcare providers' perspectives

1. To identify the facilitators of and barriers to adequate health literacy skills among patients with ACS or HF from both the patients' and their healthcare providers' perspectives.
2. To identify potential strategies and tools to improve health literacy skills among patients with ACS or HF from both patients' and healthcare providers' perspectives.

1.7. Significance of the Study

Empowerment through knowledge and health literacy is one of Qatar's national strategy targets. One of Qatar National Research Strategy (QNRS) objectives is to “*actively engage the community to raise health awareness, promote healthy behaviors, and create a culture of public participation*” [66]. However, it appears that no research has been conducted on strategies to build health literacy skills in Qatar.

This research regarding the prevalence of limited health literacy and the perspectives of patients and their healthcare providers about health literacy will play an important role in the development of policies, strategies, and interventions designed to improve health literacy. As Qatar's healthcare system has become focused in adopting prevention and self-management strategies, more effective solutions are required. Patients' and healthcare providers' perspectives will offer greater insight into the processes and actions needed for building health literacy skills among patients. This may ultimately result not only in better improvements in knowledge, health literacy skills, and self-management skills, but also in better health outcomes.

The social change impact is based on the desired goal, established by the National Health Strategy (NHS) 2018-2022 [67], to create a more health literate society. By becoming more health literate, patients will be able to understand the basic concepts of their health and advance to higher level of knowledge and skills. On the other hand, healthcare providers will be able to communicate more effectively with their patients, use strategies and tools designed to build knowledge and skills, and direct the patient to resources designed to promote health.

CHAPTER 2: LITERATURE REVIEW

2.1. Evolution of the Concept of Health Literacy

Health literacy is becoming a critical component of public health [68]. The term ‘health literacy’ first appeared in the literature in 1974 in a paper entitled “*Health Education as Social Policy*”; it discussed the need for policy solutions to increase health literacy [69]. However, it was not until nearly 25 years later that researchers began to rigorously study the idea of health literacy and develop its definition and concept [70].

The definition of health literacy has been evolving throughout history. Reaching a consensus on a definition of health literacy is complicated due to the multiple skill categories and applications that are increasingly identified as necessary to be ‘literate’ in relation to one’s health [23]. Early definitions focused on the ability to apply basic reading and numeracy skills in a healthcare context, while a newer widely cited definition focuses on the goals of being health literate, “*the capacity to obtain, process, and understand*” in a health-related context, without specification of the skills required to achieve those goals [24].

In 1990s, health literacy gained more attention and health literacy-related research increased with more interest from government and health professions. Furthermore, the first instrument to assess health literacy, REALM, was developed in 1991. In 2000s, the IOM published a report entitled “*Health Literacy: A Prescription to End Confusion*” which sent forth health literacy to national prominence [71]. Around 2010, the US Department of Health and Human Services Department (USDHHS) developed the “*National Action Plan to Improve Health Literacy*” and the Agency for Healthcare Research and Quality (AHRQ) published “*Health Literacy Universal Precautions Toolkit*” [72]. Today, there are

thousands of health literacy research articles and hundreds of health literacy programs around the world. Major recent milestones include the formation of the International Health Literacy Association, and the start of new scholarly journal, *Health Literacy Research and Practice*.

2.2. Barriers to Health Literacy

Health literacy is multi-factorial in nature, involving the participation of not only the healthcare providers or the healthcare system, but also the patients. Therefore, the key to effectively address issues of limited health literacy is through an overall understanding of health literacy barriers from the perspectives of patients, healthcare providers, and healthcare system. Several studies have investigated the perceived barriers to and factors associated with health literacy; barriers were broadly categorized into three: (1) patient-related barriers, (2) healthcare provider-related barriers, and (3) healthcare system-related barriers. Patient-related factors are subdivided into demographic characteristics, social factors, and attitudes; healthcare provider-related factors are subdivided into knowledge-related factors, interaction-related factors, and attitudes; and healthcare system-related factors are classified into process-related barriers and practice-related barriers, **Table 2.1** summarizes these factors.

2.2.1. *Patient-related barriers*

The most commonly reported patient-related barriers to health literacy is associated with patients' characteristics including age, gender, race or ethnicity, education level, income level, and language barriers [73-86]. Healthcare providers must consider age-

related communication barriers, such as presbyopia (gradual loss of near focusing that occurs with age), presbycusis (gradual loss of hearing that occurs with age), and memory loss as well as cognitive impairment when providing patient education on older adults with limited health literacy. With regards to gender, evidence showed marginal yet significant differences between genders in knowledge with women having slightly greater health literacy scores than men [74]. In general, the educational background, as well as the lay knowledge and previous experiences, were considered as important factors that positively influenced abilities to seek and understand health information, particularly in identifying reputable sources of health information [81, 87]. Communication between patients and healthcare providers is an integral component of health literacy [77]. However, patients can often face difficulty in understanding and communicating with healthcare providers due to language barriers [73]; thus, patients' language was identified as one of the main factors affecting communication and health literacy [73]. Healthcare providers identified that a patient's lack of language proficiency was a signal that they should expect some level of communication difficulty [73].

The main social factors perceived as barriers toward health literacy include lack of family and social support, difficult family situation, and cultural differences [73, 77-79, 81, 82, 85]. Some patients face difficult family or social situations, which would be a more pressing priority than a health issue and might interfere with a patient's ability to absorb and understand health information as well as inhibit patients from putting knowledge into action [77, 82]. In addition, lifestyle commitments, such as work-, study-, family-, or caregiver-related commitments, also might often mean patients were unable to prioritize their health and utilize health information [81]. Patients and healthcare providers may be

coming from different cultural background and medical language and health concepts originate from different cultures [73]. This can have a large impact on patients and healthcare providers understanding and communication [77].

As for patients' attitudes, self-consciousness and feeling shame were some of the main barriers toward health literacy [73, 77-80, 88, 89]. Patients with low health literacy may not admit that they have difficulty reading and understanding medical information and educational materials because of shame or embarrassment [79, 89]. Some healthcare providers find it hard to identify health literacy problems when patients conceal their difficulties, for example, by not seeking clarification or appearing to comprehend information [80]. Shame and embarrassment of being labeled as low literate were mentioned as one of the causes of patients' reluctance to ask questions [73]. Furthermore, the lack of patient commitment toward health literacy interventions and the lack of patient cooperation to assess health literacy were other barriers to improving health literacy [83, 88, 90].

2.2.2. Healthcare provider-related barriers

The main reported healthcare provider-related barriers toward health literacy in terms of knowledge were lack of awareness about: health literacy, ways by which patients hide their low health literacy, and available resources to improve health literacy [73, 74, 76, 78, 80, 86, 90]. Many healthcare providers never had any formal education or training about health literacy [76]; thus, they lack knowledge and understanding of health literacy definition and concept and lack awareness about the impact of low health literacy on health outcomes [74, 76, 78, 86, 90]. Consequently, many healthcare providers are unaware of

health literacy assessment tools used to assess health literacy levels, with some providers believing that health literacy assessments could occur without a screening tool [83]. In addition, the lack of awareness about ways by which patients tend to hide their low health literacy is one of the barriers toward improving health literacy [74, 80, 86].

Patient-provider interaction-related barriers towards health literacy included lack of skills, lack of trust and rapport between healthcare providers and patients, use of medical jargon, overloading patients with information, offering counseling only to those perceived as being able to understand, and inability to correctly identify patients with health literacy problems [73, 74, 76-78, 80-86, 88, 90]. Regarding the patient-provider relationship, healthcare provider's personality and approach to building rapport and relationships with their patients were identified as a potential barrier to communication and health literacy [73]. Some patients feel unapproachability of some of their healthcare professionals and they underline the importance of building a trusting relationship with their providers that would enable them to approach them freely, ask questions and seek information [73]. The absence of such relationship may lead to a lack of trust and therefore, reluctance to inquire about their medical conditions and medications [73]. Patients also expressed the need for simple language and less use of medical terminology in both verbal and written communication with healthcare providers [88]. Many patients stated that healthcare providers frequently used medical jargons in their communication and that this hindered their understanding of their medical condition and treatment options [73]. Moreover, there is a tendency by healthcare providers to stereotype patients and offer counseling only to those perceived as being able to understand [74, 86]. For example, some healthcare provider's perspective is that low health literacy is an issue only for patients with limited

educational levels, which is inconsistent with evidence and characteristics such as socioeconomic status, language, and education level can be misleading for subjective assessment of health literacy [86].

Regarding healthcare providers' attitudes, although some studies that examined attitudes towards health literacy reported that healthcare providers generally agree that low health literacy is a problem [85, 86], there is a lack of interest by healthcare providers about enhancing health literacy [74, 78, 86, 90]. This lack of interest could be due to their lack of knowledge about health literacy or due to different attitudes or misconceptions [74, 86].

2.2.3. Healthcare system-related barriers

Process-related barriers referred to organizational issues that impede health literacy such as time constraints, limited funding, and lack of resources for the healthcare providers to improve health literacy [73]. Other examples of these include lack of face-to-face interaction with patients and lack of affordable access to health services [73, 74, 76-78, 81-86, 88, 90].

Practice-related barriers referred to practice-related issues affecting incorporation of health literacy interventions. Examples of these include lack of access to complete medication records, lack of easy-to-use tools to identify low health literacy patients, lack of educational materials and resources to address patients with low health literacy, underutilization of information and communication technology, lack of interest in health promotion, lack of organizational or leadership support to promote health literacy, difficulty navigating the healthcare system, and system not being conducive to build health literacy and encourage asking questions [73, 74, 76-78, 80, 82-86, 88, 90, 91].

The service delivery model should be conducive to building health literacy and the environment should encourage asking questions. However, this could be challenging due to time and resources constraints and lack of human resources [77]. While patients acknowledge that healthcare providers have busy schedules and a high number of patients which does not allow spending more time with each patient, they believe that the limited time allocated to spend with their providers is insufficient for them to ask questions and clarify misunderstandings [73]. Similarly, healthcare providers acknowledge time constraints as one of the main barriers to spending sufficient time with their patients to ensure their understanding of their disease and medical instructions [73]. In addition, healthcare providers indicate lack of time to take part in a health literacy training program [76]. They also expect that screening patients for low health literacy would take too much time [76]. Furthermore, some healthcare providers identified the lack of easy to use health literacy assessment tools as a barrier to improving health literacy [74].

Healthcare providers might also not have an opportunity to counsel and educate their patients due to the lack of face-to-face interaction with the patients; for example, because of the lack of private counseling area within the pharmacy or the presence of convenient medication delivery mechanisms [74]. In general, there is a lack of adequate sources of information for both patients and healthcare providers [74]. Patient education materials lack visual cues like pictograms and are often written at grade levels too high for patients with low health literacy [73, 74]. Besides, there is a lack of educational materials in other languages or in easy-to-read formats [84].

There are other organization-related barriers, for example, the healthcare system is often too complex for patients to navigate and the environment is not set up to facilitate

health literacy and accommodate patients with limited health literacy [76]. Moreover, there is a lack of interest in health promotion and the majority of health services are targeted towards acute problem management [77].

Table 2.1: Factors perceived as barriers toward health literacy

Factors	References
Patient-related factors	
<i>Demographic characteristics</i>	
Age	[73-78]
Gender	[74]
Race or ethnicity	[75, 76, 80]
Level of education	[73, 75, 76, 78-81]
Level of income	[77-82]
Language and communication barrier	[73-75, 77, 78, 80, 82-86]
Cognitive impairment	[80]
<i>Social factors</i>	
Family support	[78, 81]
Social support	[77, 81]
Cultural differences	[73, 77-79, 82, 85]
<i>Attitudes</i>	
Self-consciousness	[73, 77-80, 88]
Feeling shame or stigma	[73, 78-80, 89]
Lack of commitment	[88, 90]
Lack of cooperation	[83, 90]
<i>Others</i>	
Lay knowledge and previous experiences	[81]
Lifestyle commitments	[78, 81]
Healthcare provider-related factors	
<i>Knowledge-related factors</i>	
Lack of awareness about health literacy	[74, 76, 78, 86, 90]
Lack of awareness about ways by which patients hide their low health literacy	[74, 80, 86]
Lack of awareness of available resources	[73]
<i>Interaction-related factors</i>	
Lack of skills	[76, 83]
Lack of trust and rapport	[73, 77, 78, 82, 88]
Use of medical jargon	[73, 78, 81, 85, 88]
Overloading patients with information	[81]
Tendency to stereotype patients	[74, 86]
Inability to correctly identify patients with health literacy problems	[76, 80, 83, 84, 90]

Table 2.1: Cont. Factors perceived as barriers toward health literacy

<i>Attitudes</i>	
Lack of commitment or interest	[74, 78, 86, 90]
Healthcare system-related factors	
<i>Process-related barriers</i>	
Time constraints	[73, 74, 76-78, 81-86, 88, 90]
Resources constraints	[73, 76, 77, 83, 85, 90]
Lack of face-to-face interaction with patients	[74, 86]
Lack of education programs	[76]
Lack of affordable access to health services	[77]
<i>Practice-related barriers</i>	
Lack of access to complete medication records	[74, 86]
Lack of easy-to-use health literacy assessment tools	[74, 76, 78, 83, 86]
Lack of educational materials or resources	[73, 74, 77, 78, 80, 82-85]
Limited use of information technology	[82]
Lack of interest in health promotion	[77, 82]
Lack of organizational or leadership support	[73, 76, 78, 80, 82, 85, 90, 91]
Complexity of navigating the healthcare system	[76, 77]
The system is not conducive to build health literacy	[76, 77]
The system does not encourage question asking	[73, 77, 88]

2.3. Existing Literature on Assessment of Health Literacy in Cardiovascular Diseases

In general, several instruments have been developed, validated, and used to assess health literacy skills [92-94]. Even though these measures are used to assess health literacy among different populations, their applicability and appropriateness among patients with CVDs are not widely studied. A recent systematic review identified health literacy assessment instruments available for CAD [95]. However, a comprehensive systematic review investigating health literacy assessment instruments used among patients with CVDs in general may provide added value as it will consider CVD holistically especially that the global prevalence and burden of CVDs is continuously increasing. Thus, a systematic review was conducted and published to identify, critically appraise, and

synthesize the available evidence pertaining to the instruments that have been used to measure health literacy in patients with CVDs [96].

The following electronic databases and search engines were searched for eligible articles: Cochrane Library, EMBASE, PubMed, ScienceDirect, Google, and Google Scholar. The following combinations of search keywords were used: (“literacy” OR “health literacy” OR “health communication”) AND (“instrument” OR “tool” OR “measure” OR “measurement” or “assessment” OR “screening”) AND (“cardiovascular” OR “cardiovascular disease” OR “cardiovascular condition” OR “heart disease”). Keywords were matched to database-specific indexing terms. The reference lists of identified studies were manually reviewed to further identify additional studies. Electronic searches were complemented by manually searching health literacy specialty journals, including the Journal of Health Communication. Scholarly publications, including peer-reviewed journal articles and conference proceedings, were searched in the above databases.

Included articles were studies reporting the use of a validated instrument to assess health literacy in patients with CVD that were published in English language. Studies were excluded if they included non-adult population, used a health literacy instrument that is not available in English, or were not original investigations (e.g. reviews, letters, and editorials). The screening of the studies followed a three-phase process; first by title, followed by abstract, and finally the full-text.

Data on the general characteristics of the studies including the author(s), article title, year of publication, country of the study, population characteristics, study design, study aim, and the health literacy assessment instrument used were extracted. Furthermore,

data on all the identified health literacy instruments were extracted from the original development articles. The review extracted data related to the development of each instrument, its psychometrics, as well as, other characteristics, such as the authors, journal, year of publication, sample size, number of items, and method of instrument administration.

Two approaches were used to assess the quality of the included studies; based on the risk of bias as well as the health literacy instrument's psychometric robustness. The risk of bias was assessed using the Crowe Critical Appraisal Tool (CCAT), a tool designed to appraise the methodological quality of studies included in systematic mixed-studies reviews (i.e. qualitative, quantitative, and mixed methods studies) [97]. This tool was shown to have appropriate construct validity and higher reliability than informal appraisal of research papers [98-100]. The health literacy instrument's psychometric robustness was assessed using validity and reliability data reported in the respective instrument's development and validation studies.

This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. The search yielded 696 studies and after removal of duplicates, 537 studies remained. Of these, 89 titles and abstracts met the initial inclusion criteria and their full texts were further assessed for eligibility. Forty-six articles were excluded for different reasons following the full-text review (**Figure 2.1**). The reasons for exclusion included: the population studied included individuals without CVDs (n = 15); the study did not use an instrument to measure health literacy skills or that the used instrument was not reported in the article (n = 13); the paper was not an original investigation (n = 13); the instrument used to assess health literacy was

not validated (n = 3); and the instrument used to assess health literacy was not available in English language (n = 2). Finally, 43 articles were included in the review.

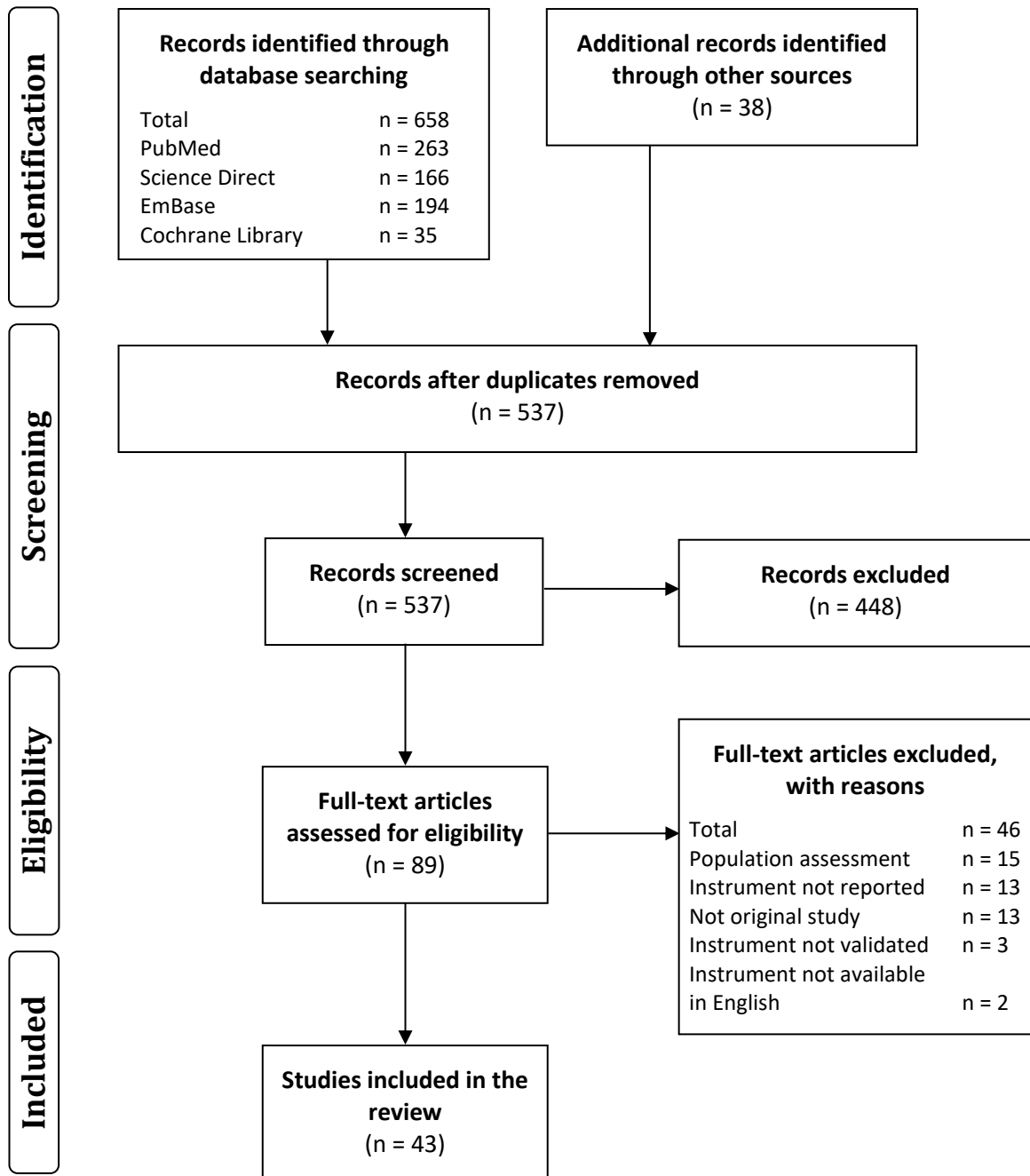


Figure 2.1: Flow diagram of literature search results

Included studies were published between 2002 and 2017. Of the 43 studies included, 20 were cross-sectional observational studies, 12 were randomized controlled trials, seven were retrospective or prospective cohort studies, two were mixed-method studies, and two studies utilized other types of research designs. Thirteen studies included patients with HF, nine included patients with hypertension, seven included patients with CHD, seven included patients with ACS, and 11 studies included patients with other types of CVDs. The sample size of the included studies ranged from 17 to 12,517 participants. Most of the studies (n = 39) were conducted in the United States, three studies were conducted in the United Kingdom, and one study was conducted in Australia. Overall, 11 distinct health literacy assessment instruments were utilized in the 43 studies among patients with varying types of CVDs (**Table 2.2**).

There was no wide variation in the quality of the studies, with CCAT scores ranging between 78% and 100%. The main limitations in the cross-sectional studies were lack of reporting of: sample size, sampling technique, and response rate. On the other hand, the most common limitations among randomized controlled trials were lack of reporting of: allocation concealment, blinding, and appropriate description of the generalizability of the study results. Other study designs were limited mainly due to insufficient description of the sample size and sampling method. In general, the limitations of the included studies were not believed to have affected the validity and reliability of the results.

Table 2.2: Summary of the characteristics of the included studies (n=43)

Categories	n	%
Year of study publication		
2002 – 2003	1	2.3
2004 – 2005	2	4.7
2006 – 2007	4	9.3
2008 – 2009	8	18.6
2010 – 2011	5	11.6
2012 – 2013	8	18.6
2014 – 2015	9	20.9
2016 – 2017	6	14.0
Study design		
Cross-sectional study	20	46.5
Randomized controlled trial	12	27.9
Cohort study	7	16.3
Mixed method study	2	4.7
Before-and-after study	1	2.3
Longitudinal study	1	2.3
Region where the study was conducted		
North America	39	90.7
Europe	3	7.0
Australia	1	2.3
Population studied*		
Heart failure	13	30.2
Hypertension	9	20.9
Coronary heart disease	7	16.3
Acute coronary syndrome	7	16.3
On warfarin or anti-thrombotic therapy	3	7.0
Dyslipidemia or on statin therapy	2	4.7
General cardiology	2	4.7
Atrial fibrillation	1	2.3
Open heart surgery	1	2.3
Patients with pacemakers	1	2.3
Patients enrolled in cardiac rehabilitation	1	2.3

Table 2.2: Cont. Summary of the characteristics of the included studies (n=43)

Health literacy instrument used*		
S-TOFHLA	19	44.2
REALM	13	30.2
3-item BHLS	6	14.0
TOFHLA	4	9.3
NVS	4	9.3
REALM-SF	2	4.7
16-item instrument	2	4.7
METER	2	4.7
REALM-R	1	2.3
HBP-HLS	1	2.3
BSAIT	1	2.3
Nature of health literacy instrument used		
Objective measure only	35	81.4
Subjective measure only	6	14.0
Both	2	4.7

*Items are not mutually exclusive

In terms of health literacy assessment instruments used among CVD patients in the included studies, 10 instruments were generic (n = 42), while only one instrument, the High Blood Pressure-Health Literacy Scale (HBP-HLS), was disease-specific (n = 1). Six studies used only a subjective measure (i.e. instruments that rely on self-reported health literacy) to assess health literacy. The rest of the studies (n = 37) used at least one objective health literacy instrument. Typically, objective instruments evaluate health literacy skills by answering questions related to reading comprehension, numeracy, or word recognition and pronunciation, while subjective instruments capture self-reported confidence on one's own health literacy skills.

The S-TOFHLA [58] was used in nearly half of the CVD studies (n=19; 44%), whereas the full version, TOFHLA [57], was used in only four studies. The REALM [54]

was the second most popular instrument, used in 13 CVD studies, while the shorter versions, REALM-SF [55] and REALM-R [56], were used in only three studies. Subjective measures of health literacy, the 3-item BHLS [101] and the 16-item instrument [102], were the third most popular instruments used in eight studies. The NVS [59] was used in four studies and the Medical Term Recognition Test (METER) [103] was used in two studies, while the Basic Skills Agency Initial Assessment Test (BSAIT) [104] was used in one of the studies included in the review. The only disease-specific instrument identified, HBP-HLS [105], was used in one study.

There are differences among the identified instruments used to measure health literacy. **Table 2.3** summarizes the characteristics of the identified instruments used to assess health literacy in CVDs. Briefly, to compare the three most commonly used instruments: the REALM and S-TOFHLA both assess a patient's functional health literacy while the 3-item BHLS assesses the patient's overall confidence in health-related tasks (e.g. confidence filling out a medical form) [54, 58, 101]. The REALM and the 3-item BHLS take the least amount of time while the S-TOFHLA requires the largest amount of time, 1-2, 3 and 15 minutes, respectively. The longer the time spent assessing health literacy, the greater is the validity and the reliability of the tool. The REALM and the 3-item BHLS require a clinician to administer the instrument, while the S-TOFHLA requires oral instructions, but the patient completes the instrument on their own within the time limits.

The final health literacy categorical assessment of the top three instruments is either dichotomous (BHLS) or trichotomous (REALM and S-TOFHLA). The REALM total score is out of 66 and the interpretation of the result is described as grade-level reading

(e.g. a score of 34 would be interpreted as 4th-6th grade reading level). Inadequate health literacy has been used to describe those with a 6th grade reading level or lower (i.e. < 44). Marginal health literacy describes those with between a 6th grade reading level and an 8th grade reading level (i.e. 45-60) and an adequate health literacy as those with at least a 9th grade reading level (i.e. > 61) [54]. The S-TOFHLA reading comprehension score is from 0 to 36. Scores of 0-16 and 17-22 identify patients as inadequate or marginal health literate, respectively, while scores greater than 23 identify patients as adequate health literate [58]. The 3-item BHLS scores range from 0 to 12 but its interpretation depends on the comparison tool used (REALM or S-TOFHLA) [101]. The final interpretation is identifying patients as (1) adequate or (2) inadequate or marginal.

Table 2.3: Characteristics of the identified health literacy instruments

Measure	Type of measure				Number of items	Administration mode	Time	Scoring system	Measurement properties	Reference
	Word recognition and pronunciation	Numeracy	Reading comprehension	Self-report confidence in health literacy skills						
REALM	Yes	No	No	No	66 words	Clinician/ researcher administered	<3 min	Score range: 0-66 <ul style="list-style-type: none"> • 0-18: ≤ 3rd grade • 19-44: 4th-6th grade • 45-60: 7th-8th grade • 61-66: ≥9th grade 	<ul style="list-style-type: none"> • Reliability: Cr α: 0.96 • Validity: 0.97 (with PIAT-R), 0.88 (with WRAT-R), 0.96 (with SORT-R) 	[54]
REALM-SF	Yes	No	No	No	7 words	Clinician/ researcher administered	<1 min	Score range: 0-7 <ul style="list-style-type: none"> • 0: ≤ 3rd grade • 1-3: 4th-6th grade • 4-6: 7th-8th grade • 7: ≥ 9th grade 	<ul style="list-style-type: none"> • Reliability: Cr α: 0.97 • Validity: 0.94 (with REALM), 0.83 (with WRAT-R) 	[55]
REALM-R	Yes	No	No	No	8 words	Clinician/ researcher administered	<2 min	Score range: 0-8 <ul style="list-style-type: none"> • ≤6: inadequate • 7-8: adequate health literacy 	<ul style="list-style-type: none"> • Reliability: Cr α: 0.91 • Validity: 0.72 (with REALM), 0.64 (with WRAT-R) 	[56]

Table 2.3: Cont. Characteristics of the identified health literacy instruments

TOFHLA	No	Yes	Yes	No	50-item reading comprehension; administered 17-item numeracy	Self-administered	22 min	Scores range: 0-100 <ul style="list-style-type: none"> • <60: inadequate • 60-75: marginal • >75: adequate health literacy 	<ul style="list-style-type: none"> • Reliability: Cr α: 0.98 • Validity: 0.84 (with REALM), 0.74 (with WRAT-R) 	[57]
S-TOFHLA	No	Yes	Yes	No	36-item reading comprehension; administered 4-item numeracy	Self-administered	15 min	Scores range: 0-100 <ul style="list-style-type: none"> • 0-53: inadequate • 54-66: marginal • 67-100: adequate health literacy 	<ul style="list-style-type: none"> • Reliability: Cr α: 0.97 (reading comprehension), 0.68 (numeracy) • Validity: 0.91 (with TOFHLA), 0.80 (with REALM) 	[58]
3-item BHLS	No	No	No	Yes	3 questions	Self-administered or clinician/researcher administered	1-2 min	Score range: 0-12 <ul style="list-style-type: none"> • High scores: high health literacy skills • Low scores: low health literacy skills 	<ul style="list-style-type: none"> • AUROC: 0.66-0.74 (based on S-TOFHLA), 0.72-0.84 (based on REALM) • Sensitivity: 47-60 (based on S-TOFHLA) • Specificity: 79-83 (based on S-TOFHLA) 	[101]

Table 2.3: Cont. Characteristics of the identified health literacy instruments

Instrument	Yes	No	No	Yes	Number of questions	Administered by	Duration	Sum score	Reliability	Validity	AUROC	Reference
16-item instrument	No	No	No	Yes	16 questions	Self-administered or clinician/researcher administered		Sum score (0-5 each item), categorized as inadequate, marginal, or adequate			• AUROC: 0.68-0.87 (based on S-TOFHLA)	[102]
METER	Yes	No	No	No	40 medical words and 40 non-medical words	Clinician/researcher administered	2 min	Score Range: 0-40: • Low literacy (0-20) • Marginal literacy (21-34) • Functional literacy (35-40)	• Reliability: Cr α : 0.93	• Validity: 0.74 (with REALM) • 75% correct identification and 8% false positives		[103]
HBP-HLS	Yes	No	No	No	30 words	Clinician/researcher administered	10-15 min	Sum score (0-30 and 0-10 for each self-administered item)	• Reliability: Cr α : 0.93	• Validity: 0.80 (with Modified TOFHLA), 0.76 (with Modified NVS)		[105]
NVS	No	Yes	Yes	No	6 questions on an ice cream nutrition label	Self-administered	3-6 min	Scores range: 1-6 • <4: limited health literacy	• Reliability: Cr α : 0.76	• Validity: 0.59 (with TOFHLA) • AUROC: 0.88 (based on TOFHLA) • Sensitivity: 72% • Specificity: 87%		[59]

Table 2.3: Cont. Characteristics of the identified health literacy instruments

BSAIT	No	No	Yes	No	72 questions	Self-administered	20 min	Score range: 0-72	• Reliability: α : 0.70	[104]
								• 64 or less: low general literacy		

AUROC: Area Under the Receiver Operating Characteristic curve; **3-item BHLS**: Three-item Brief Health Literacy Screen; **BSAIT**: Basic Skills Agency Initial Assessment Test; **Cr α** : Cronbach's alpha; **HBP-HLS**: High Blood Pressure – Health Literacy Scale; **ICC**: Intraclass Correlation Coefficient; **METER**: Medical Term Recognition Test; **NVS**: Newest Vital Sign; **PIAT-R**: Peabody Individual Achievement Test – Revised; **REALM**: Rapid Estimate of Adult Literacy in Medicine; **REALM-R**: Rapid Estimate of Adult Literacy in Medicine – Revised; **REALM-SF**: Rapid Estimate of Adult Literacy in Medicine – Short Form; **SORT-R**: Slosson Oral Reading Test – Revised; **S-TOFHLA**: Short Test of Functional Health Literacy in Adults; **TOFHLA**: Test of Functional Health Literacy in Adults; **WRAT-R**: Wide Range Achievement Test – Revised.

To our knowledge, this systematic review is one of the first to attempt to identify publications utilizing health literacy assessment instruments in CVDs collectively [96]. This review also provides a comprehensive overview and analysis of the characteristics, quality, and psychometrics of these instruments. The S-TOFHLA and the REALM were the most commonly used instruments to assess health literacy in CVD population. This finding is similar to a systematic review conducted by Ghisi et al. aimed to assess health literacy screening instruments in CAD patients [95], and two other systematic reviews by Duell et al. and Al Sayah et al. aimed to identify optimal health literacy measurement for the clinical setting [93] and in patients with diabetes [106], respectively. Objective (performance-based) measures of health literacy were more commonly utilized in studies than subjective (self-reported) measures. Furthermore, only one disease-specific instrument, the HBP-HLS, was identified in this review. Few other CVD-specific instruments were identified; however, they were excluded from the review because they were either not validated or not available in English language.

CHAPTER 3: METHODOLOGY

3.1. Ethical Considerations

Ethics approval for conducting this study was obtained from both the Medical Research Committee (MRC), Hamad Medical Corporation (HMC) [approval reference number: MRC-02-17-087] and the Institutional Review Board (IRB), Qatar University (QU) [approval reference number: QU-IRB 955-E/18] (see **Appendix A** for approval letters). Informed consent for both Phase I and Phase II was obtained from all participants after receiving verbal and/or written information. The informed consent form included a statement about the purpose of the research, the data collection process, the expected duration of participation, and any possible risks or discomfort as well as potential benefits from participation. It also had stated that participation in the study is voluntary and individuals have the right to decline or withdraw from participation at any time. Moreover, participants were informed that all information they provide will be treated as confidential and utilized only for the purpose of the study; no individual would be identified in publications or reports.

Patients' confidentiality and privacy were addressed carefully during and after the end of the study. Patients' data and all generated documents were kept secured using key-locked cupboards and passwords by the principal investigator. There are no risks or harm following participation and no pressure for subjects to participate in the study. The study did not provide any financial incentives for participants.

3.2. Study Setting

The study was conducted at Heart Hospital in Qatar, a member of HMC. Heart Hospital is a specialist tertiary hospital that provides care in cardiology and cardiothoracic surgery for the adult population of Qatar. The center has a 20-bed coronary care unit, a 12-bed cardiothoracic intensive care unit (CICU), a 24-bed surgical high-dependency unit (HDU), and a 60-bed ward. The outpatient department (OPD) provides care to all patients with diagnoses of heart diseases or a heart-related illness who need a comprehensive evaluation and coordinated outpatient care [107].

3.3. Phase I: Evaluation of Health Literacy Skills among Patients with ACS and HF

in Qatar

3.3.1. *Study design*

Phase I of the study was a prospective, cross-sectional descriptive study in which quantitative data (i.e. patients' health literacy levels) were collected using two health literacy assessment instruments (S-TOFHLA and 3-item BHLS). This enabled the identification of the current levels of health literacy and the determination of the prevalence of limited health literacy among patients with ACS and/or HF in Qatar. Participants' socio-demographic and clinical information was collected to identify characteristics of patients with limited health literacy.

3.3.2. *Study population*

Limited health literacy is prevalent among adult populations studied around the world in general [108]. However, ACS and HF are common chronic diseases that require

significant self-care and management [13, 18]. The complexity of care required for ACS and HF puts patients with limited health literacy at substantial risk for adverse health outcomes including hospitalization, emergency visits, poor quality of life, and mortality [50, 52, 53]. Thus, the target population is adult patients with ACS, HF, or both disease conditions receiving care at Heart Hospital in Qatar.

According to the American Heart Association (AHA), ACS refers to a spectrum of unstable CAD where the blood supplied to the heart muscle is suddenly blocked. This includes unstable angina (UA), non-ST-segment elevation myocardial infarction (NSTEMI), and ST-segment elevation myocardial infarction (STEMI) [109].

On the other hand, HF is a condition in which the heart muscle is unable to pump out sufficient amount of blood to meet the metabolic needs of the body. It can be caused by structural defects, functional abnormalities (ventricular dysfunction), or a sudden overload beyond its capacity. Diastolic HF is caused by abnormal myocardial relaxation during diastole leading to defective cardiac filling, while systolic HF is caused by abnormal myocardial contraction during systole leading to defective cardiac emptying [110].

3.3.3. Participants and eligibility criteria

Patients were eligible to be enrolled in the study if they were 18 years of age or older, diagnosed with ACS, HF, or both, and are outpatients receiving treatment at Heart Hospital. Patients were excluded from the study if they had any of the following criteria: documented sight impairment, hearing impairment or cognitive difficulty or patients who do not speak any of the study languages (English, Arabic, Hindi, Urdu, Tamil, Tagalog, or Malayalam).

3.3.4. Sample size determination

The study aimed to identify the level of health literacy in ACS and HF patients in an ordinal fashion, that is inadequate, marginal, or adequate health literacy. Therefore, sample size calculation followed the cross-sectional studies sample size calculation of qualitative variables [111]. The following equation was used to calculate the sample size:

$$\text{Sample size} = \frac{Z_{1-\alpha/2}^2 p(1-p)}{d^2}$$

Where $Z_{1-\alpha/2}$ is the standard normal variate, and Z is the Z statistic for the level of confidence chosen to present the study results with 95% confidence interval (CI). At 5% type-1 error level ($P < 0.05$), $Z_{1-\alpha/2}$ is 1.96. Whereas, p is the expected proportion or prevalence of the outcome of interest in the population. The exact prevalence of low health literacy among patients with CVD, including ACS and HF, in Qatar or other Arab countries is unknown. Based on previous studies conducted in the United States, the prevalence of limited health literacy among adult patients with ACS or HF is estimated to be 19% [112, 113]. Thus, the expected p for this study is 0.19. The absolute error or precision (d) was chosen to be 5% with 95% CI that gives the value of 0.05. Therefore:

$$\text{Sample size} = \frac{1.96^2 \times 0.19(1 - 0.19)}{0.05^2} = 237$$

The minimum effective sample size required was 237 according to the above assumptions. To account for missing data, a 30% increase in the sample size was targeted. A sample of 300 patients with ACS and/or HF was targeted to assess the levels of health literacy.

3.3.5. Sampling technique

A convenient sample of adults with ACS and/or HF was recruited from Heart Hospital while waiting to be seen by their healthcare provider in a follow-up clinic. Convenient sampling was used due to the absence of a sampling frame, which hindered the ability to perform a probability sampling technique such as simple random sampling.

3.3.6. Recruitment

Eligible participants were identified through the electronic medical records database (CERNER). Patients who provided an informed consent to participate in this study and fulfilled the eligibility criteria were included in this study. From those, some participants were purposively selected and asked to participate in Phase II of this study. Contact information (phone number) of individuals who agreed to participate in Phase II was collected. This contact information was discarded after the completion of Phase II.

3.3.7. Outcome measures

The primary outcome of this phase was patients' health literacy level. Health literacy level is categorized differently by different authors and assessment tools. For example, health literacy is categorized by REALM to grade levels (3rd grade or less; 4th through 6th grade; 7th or 8th grade; 9th grade or more) [54]; whereas, it is categorized by S-TOFHLA and 3-item BHLS as inadequate, marginal, or adequate health literacy level (refer to **Table 3.1** and **3.2**) [58, 101]. Below is a description of the health literacy scoring method that was used for this study:

- 1) Adequate health literacy: Patients who have adequate functional health literacy should be able to read, understand, and interpret most health texts.
- 2) Marginal or inadequate health literacy: Patients who have marginal or inadequate functional health literacy will have difficulty understanding and interpreting most health materials. As a result, they would not be able to follow directions for their health care; for example, they are likely to take their medications incorrectly or fail to follow prescribed diets or treatment regimens. Modifications must be made in the healthcare setting in order to accommodate these individuals.

Table 3.1: S-TOFHLA scoring system*

Score	Level	Functional health literacy description
0 – 16	Inadequate functional health literacy	Unable to read and interpret health texts
17 – 22	Marginal functional health literacy	Has difficulty reading and interpreting health texts
23 – 36	Adequate functional health literacy	Can read and interpret most health texts

*Standard scoring based on the tool’s developers

Table 3.2: 3-item BHLS scoring system*

Score	Level
0 – 6	Inadequate functional health literacy
7 – 9	Marginal functional health literacy
10 – 12	Adequate functional health literacy

*Standard scoring based on the tool’s developers

3.3.8. *Study instruments*

The data collection tool for this research project consisted of three sections: the baseline demographic and clinical characteristics section, the S-TOFHLA section, and the 3-item BHLS section (see **Appendix B** for the data collection tool). The baseline demographic characteristics collected included age, gender, marital status, nationality, education level, occupation, and spoken languages. The clinical data gathered included chronic medical conditions, current medications, most current weight/height/BMI, SBP, DBP, HR, cholesterol levels, and HbA1c.

- 1) The S-TOFHLA consists of 36 items reading comprehension section from passages of instructions to prepare for an upper gastrointestinal test and the patient rights and responsibilities section of an insurance (Medicaid) application form. It is a reliable and valid measure of patient's functional health literacy levels [58]. The S-TOFHLA has been widely used to identify patients, including ACS and HF patients, with limited health literacy skills in research and clinical settings [112]. An Arabic version of the S-TOFHLA was validated in Lebanon. It was adapted by modifying the Medicaid passage according to a general health insurance scheme [64]. Similarly, in this study, the English S-TOFHLA Medicaid section was modified with a general passage on health insurance.
- 2) The 3-item BHLS assesses individuals' perceived ability to read and understand health-related information [101]. The tool consists of three questions that ask about how frequently the patient seeks help to read hospital materials, how frequently the patient has problems in understanding written information, and

how confident the patient is with filling out medical forms. Individuals are asked to choose between: all of the time, most of the time, some of the time, a little of the time, or none of the time. These screening questions have been validated as an instrument to rapidly assess health literacy by clinical staff in busy clinical settings [101]. An Arabic version of the 3-item BHLS was validated in Lebanon [64].

Two different health literacy assessment instruments were used for triangulation purposes. The S-TOFHLA and 3-item BHLS were selected, because they are considered gold standard well-validated and reliable instruments for the assessment of health literacy [58, 101]. Furthermore, based on the systematic review we conducted to identify health literacy assessment instruments used in CVD patients, S-TOFHLA was the most commonly used by studies, while the 3-item BHLS was the most commonly used subjective measure of health literacy in CVD patients [96]. Besides, Arabic versions of S-TOFHLA and 3-item BHLS were developed and validated in a previous study [64].

The data collection tool was available in Arabic and English languages. Due to the multicultural composition of Qatar's population, the study instruments were translated from English to other languages commonly spoken in Qatar including Hindi, Urdu, Tamil, Tagalog, and Malayalam.

3.3.9. Data collection process

The researcher identified eligible candidates through the electronic medical record database (CERNER). Each patient was briefed about the study and given the informed consent form. Written consent was obtained from all patients who agreed to participate in

the study. The data collection process was expected to last for 10 to 15 minutes on the average. First, demographic and clinical data were obtained from the electronic medical records and verified by asking the patient. Then, the interviewer administered the 3-item BHLS. Finally, the S-TOFHLA was administered face-to-face, where the interviewer presented the tool from a scripted introduction. Once introduced, a patient was given the reading comprehension passages to complete.

3.3.10. Data analysis

The data collected were analyzed using IBM Statistical Package for Social Sciences (SPSS®) software for Windows version 23.0 (IBM Corp, Armonk, New York, USA). Descriptive and inferential analyses of the data were performed as appropriate. Kolmogorov-Smirnov and Shapiro–Wilk tests were used to check the normality of data distribution, which indicated that the data were not normally distributed for all continuous variables. Therefore, patients’ demographic and clinical data, as well as health literacy scores, were presented descriptively as median (IQR) for continuous variables and as frequencies and percentages for categorical variables. Mann-Whitney U and Kruskal-Wallis tests were used to compare two groups and more than two groups, respectively. Associations between different variables and health literacy scores were tested using Spearman rho correlation test for continuous or ordinal variables and Chi-Square or Fisher’s Exact tests for categorical variables. For all statistical tests, a two-sided P-value <0.05 was considered statistically significant.

3.4. Phase II: Identification of the Facilitators of and Barriers to Health Literacy among Patients with ACS and HF in Qatar

3.4.1. *Patients' perspective*

3.4.1.1. *Study design*

Phase II of this study was a qualitative study using one-to-one interview conducted with patients and focus group discussions conducted with healthcare providers. Qualitative research is appropriate to uncover perceptions, beliefs, and experiences that underlie individuals' health behaviors [114]. It can allow in-depth understanding of different causes of limited health literacy as well as facilitators and barriers to improving health literacy. This phase can give valuable information which can be targeted for future interventions.

3.4.1.2. *Study population*

The population targeted to study "patients' perspective" was the same population as Phase I (quantitative) which is adult patients with ACS and/or HF receiving care at Heart Hospital in Qatar.

3.4.1.3. *Participants selection*

Participants were purposively selected from those who participated in Phase I and were invited to enroll in Phase II interviews. Patients were selected from different health literacy levels (inadequate, marginal, and adequate), age groups, ethnic and cultural groups, and both genders to capture all perspectives and to identify any potential differences in facilitating and limiting factors based on different characteristics. However, the selection was limited to patients who can understand English and/or Arabic languages only as the

investigators could only speak these two languages.

The study subjects were recruited until saturation was reached. Saturation is the point at which no new concepts or ideas emerge from the review of data obtained from a sample that is diverse in characteristics and experiences [115]. It is a point in which further data collection becomes redundant and fails to contribute to the study dimensions and categories development [116]. It is not possible to know the exact number of participants needed in advance [117].

3.4.1.4. Interview process

Interviews were planned to be conducted face-to-face with ACS and HF patients over a duration of 30 to 45 minutes [115, 116]. The interview was in either English or Arabic language, based on the participants' preference, and it was audiotaped for transcribing purposes.

3.4.1.5. Interview guide

The interview focused on barriers and challenges faced by ACS and HF patients with limited health literacy as well as potential facilitators and possible strategies that can be utilized to improve health literacy skills. A semi-structured interview guide was developed from an extensive review of previous literature investigating similar topics, and questions were prepared to help guide the interview. The questions were open-ended to allow participants to express their own views and perceptions.

3.4.1.6. Validation of interview guide

After developing the interview guide, it was reviewed and validated by two experts in the field of health literacy and CVD with experience in qualitative research. The purpose was to ensure the appropriateness and comprehensiveness of the questions. Modifications were applied to the questions as appropriate.

3.4.1.7. Transcribing

The interviews were audiotaped using a digital audio recorder for transcribing and analysis purposes. The audiotaped sessions were transcribed verbatim with the aid of the recorder's notes from each session. If the interview was conducted in Arabic, it was translated into English language by the researcher. In case of uncertainty or unclear audio, the opinion of another member of the research team was sought and discussion took place until a consensus was achieved. Approval for voice recording was sought from participants prior to the interview.

3.4.1.8. Data analysis

A thematic analysis utilizing inductive and deductive approaches of data analysis was performed. First, transcripts were read for familiarization with data, then initial codes were generated by documenting reoccurring patterns. After that, themes were generated by combining relevant codes. Consensus of all research team members was required to finalize the themes.

3.4.2. Healthcare providers' perspective

3.4.2.1. Study design

The design followed a focus group structure among healthcare providers using a methodology previously described in the literature [117, 118]. This methodology was chosen on the basis that it would allow for the in-depth exploration of the perceptions and beliefs of healthcare providers about the factors associated with and the barriers to improving health literacy as well as potentially effective strategies and tools that can be implemented to improve health literacy in patients with ACS or HF.

3.4.2.2. Study population

The target population was healthcare providers who were directly involved in managing patients with ACS and/or HF. These included physicians, pharmacists, nurses, dietitians, physiotherapists, occupational therapists, and social workers at Heart Hospital who were involved in the care of patients with ACS or HF.

3.4.2.3. Participants' selection

Diverse participants based on, for example, the profession, specialty, years of experience, and gender were purposively selected to obtain different opinions and point of views. The study participants were recruited until saturation was reached. The concept of saturation has been previously described in section 3.4.1.3.

3.4.2.4. Focus group discussion process

A focus group session was planned to last for a duration of about 45 to 60 minutes,

comprising of 6 to 9 participants from different healthcare professions as listed previously [115, 116]. The sessions were conducted in English language and were audiotaped for transcribing and analysis purposes.

Each session involved two of the investigators; one facilitator and one recorder. The facilitator was moderating the session and ensuring equal opportunities for all participants to discuss their point of views, without inferring an opinion, agreement, or disagreement. The recorder, on the other hand, was taking notes of the sessions about the tone, body language and actual quotes of participants. The recorder also made a sketch of the seating arrangement and participants coded names to ease transcribing.

3.4.2.5. Focus group discussion guide

A set of questions were developed for each of the study objectives in this phase to help guide the discussion and avoid losing the study's focus. Each session started by a brief introduction to the study and introducing the participants, then probing the discussion to the factors associated with limited health literacy, and discussing the current barriers and challenges faced in communication with ACS or HF patients having limited health literacy. Finally, moving on to potentially effective interventions, strategies and tools that can be employed to address these factors and barriers and that can be used to improve health literacy among ACS and HF patients having limited health literacy. The probing questions were identified from extensive literature review.

3.4.2.6. Validation of focus group discussion guide

The comprehensiveness and appropriateness of the focus group discussion guide

were checked by experts in the field of health literacy or CVD with relevant experience in qualitative research to ensure the coverage and validity of the questions.

3.4.2.7. Transcribing

The audiotaped sessions were transcribed verbatim with the aid of the recorder's notes from each session. In case of uncertainty or ambiguity of audio, the opinion of another member of the research team was sought and discussion took place until a consensus was achieved.

3.4.2.8. Data analysis

A thematic analysis utilizing inductive and deductive approaches of data analysis was performed. First, transcripts were read for familiarization with the data, then they were coded for common phrases that discuss the same idea. Comparison of codes was conducted, and similar codes were combined to generate themes. Irrelevant codes were discarded, and similar category codes were put under respective themes. Consensus of all research team members was required to finalize the themes.

3.4.3. Data integration and interpretation

Facilitators and barriers, as well as suggested strategies and tools to improve health literacy in patients with ACS and/or HF, were organized and categorized based on the frequency of reporting, and then they were discussed individually. Data interpretation of Phase II was conducted through comparison and combining of results from the two perspectives (patients' and healthcare providers' perspectives).

3.4.4. Quality measures

Measure of quality of qualitative research are important to ensure the robustness and quality of research outcomes. Quality measures and trustworthiness criteria in qualitative research include dependability, credibility, confirmability, transferability, and reflexivity [119]. The dependability criterion is similar to reliability in quantitative research and aims to ensure that the research outcomes are repeatable and consistent [119]. This was addressed by describing the methodology in detail, peer review, and maintaining a database of all research data and records. The credibility criterion is similar to validity in quantitative research and aims to ensure the generation of valid results and credible conclusions [119]. It was maintained through triangulation of data, peer review process, and implementation of appropriate data analysis. Confirmability corresponds to objectivity in quantitative research and aims to eliminate influence of results by the researcher's perspective [119]. This was addressed by maintaining records of all research-related activities and documents for examination by independent researchers. Transferability corresponds to external validity in quantitative research and identifies the generalizability of research findings to similar settings [119]. It was maintained by providing detailed description of the study setting and participants and credible interpretation of the data. Reflexivity describes the researcher's influence on the research process [119]; thus, a description of the researcher's experiences and previous relationships with participants is provided.

Standards for Reporting Qualitative Research (SRQR), a 21-item tool for comprehensive reporting of qualitative studies, was utilized to improve the quality of reporting of this qualitative research study [120].

CHAPTER 4: RESULTS

4.1. Phase I: Evaluation of Health Literacy Skills among Patients with ACS and HF

4.1.1. Demographic characteristics

A total of 300 patients were enrolled in Phase I of this study from April 2018 to August 2018. The demographic characteristics of the study population are presented in **Table 4.1**. Among the 300 participants who were enrolled in the study, the median (IQR) age was 55 (11) years, the majority were male (88%) and non-Qatari (94%). The highest education level completed was university education for approximately half (48%) of the sample, while about 40% of the participants had a maximum of high school education or less. The majority (89%) of participants can read and write in English, over half (54%) can read and write in Arabic, 41% can read and speak in Hindi, and about one-third (34%) can read and write in Urdu. Most participants received health information within the past 6 months from a physician (93%), a pharmacist (78%), or a nurse (67%).

Table 4.1: Demographic characteristics of the study participants (n=300)

Variable	n (%)
Age	
<60 years	226 (75.3)
≥60 years	74 (24.7)
Gender	
Male	265 (88.3)
Female	35 (11.7)
Marital status	
Single	27 (9.0)
Married	272 (90.7)
Divorced/widowed/separated	1 (0.3)

Table 4.1: Cont. Demographic characteristics of the study participants (n=300)

Nationality	
Qatari	17 (5.7)
Non-Qatari	283 (94.3)
Country of origin	
India	78 (26.0)
Egypt	46 (15.3)
Bangladesh	31 (10.3)
Others	26 (8.7)
Pakistan	25 (8.3)
Qatar	17 (5.7)
Sudan	14 (4.7)
Philippines	12 (4.0)
Syria	12 (4.0)
Sri Lanka	11 (3.7)
Jordan	9 (3.0)
Palestine	8 (2.7)
Nepal	5 (1.7)
Lebanon	4 (1.3)
Iran	2 (0.7)
Education level	
None	1 (0.3)
Primary school	7 (2.3)
Middle school	27 (9.0)
High school	84 (28.0)
College/diploma	21 (7.0)
University	144 (48.0)
Post-graduate	16 (5.3)
Languages spoken*	
English	266 (88.7)
Arabic	161 (53.7)
Hindi	122 (40.7)
Urdu	103 (34.3)
Malayalam	39 (13.0)
Tagalog	14 (4.7)
Tamil	3 (1.0)
Other	60 (20.0)
Occupation	
Unemployed	21 (7.0)
Management	27 (9.0)
Finance/accounting	20 (6.7)
Medical/healthcare	12 (4.0)
Driving	20 (6.7)
Retail salesperson	13 (4.3)

Table 4.1: Cont. Demographic characteristics of the study participants (n=300)

Retired	17 (5.7)
Administration	24 (8.0)
Engineering	29 (9.7)
Teaching	6 (2.0)
Labor	39 (13.0)
Cashier	2 (0.7)
Secretary	2 (0.7)
Others	68 (22.7)
Health information source*	
Physician	280 (93.3)
Pharmacist	234 (78.0)
Physiotherapist	29 (9.7)
Nurse	200 (66.7)
Dietician	16 (5.3)
Person in charge of medications (at home)	
Self	298 (99.3)
Spouse/partner	2 (0.7)

*Items are not mutually exclusive

4.1.2. Clinical characteristics

The clinical characteristics of the study population are presented in **Table 4.2**. The majority (89%) of participants had ACS, while 21% had HF. The most reported chronic comorbidities included hypertension (66%), diabetes (48%), and dyslipidemia (41%). The median (IQR) number of comorbidities was 3 (2) diseases. The most reported chronic oral medications used by participants were antiplatelets (94%), statins (91%), beta-blockers (88%), and ACEI or ARB (77%) with median (IQR) number of medications of 6 (3) medications. The median (IQR) BMI of the study participants was 28 (6.6) kg/m² which is considered overweight.

Table 4.2: Clinical characteristics of the study participants (n=300)

Variable	n (%)	Median (IQR)
Diagnosis		
HF only	32 (10.7)	
ACS only	237 (79.0)	
HF and ACS	31 (10.3)	
NYHA classification [†]		
I	13 (21.0)	
II	31 (50.0)	
III	14 (22.6)	
IV	4 (6.5)	
ACS type [†]		
STEMI	90 (39.6)	
NSTEMI	108 (47.6)	
UA	29 (12.8)	
HF duration (years)		2.0 (1.0)
ACS duration (years)		2.4 (4.0)
Comorbidities*		
Diabetes	145 (48.3)	
Hypertension	199 (66.3)	
Dyslipidemia	123 (41.0)	
Renal dysfunction	18 (6.0)	
Liver dysfunction	2 (0.7)	
AF	18 (6.0)	
Other	78 (26.0)	
Number of comorbidities		3.0 (2.0)
Medication*		
Beta-blocker	265 (88.3)	
Antiplatelet	281 (93.7)	
Statin	274 (91.3)	
ACEI/ARB	231 (77.0)	
CCB	69 (23.0)	
Diuretic	85 (28.3)	
Other	220 (73.3)	
Number of oral medications		6.0 (3.0)
Smoking status		
Never	169 (56.3)	
Former	73 (24.3)	
Current	58 (19.3)	
Weight (kg)		80.0 (19.4)
Height (cm)		169.0 (10.0)
BMI (kg/m ²)		28.0 (6.6)

Table 4.2: Cont. Clinical characteristics of the study participants (n=300)

SBP (mmHg)	128.0 (27.0)
DBP (mmHg)	77.5 (13.0)
HR (bpm)	71.0 (16.0)
Total cholesterol (mmol/L)	3.5 (1.5)
LDL (mmol/L)	1.9 (1.2)
HDL (mmol/L)	1.0 (0.4)
TG (mmol/L)	1.4 (1.0)
HbA1c (%)	6.1 (1.9)

*Items are not mutually exclusive (i.e. multiple options response)

†Some missing values

4.1.3. Health literacy characteristics

The health literacy characteristics of the study population are presented in **Table 4.3**. Among the participants, 36% had inadequate or marginal health literacy according to S-TOFHLA while over half (54%) had inadequate or marginal health literacy according to 3-item BHLS. **Table 4.4** represents the level of agreement between S-TOFHLA and 3-item BHLS using Cohen's Kappa test. The kappa value was 0.46, indicating moderate agreement between S-TOFHLA and 3-item BHLS ($p \leq 0.001$). Ninety-five percent of patients categorized as adequate health literate based on 3-item BHLS were also categorized as adequate health literate based on S-TOFHLA, while 55% of patients categorized as inadequate health literate based on 3-item BHLS were also categorized as inadequate health literate based on S-TOFHLA. Only 2.2% of patients categorized as adequate health literate based on 3-item BHLS were categorized as inadequate health literate based on S-TOFHLA, while 14% of patients categorized as inadequate health literate based on 3-item BHLS were categorized as adequate health literate based on S-TOFHLA.

Table 4.3: Health literacy characteristics of the study participants (n=300)

Variable	n (%)	Median (IQR)
S-TOFHLA score*		31.0 (16.0)
S-TOFHLA category		
Adequate (23 – 36)	192 (64.0)	
Inadequate or marginal (0 – 22)	108 (36.0)	
BHLS score [†]		9.0 (4.0)
BHLS category		
Adequate (10 – 12)	139 (46.3)	
Inadequate or marginal (0 – 9)	161 (53.7)	

*S-TOFHLA scores range from 0 to 36

[†]BHLS scores range from 0 to 12

Table 4.4: S-TOFHLA versus 3-item BHLS crosstabulation (n=300)

Health literacy test	3-item BHLS category			
	Adequate	Marginal	Inadequate	
	n (%)			
S-TOFHLA category	Adequate	132 (95.0)	52 (49.5)	8 (14.3)
	Marginal	4 (2.9)	39 (37.1)	17 (30.4)
	Inadequate	3 (2.2)	14 (13.3)	31 (55.4)

4.1.4. Patients' characteristics based on adequacy of health literacy

The demographic characteristics of adequate versus inadequate or marginal health literacy patients based on S-TOFHLA are presented in **Table 4.5**. There were statistically significant differences in some demographic characteristics between patients with adequate health literacy and patients with inadequate or marginal health literacy using S-TOFHLA. Those include the education level where 78% of patients with adequate health literacy had

either undergraduate or postgraduate university education as compared to less than 10% of patients with inadequate or marginal health literacy ($p \leq 0.001$). In addition, there were significant differences between adequate and inadequate or marginal health literacy patients in relation to the languages they speak; 63% of patients with adequate health literacy can read and write in Arabic as compared to 37% of patients with inadequate or marginal health literacy ($p \leq 0.001$). Moreover, among patients with adequate health literacy, 29% speak Hindi and 23% speak Urdu as compared to 62% who speak Hindi and 54% who speak Urdu among patients with inadequate or marginal health literacy ($p \leq 0.001$). Furthermore, there were statistically significant differences between adequate and inadequate or marginal health literacy patients in relation to occupation ($p \leq 0.001$) as well as health information source, specifically physiotherapist ($p \leq 0.001$) and nurse ($p = 0.041$) as sources of health information.

Table 4.5: Demographic characteristics based on S-TOFHLA category

Variable	Adequate (n=192)	Inadequate or marginal (n=108)	P-value [†]
	n (%)		
Age			
<60 years	149 (77.6)	77 (71.3)	0.224
≥60 years	43 (22.4)	31 (28.7)	
Gender			
Male	170 (88.5)	95 (88.0)	0.881
Female	22 (11.5)	13 (12.0)	
Marital status			
Single	12 (6.3)	15 (13.9)	0.066
Married	179 (93.2)	93 (86.1)	
Divorced/widowed/separated	1 (0.5)	0 (0.0)	

Table 4.5: Cont. Demographic characteristics based on S-TOFHLA category

Nationality			
Qatari	14 (7.3)	3 (2.8)	0.124 [‡]
Non-Qatari	178 (92.7)	105 (97.2)	
Education level			
None	0 (0.0)	1 (0.9)	≤0.001
Primary school	0 (0.0)	7 (6.5)	
Middle school	5 (2.6)	22 (20.4)	
High school	25 (13.0)	59 (54.6)	
College/diploma	12 (6.3)	9 (8.3)	
University	136 (70.8)	8 (7.4)	
Post-graduate	14 (7.3)	2 (1.9)	
Languages spoken*			
Arabic	121 (63.0)	40 (37.0)	≤0.001
English	171 (89.1)	95 (88.0)	0.773
Hindi	55 (28.6)	67 (62.0)	≤0.001
Urdu	45 (23.4)	58 (53.7)	≤0.001
Tamil	2 (1.0)	1 (0.9)	1.000 [‡]
Tagalog	8 (4.2)	6 (5.6)	0.584
Malayalam	21 (10.9)	18 (16.7)	0.157
Other	26 (13.5)	34 (31.5)	≤0.001
Occupation			
Unemployed	10 (5.2)	11 (10.2)	≤0.001
Management	25 (13.0)	2 (1.9)	
Finance/accounting	19 (9.9)	1 (0.9)	
Medical/healthcare	12 (6.3)	0 (0.0)	
Driving	0 (0.0)	20 (18.5)	
Retail salesperson	4 (2.1)	9 (8.3)	
Retired	13 (6.8)	4 (3.7)	
Administration	20 (10.4)	4 (3.7)	
Engineering	27 (14.1)	2 (1.9)	
Teaching	6 (3.1)	0 (0.0)	
Labor	6 (3.1)	33 (30.6)	
Cashier	1 (0.5)	1 (0.9)	
Secretary	1 (0.5)	1 (0.9)	
Others	48 (25.0)	20 (18.5)	
Health information source*			
Physician	177 (92.2)	103 (95.4)	0.289
Pharmacist	156 (81.3)	78 (72.2)	0.070
Physiotherapist	27 (14.1)	2 (1.9)	≤0.001[‡]
Nurse	136 (70.8)	64 (59.3)	0.041
Dietician	11 (5.7)	5 (4.6)	0.684

Table 4.5: Cont. Demographic characteristics based on S-TOFHLA category

Person in charge of medications (at home)			
Self	191 (99.5)	107 (99.1)	1.000 [‡]
Spouse/partner	1 (0.5)	1 (0.9)	

*Items are not mutually exclusive

†P-values were calculated using Chi-square test

‡P-values were calculated using Fisher's Exact test

Similar comparisons were conducted between adequate and inadequate or marginal health literacy (S-TOFHLA) patients regarding their clinical and health literacy characteristics that are available in **Appendix C** and **D**. In addition, for purpose of triangulation, the same comparisons were repeated using 3-item BHLS health literacy categorization and the findings were similar (**Appendix E, F, and G**).

4.1.5. Differences in health literacy scores across different patients' characteristics

There was a statistically significant difference in health literacy based on marital status, where the median (IQR) S-TOFHLA score was 19 (16) among single patients as compared to 31 (15) among married patients ($p=0.010$). Similarly, there was a statistically significant difference in health literacy score based on education level, where the median (IQR) S-TOFHLA score for patients with high school education or less ranged from 16 (6) to 19 (9) as compared to 34 (4) to 35 (3) for patients with undergraduate or postgraduate university education, respectively ($p\leq 0.001$). Moreover, the median (IQR) S-TOFHLA scores differed significantly according to whether or not the patient speaks Arabic, English, Hindi, Urdu, Malayalam, or other languages (p -values range from ≤ 0.001 to 0.035). The S-TOFHLA scores also differed significantly based on country of origin ($p\leq 0.001$),

occupation ($p \leq 0.001$), and whether or not the patient received health information within the past 6 months from a pharmacist ($p = 0.008$), physiotherapist ($p \leq 0.001$) or nurse ($p = 0.004$). **Table 4.6** presents S-TOFHLA scores across different demographic characteristics.

Table 4.6: Differences in S-TOFHLA scores across different demographic characteristics

Variable	n (%)	Median (IQR)*	P-value
Age			
<60 years	226 (75.3)	31.0 (15.0)	0.377 [‡]
≥60 years	74 (24.7)	28.5 (17.0)	
Gender			
Male	265 (88.3)	31.0 (16.0)	0.682 [‡]
Female	35 (11.7)	31.0 (19.0)	
Marital status			
Single	27 (9.0)	19.0 (16.0)	0.010[§]
Married	272 (90.7)	31.0 (15.0)	
Nationality			
Qatari	17 (5.7)	30.0 (8.0)	0.936 [‡]
Non-Qatari	283 (94.3)	31.0 (16.0)	
Country of origin			
Qatar	17 (5.7)	30.0 (8.0)	≤0.001[§]
Egypt	46 (15.3)	34.0 (5.0)	
Palestine	8 (2.7)	33.5 (12.0)	
Lebanon	4 (1.3)	34.0 (4.0)	
Syria	12 (4.0)	33.0 (14.0)	
Sudan	14 (4.7)	34.0 (2.0)	
Jordan	9 (3.0)	35.0 (6.0)	
India	78 (26.0)	25.0 (15.0)	
Pakistan	25 (8.3)	23.0 (18.0)	
Sri Lanka	11 (3.7)	16.0 (24.0)	
Nepal	5 (1.7)	22.0 (8.0)	
Bangladesh	31 (10.3)	17.0 (8.0)	
Philippines	12 (4.0)	33.0 (13.0)	
Iran	2 (0.7)	34.5 (-)	
Others	26 (8.7)	36.0 (3.0)	

Table 4.6: Cont. Differences in S-TOFHLA scores across different demographic characteristics

Education level			
Primary school	7 (2.3)	16.0 (6.0)	≤0.001[§]
Middle school	27 (9.0)	17.0 (8.0)	
High school	84 (28.0)	19.0 (9.0)	
College/diploma	21 (7.0)	31.0 (15.0)	
University	144 (48.0)	34.0 (4.0)	
Post-graduate	16 (5.3)	35.0 (3.0)	
Languages spoken [†]			
Arabic			
Yes	161 (53.7)	33.0 (13.0)	0.001[‡]
No	139 (46.3)	23.0 (17.0)	
English			
Yes	266 (88.7)	31.0 (16.0)	0.014[‡]
No	34 (11.3)	26.0 (15.0)	
Hindi			
Yes	122 (40.7)	22.0 (16.0)	≤0.001[‡]
No	178 (59.3)	33.0 (11.0)	
Urdu			
Yes	103 (34.3)	22.0 (16.0)	≤0.001[‡]
No	197 (65.7)	33.0 (13.0)	
Tamil			
Yes	3 (1.0)	27.0 (-)	0.788 [‡]
No	297 (99.0)	31.0 (16.0)	
Tagalog			
Yes	14 (4.7)	30.0 (17.0)	0.806 [‡]
No	286 (95.3)	31.0 (16.0)	
Malayalam			
Yes	39 (13.0)	24.0 (14.0)	0.035[‡]
No	261 (87.0)	31.0 (16.0)	
Other			
Yes	60 (20.0)	22.0 (18.0)	≤0.001[‡]
No	240 (80.0)	32.0 (14.0)	
Occupation			
Unemployed	21 (7.0)	20.0 (19.0)	≤0.001[§]
Management	27 (9.0)	34.0 (5.0)	
Finance/accounting	20 (6.7)	34.0 (3.0)	
Medical/healthcare	12 (4.0)	36.0 (0.0)	
Driving	20 (6.7)	17.50 (6.0)	
Retail salesperson	13 (4.3)	20.0 (12.0)	
Retired	17 (5.7)	29.0 (13.0)	
Administration	24 (8.0)	33.0 (7.0)	
Engineering	29 (9.7)	34.0 (4.0)	

Table 4.6: Cont. Differences in S-TOFHLA scores across different demographic characteristics

Teaching	6 (2.0)	35.5 (3.0)	
Labor	39 (13.0)	18.0 (9.0)	
Cashier	2 (0.7)	24.5 (-)	
Secretary	2 (0.7)	17.5 (-)	
Others	68 (22.7)	31.0 (13.0)	
Health information source [†]			
Physician			
Yes	280 (93.3)	31.0 (17.0)	0.472 [‡]
No	20 (6.7)	30.5 (12.0)	
Pharmacist			
Yes	234 (78.0)	32.0 (14.0)	0.008[‡]
No	66 (22.0)	25.5 (17.0)	
Physiotherapist			
Yes	29 (9.7)	35.0 (4.0)	≤0.001[‡]
No	271 (90.3)	25.5 (16.0)	
Nurse			
Yes	200 (66.7)	32.0 (14.0)	0.004[‡]
No	100 (33.3)	27.0 (16.0)	
Dietician			
Yes	16 (5.3)	31.5 (13.0)	0.902 [‡]
No	284 (94.7)	31.0 (16.0)	
Person in charge of medications (at home)			
Self	298 (99.3)	31.0 (16.0)	0.652 [§]
Spouse/partner	2 (0.7)	26.0 (-)	

*S-TOFHLA scores range from 0 to 36

[†]Items are not mutually exclusive

[‡]P-values were calculated using Mann Whitney-U test

[§]P-values were calculated using Kruskal Wallis test

Table 4.7 and **Table 4.8** represent S-TOFHLA scores across different clinical and health literacy characteristics, respectively. There was no statistically significant difference in S-TOFHLA scores among patients with different diagnosis (p=0.791). Participants with adequate health literacy (as categorized by S-TOFHLA and BHLS) had significantly higher health literacy scores compared to those with inadequate or marginal health literacy (see

Table 4.8).

In addition, for the purpose of triangulation, the differences in 3-item BHLS scores across different demographic, clinical, and health literacy characteristics were analyzed and the findings were similar to those obtained from S-TOFHLA (**Appendix H, I, and J**).

Table 4.7: Differences in S-TOFHLA scores across different clinical characteristics

Variable	n (%)	Median (IQR)*	P-value
Diagnosis			
HF only	32 (10.7)	33.0 (14.0)	0.791 [‡]
ACS only	237 (79.0)	31.0 (16.0)	
HF and ACS	31 (10.3)	29.0 (13.0)	
NYHA classification**			0.043[‡]
I	13 (21.0)	35.0 (4.0)	
II	31 (50.0)	31.0 (12.0)	
III	14 (22.6)	24.0 (16.0)	
IV	4 (6.5)	20.5 (17.0)	
ACS type**			0.127 [‡]
STEMI	90 (39.6)	28.0 (16.0)	
NSTEMI	108 (47.6)	31.0 (16.0)	
UA	29 (12.8)	33.0 (15.0)	
Comorbidities [†]			
Diabetes			0.749 [§]
Yes	145 (48.3)	31.0 (15.0)	
No	155 (51.7)	31.0 (17.0)	
Hypertension			0.067 [§]
Yes	199 (66.3)	32.0 (15.0)	
No	101 (33.7)	27.0 (16.0)	
Dyslipidemia			0.011[§]
Yes	123 (41.0)	32.0 (14.0)	
No	177 (59.0)	28.0 (17.0)	
Renal dysfunction			0.766 [§]
Yes	18 (6.0)	30.0 (17.0)	
No	282 (94.0)	31.0 (16.0)	
Liver dysfunction			0.538 [§]
Yes	2 (0.7)	29.0 (-)	
No	298 (99.3)	31.0 (16.0)	
AF			0.130 [§]
Yes	18 (6.0)	34.0 (11.0)	
No	282 (94.0)	31.0 (16.0)	

Table 4.7: Cont. Differences in S-TOFHLA scores across different clinical characteristics

Other			
Yes	78 (26.0)	33.0 (16.0)	0.415 [§]
No	222 (74.0)	30.5 (16.0)	
Smoking status			
Never	169 (56.3)	31.0 (17.0)	0.495 [‡]
Former	73 (24.3)	29.0 (13.0)	
Current	58 (19.3)	29.0 (15.0)	

*S-TOFHLA scores range from 0 to 36

**Missing values

†Items are not mutually exclusive

‡P-values were calculated using Kruskal Wallis test

§P-values were calculated using Mann Whitney test

Table 4.8: Differences in S-TOFHLA scores across different health literacy characteristics

Variable	n (%)	Median (IQR)*	P-value [†]
S-TOFHLA category			
Adequate (23 – 36)	192 (64.0)	34.0 (13.0)	≤0.001
Inadequate or marginal (0 – 22)	108 (36.0)	17.0 (7.0)	
BHLS category			
Adequate (10 – 12)	139 (46.3)	35.0 (4.0)	≤0.001
Inadequate or marginal (0 – 9)	161 (53.7)	21.0 (13.0)	

*S-TOFHLA scores range from 0 to 36

†P-values were calculated using Mann Whitney U-test

Table 4.9 and **Table 4.10** indicate the correlations between patients' characteristics and S-TOFHLA and 3-item BHLS, respectively, while **Table 4.11** indicates the correlation between S-TOFHLA and 3-item BHLS. There is strong positive correlation between S-TOFHLA levels and 3-item BHLS levels ($r=0.66$, $p\leq 0.001$) as well as between S-TOFHLA scores and 3-item BHLS scores ($r=0.71$, $p\leq 0.001$).

Table 4.9: Correlation between patient characteristics and S-TOFHLA score

Variable	Correlation coefficient	P-value*
Demographic characteristics		
Age	0 .019	0.748
Clinical characteristics		
Duration since HF diagnosis	0.035	0.794
Duration since ACS diagnosis	0.012	0.839
Number of comorbidities	0.138	0.017
Number of medications	-0.072	0.211

*P-values calculated using Spearman's rho test

Table 4.10: Correlation between patient characteristics and BHLS score

Variable	Correlation coefficient	P-value*
Demographic characteristics		
Age	0.014	0.807
Clinical characteristics		
Duration since HF diagnosis	0.149	0.265
Duration since ACS diagnosis	-0.013	0.834
Number of comorbidities	0.073	0.209
Number of medications	-0.061	0.291

*P-values calculated using Spearman's rho test

Table 4.11: Correlation between S-TOFHLA and BHLS

Variable	Correlation coefficient	P-value*
S-TOFHLA category vs BHLS category	0.660	≤0.001
S-TOFHLA score vs BHLS score	0.707	≤0.001

*P-values calculated using Spearman's rho test

4.2. Phase II: Identification of the Facilitators of and Barriers to Health Literacy
among Patients with ACS and HF in Qatar

4.2.1. *Demographic characteristics*

A total of six focus groups involving 40 healthcare providers were conducted in Phase II of this study during the month of January 2019. Three of the six focus groups were homogenous, where the focus groups included participants of the same profession, with pharmacists, physicians, and nurses in each group. The other three focus groups were heterogeneous, where the focus groups included participants of different professions, with a mixture of pharmacists, physicians, nurses, dieticians, and physiotherapists. The different professions of the healthcare providers are presented in **Table 4.12**.

Table 4.12: Professions of the healthcare providers who participated in the focus group interviews (n=40)

Profession (abbreviation)	n (%)
Pharmacist (PHAR)	14 (35)
Clinical pharmacist	8 (20)
Staff pharmacist	5 (12.5)
Pharmacy administrator	1 (2.5)
Pharmacy Technician (PT)	2 (5)
Physician (PHY)	10 (25)
Nurse (N)	9 (22.5)
Physiotherapist (PHYSIO)	3 (7.5)
Staff physiotherapist	2 (5)
Physiotherapy administrator	1 (2.5)
Dietician (DIET)	2 (5)

In addition, 11 one-to-one interviews were conducted with patients in Phase II of this study from June 2019 to July 2019. The demographic and health literacy characteristics of the patients that participated in the interviews are presented in **Table 4.13**.

Table 4.13: Characteristics of the patients who participated in the one-to-one interviews (n=11)

Participant	Age (years)	Gender	Country of origin	Education level	s-TOFHLA level	BHLS level
P1	62	Female	Qatar	Middle school	Inadequate	Inadequate
P2	56	Male	Egypt	High school	Adequate	Marginal
P3	43	Male	Sri Lanka	University	Adequate	Adequate
P4	59	Male	Sudan	University	Adequate	Marginal
P5	55	Male	UK	University	Adequate	Adequate
P6	57	Male	Egypt	University	Adequate	Adequate
P7	45	Male	India	High school	Marginal	Marginal
P8	55	Female	Palestine	University	Adequate	Adequate
P9	56	Female	Jordan	High school	Inadequate	Inadequate
P10	50	Male	India	High school	Inadequate	Inadequate
P11	40	Male	Bangladesh	Middle school	Inadequate	Inadequate

4.2.2. *Facilitators and barriers to health literacy*

Although, there was a difference between the patients' and the healthcare providers' perspectives, similar themes related to the barriers and facilitators to health literacy emerged from the two groups. **Table 4.14** represents all the identified themes, categories, and codes that emerged from the qualitative analysis.

Table 4.14: Themes, categories, and codes related to health literacy barriers and facilitators that emerged from the focus interviews

Themes	Categories	Codes
1. Patient attributes and attitudes	Demographic characteristics	<ul style="list-style-type: none"> • Gender difference • Old age • Socioeconomic status • Education level • +/- Literacy • Disability <ul style="list-style-type: none"> ○ Mobility impairment ○ Hearing and visual difficulties • Having polypharmacy
	Attitudes/attributes	<ul style="list-style-type: none"> • Patient self-confidence • Lack of trust • Resistance/lack of cooperation • Patient reluctance • Misconception • +/- Proactivity in asking questions • Denial • Carelessness • Use of reliable information source • Family caregiver • Cultural norms
	Psycho-cognitive function	<ul style="list-style-type: none"> • Forgetfulness • Cognitive status • +/- Understanding instructions • Psychological status

Table 4.14: Cont. Themes, categories, and codes related to health literacy barriers and facilitators that emerged from the focus interviews

2. Healthcare provider skills, attitudes, and professionalism	Skills	<ul style="list-style-type: none"> • Education/counseling <ul style="list-style-type: none"> ○ Counseling skills ○ Explanation of medical terms ○ Individualizing patient care ○ +/- Amount of information • Use of simple language • Use of medical jargon • Patient empowerment
	Attitudes	<ul style="list-style-type: none"> • Pleasant staff
	Professionalism	<ul style="list-style-type: none"> • Multidisciplinary team
3. Communication	Provider-patient interaction	<ul style="list-style-type: none"> • Rapport • Preference for a single provider
	Linguistic factors	<ul style="list-style-type: none"> • Language barrier • Multilingual staff • +/- Translation
4. Facility attributes	Physical condition	<ul style="list-style-type: none"> • Small setting • Small waiting area • Pharmacy layout • Pharmacy counselling area • Satellite pharmacy
	User-friendliness	<ul style="list-style-type: none"> • Difficulty in differentiating care facilities • +/- Navigation
	Functionality	<ul style="list-style-type: none"> • Interruption/distraction • Lack of privacy

Table 4.14: Cont. Themes, categories, and codes related to health literacy barriers and facilitators that emerged from the focus interviews

5. Care process	Workflow	<ul style="list-style-type: none"> • Work scheduling • Waiting time • +/- Appointments
	Others	<ul style="list-style-type: none"> • Valuing quantity of work over quality • Role of primary healthcare • Use of technology
6. Resources	Administrative factors	<ul style="list-style-type: none"> • -/+ Human resources • Time constraint • Home visit
	Educational resources	<ul style="list-style-type: none"> • +/- Written material • Online educational resources • Health literacy assessment tools
	Health literacy tools and strategies	<ul style="list-style-type: none"> • Teach back method • Visual aid and pictograms • Medication adherence enhancement tools <ul style="list-style-type: none"> ○ Medication-scheduling tools ○ Pillbox

4.2.2.1. Theme 1: Patient attributes and attitudes

Patient attributes and attitudes were identified as factors facilitating as well as impeding health literacy among patients with CVDs. The diversity of the codes identified within this theme generated three categories. These include demographic characteristics, attributes and attitudes, and psycho-cognitive function.

- Demographic characteristics

Gender differences: Some healthcare providers perceived that gender differences between the patient and the healthcare provider may hinder the communication and the ability of the patient to ask questions specifically regarding sensitive matters.

“Yeah... In most of the time, they will ask freely, sometime, like, gender differences, like sensitive issues, wouldn't discuss it with female... But in general, they don't have issue asking, this is my experience.” PHAR1

Old age: Some healthcare providers perceived that older individuals or elderly patients tend to have lower health literacy than younger adults due to their inability to express their educational needs, more dependence on their families, and having age-related disabilities.

“...in elderly people, sometimes they don't know how to express themselves, the very old patients, cardiac patients, usually they are old, some of them they don't know to express themselves as symptoms wise. Of course, sometimes you need to deal with the family rather than the patients especially in this part of the world. Sometimes families asking you to hide the information about the

patient about the prognosis.” PHY1

“...because we get, maybe, elderly people who have no medical background and sometimes like even if you want to communicate with them or like educate them, it's pointless. Like the family members will tell you "No just talk to me and I will explain to him later"... like he will not understand you, he will not, we will take care of his food, like he will not know how to, you know, apply your tips and things like that.” DIET1

“Our average, half of our patients are above 65, 68, 70. I'm talking about, like, outpatient setting, okay, especially heart failure, they are like, kind of, let's say 20% would have such a problem, either hearing, either can't talk, you would talk to caregivers, tired, they don't want to hear, so usually the caregiver would help a little bit.” PHAR1

Socioeconomic status: Similarly, healthcare providers identified the patient's socioeconomic status as a barrier to communication with the patient as this can impact the continuity of care and can push some patients to refrain from fully disclosing what they perceive to be information that can affect their fit-for-work status.

“Yeah, he understands but he says that “I want to stay here [in Qatar], so just make me fit and I will be”, and when you make them fit they will never come back again to the hospital, so this is again a big problem. So sometimes some patients they will hide their condition. Actually, it is common with the Medical Commission Clinic. So patients I have seen in Medical Commission Clinic,

they will hide their symptoms when they come to the hospital and they know that if they tell the truth, that I am having heart problem, I will not get resident permit here, so they will say "I don't have any problem, I am walking, I am running", but when you listen to the heart, he has all the murmurs and he has all the problems and he will be denying that, I don't have any problem, his heart rate is 110 but he says that "I am fine". So, because of the fear to lose the job." PHY5

In addition, healthcare providers indicated that some patients with low socioeconomic status are not confident in expressing themselves and enquiring about their health, which can hinder the educational process.

"Some patient feel that they have lower social class, so this is why if they come to talk to, they come to the hospital, where they feel that all of them are well educated and all of them having higher degrees. So, this creates a barrier also, they will not ask questions, maybe they will not ask about their, they don't know their rights in the hospital which can also negatively affect their learning."

PHAR14

Education level: The level of education can contribute to the patient's ability to comprehend and understand the instructions given by the healthcare provider. It was mostly perceived that those who are more educated are more likely to be health literate than those who are less educated.

"A good proportion of patients, they are not educated, they are like labors or

something, so they don't know how to navigate through the hospital based on the signs. Because of the level of education, even if you tell them, they don't grasp what you're saying, they will keep on asking, they will go out of the room and will come back and say, "what was the second thing you said?". So, I don't think that we can correct that, it's from basic.” PHY3

Literacy: Apart from the patient’s level of education, some healthcare professionals specified the patient’s general literacy level as a factor affecting the healthcare provider’s ability to give extensive details and the patient’s ability to comprehend the education and the instructions provided.

“...sometimes you have time, okay, but like the literacy or the patient's understanding doesn't allow you to go further than "take one tablet", "only one tablet of this and this and this", and make sure that he, and he should take every day. More than that, you feel as much as you will try to explain why this medication is important, it's useless, even if you have time.” PHAR1

“Because I work in outpatient, and I work, I'm translating mostly to Indian and Pakistani patients, it's very difficult for them because sometimes they don't, for example, if I'm saying for a heart rate control, it's very difficult to even let them understand what is heart rate and what this medication will do for you... At the end, we have to stick to "take one tablet once daily in the morning" or whatever.” PT1

“...something very basic, how will you explain for someone, okay

hypertension, he doesn't know, high blood pressure, you show him the number, what else I can do for him, sometimes you might face it but very rarely, I had a patient who thought he has two hearts, the human being has two hearts. Sometimes, you know, the knowledge of the patient, the level of literacy.”

PHY1

Disability: Some of the healthcare provider interviewees identified the presence of some form of disability such as mobility impairment and hearing or visual difficulty as a barrier to health literacy. One healthcare provider stated that patients with mobility impairment and who are bedridden have very limited time with the physician during the clinic appointment if they are transported by an ambulance, which limits their educational opportunity.

“... bedridden or geriatric patients are brought on a stretcher by EMS [Emergency Medical Services], they have limited time, so you have to finish fast, ... there is no available patient history and rarely they will get family with them, so the nurse or the caregiver will be with them, ... It's not frequent, but you will see it in clinic maybe once or twice every week or another week. The bed-bound patient, bedridden patient, their care is not optimum... the bed-bound patient is brought with stretcher, he is not communicating with you and there is no one to take history from him, will just see his chart file, renew his medication, it's not optimal, could be improved.” PHY6

In addition, some healthcare providers recognized visual or auditory impairment as

a factor influencing the patient's health literacy and suggested the use of tools and methods to optimize the communication between the healthcare providers and the patient.

“Some cases also have problems, patients with hearing problems, these patients, in outpatient setting, even when you raise your voice, they cannot hear you well, that's an issue with some cases.” PHAR10

“Of course, of course, like, we have some elderly patients and the relatives are very helpful in informing us that they have some visual or auditory impairment. So, we have to talk louder sometimes, like, even up to the point of shouting just to ask for information, yeah, we do encounter such patients, such cases.”

PHYSIO2

Having polypharmacy: Polypharmacy is common among patients with CVDs as the appropriate management of the disease condition will require the concurrent use of multiple medications by the patient. Some healthcare providers stated that polypharmacy challenges their ability to provide education and instruction to the patients regarding each medication as it is considered a massive amount of information.

“I think if we have especially for the discharge patients, because after 02:00 we do the counseling for the discharge patients in the outpatient... so the counseling is very hard for us and there are a lot of medications.” PHAR9

“I think when they get information, all the information in the pharmacy, they're already so overwhelmed with how to take their medications and if you start

explaining it's overwhelming for them and they will forget, and they will have 5 or 6 or 7 medications... And the patient is overwhelmed to take high doses of education.” PT1

- Attitudes and attributes

Patient self-confidence: The interviewed healthcare providers noted that the patient’s level of self-confidence can affect their capability to communicate openly with the healthcare provider and ask questions comfortably. This could limit the patient’s ability to deepen their understanding and clarify any misconceptions.

“Most of them, they are a bit of, aware that they are not literate enough and they are of poor socioeconomic status, so when they come to a hospital setting where they see people, different people, so they won't be confident to talk loudly or say boldly what they feel. They're a bit shy, they might hesitate to say, even if I speak the same language of most of the labor class, they don't open up.”

PHY3

“Especially that they cannot really vocalize all these concerns to us, again goes back to probably the personality,... kind of different from the inpatient and the outpatient setting, where people kind of more confident, they can vocalize, they can excessively accept or not accept whatever recommendations you're saying.” PHAR12

Lack of trust: Some healthcare providers identified the lack of trust of the patient as a factor that affects patient’s acceptance of the information and recommendations

provided by the healthcare professional. Some patients lack trust in the healthcare system in general in the country and are more confident with the health information received abroad.

“It's very common, very common, "in the UK they prescribed it as two tablets, why you are changing?"; "in UK they are giving me this brand, I don't want your brand", although it's like the same medication with the same active ingredients...” PHAR3

On the other hand, some patients seem to not trust the opinion of a single healthcare provider and insist on gathering information from multiple providers.

“Some people, they ask different opinions, they want to hear it from everyone, so they keep telling us "No, I don't know" ...” PHY1

Resistance and lack of cooperation: This is identified as a barrier to health literacy. Some healthcare providers face a challenge in convincing some patients about a specific health instruction or recommendation. Often the patients are not interested in changing the way they are dealing with the diseases.

“So, I was telling the patient” You have to take this tablet and this tablet, one in the morning and one in the evening”, like it was a diuretic, he was telling me “No”, and he was admitted with fluids and congestion. He will not, “why not?”, "because I want my old dose and I don't want to change it". Yeah, "I will take one tablet", but you were admitted with fluids, let's adjust it, "no, I

want it this way..." PHAR3

"...they stick to their own perception about whatever disease or condition or whatever, they stick to their own perceptions and they cannot understand no matter how much you are trying to explain that, even simple words, they cannot accept the idea, so that comes again back to the issue of trust, this is one and the most important thing." PHY7

Patient reluctance: Patient reluctance was identified as a barrier to health literacy as it limits the patient's active involvement in their healthcare and decision-making as well as following the provider's instructions.

"Because most of our patients are kind of workers, so they kind of feel afraid or reluctant to ask, to communicate, to discuss. So, I believe this could also be one of the barriers to proper health literacy." PHAR12

Misconception: Some healthcare providers noted that some patients come with misconceptions or incorrect beliefs that make it difficult for them to convince the patient with scientifically proven evidence because it contrasts with their perception.

"Sometimes... some patients they come to me with some perceptions, like for example, metformin will harm my kidney, if I'm on warfarin I should completely stop eating greens, diuretic will harm my kidney. Sometimes they have wrong perceptions; I don't know whether they got it from, the community or from other healthcare providers. So, we face this quite a lot, to be

honest.” PHAR2

“For the diuretic, I have a patient who stopped spironolactone because he knows that it's a diuretic, but he doesn't know that we don't use it as a diuretic, but he was taught it's a diuretic... to remove the water, but actually we use it for its prognostic benefit, so he stopped spironolactone because of frequent urination, but haven't reduced his Lasix®.” PHAR1

“I mean those are personal patient phenomena, like now, I was dealing with one patient who's convinced that the cholesterol management is in my hand, not in her hand. She is eating junk and junk food every day, she is thinking that the management is in my hand, not in her hand. So, I spent almost 35 minutes just to chit-chat with her, just now. So, there are patient perceptions... that need to be considered.” PHY8

Proactivity in asking questions: Lack of proactivity to ask questions was identified as a barrier to health literacy since patients who do not ask questions and inquire more about unclear information and instructions will miss the opportunity to improve their understanding and knowledge. In the following quote, the lack of proactivity in asking questions is in relation to navigating the hospital and reaching the appropriate location of care.

“It happens frequently, and also we have patients who have referral to heart hospital, they come to take a number from the pharmacy and then you check with them what's the issue? they have referral to the OPD for the clinics, they

don't have anything to do with pharmacy, but they didn't know where to go, they didn't ask, they didn't feel comfortable to ask, so they just went to take number.” PHAR10

“Because sometimes, you will go and talk for like 10, 15 minutes with a patient, he wouldn't even ask a question, this is when I know he is not even listening...”

PHAR12

Denial: Similarly, patient’s denial was recognized as a barrier to communication, thus, health literacy. Patients who are not accepting their health condition and disease status will not absorb the healthcare provider’s instructions and recommendations.

“But sometimes they're in a state of denial, "I am okay", they don't want to listen to anything you say.” PHY2

Carelessness: One healthcare provider noted that some patients do not care much about their health status or the seriousness of their disease condition. Some do not care about the information and the education provided by the healthcare professionals regarding their disease condition.

“It's not that they don't understand, but they don't take it as much serious as it should be...” PHY1

Use of reliable information source: Reliable health information sources, beside the healthcare provider, are an important contributor to the patient knowledge and health literacy. Some patients indicated that they face difficulty in identifying reliable information

sources.

“To have more information or resources for trusted information, because if you read in the Internet, sometimes every website says something different, you can't know if this information is true or wrong, so to get resources from the doctor is better.” P7

“I sometimes read information from the Internet and some people send me health information in WhatsApp, but I don't know if this information is right but if it was provided by the doctor you know that it is the right information.”

P4

Family caregiver: The caregiver, whether a family member or a friend, can influence the relationship and communication between the patient and the healthcare provider. Some patients and healthcare providers stated that the presence of the caregiver during the patient-provider interaction is beneficial for the patient.

“Like sometimes, like today, the man, the patient, I ask him any question, like how do you take this? He doesn't know how to answer, the wife is answering all questions, she reminds him of everything.” PHAR3,

“Some of the caregivers, like one of them today, she knows if Mama is having bleeding or not, but Mama is not sure, she's always afraid, the patient herself, she's saying "yes I have bruises, I have bleeding" but the caregiver, she told me "no, no, no, Mama is okay, I'm checking her every day, no bleeding,

nothing" And I know that they are caring, they bring the patient and they will tell me "no I give this tablet, I give this tablet, we still have stock at home, don't give us" everything they know about it. For me, because it's only warfarin, so most of the caregivers are really aware and they know which tablets and everything." PHAR2

"I feel that they are really supportive, I mean someone who comes with the patient, he's really supportive for that patient and believe me patients in the acute illness, they need a big support." PHAR14

In addition, some healthcare providers noted that, sometimes, they communicate mainly with the caregivers due to barriers limiting direct communication with the patient.

"To me yes, because sometimes the family, the caregivers are educated, so they know the medications, some of them even healthcare providers and they understand and at least they help us with making decisions sometimes about the patient condition because sometimes, those patients they don't understand their health condition quite well, so the family members pass it to them or explain it to them in a good way, their own way, their own approach, sometimes they are able to convince them to go for procedure or not." PHAR8

"For us, the patient came to our CCU, for example, if the patient is illiterate and he comes with his friend and his friend is a little bit educated, we can explain to the patient and to that guy who's accompanying the patient about the health care, of the health case of that patient, about the medications, and

he can help him. And sometimes they live with each other, many of them live with each other, so he will help him with the medication, he will help him with the transportation, if he understands his illness, for example, so for myself, I found it really helpful.” PHAR14

“Yeah, but most of the time, it is helpful because if the patient is old and cannot read or write like old Mama old Papa, so if her son is there, her daughter is there, he or she is helping at least in filling the form, as you said, sometimes this relative he is more educated, so he can speak different languages, he can help with this stuff, like that, yeah, it helps.” N1

“There are also some few instances in which you really need the relative to be there because of the neurological condition of the patient himself or herself, like, yeah, because of the medical condition of the patient, he has a neurological impairment, like lapses in memory, so his or her relative has to be there to help in the counselling process.” PHYSIO2

Conversely, some healthcare providers noted that the presence of the caregiver during the patient-provider interaction could interrupt and hinder the communication process.

“On the other hand, the patient in the other room, like he is for discharge, and he's willing to listen, the patient himself, he's completely willing to listen, but the son like "we're in hurry, we want to leave, we're in hurry", even the co-patient could be like worsening the communication process.” PHAR3.

“Depends on how willing the caregiver wants to be involved, for example, some caregivers will just come to drop their parents and just stand next to them probably pay for their medicine and that's it, they are not really involved, they don't have the will or the time or the energy to listen, to help understand or at least explain to them, to the patient later on, for example, the disease. Sometimes they might be problematic, so they actually make noises and giving the looks that you should really hurry up because, you know, I have something to do, so this might make you wrap the education session quickly or feel intimidated because you don't want to be shouted at.” PHAR12

Cultural norms: Due to the multinational and multicultural nature of the country, cross-cultural communication is common between patients and healthcare providers. Some healthcare providers stated that some cultural aspects cause challenges when they are trying to educate patients and implement changes and modifications.

“...changing like the behaviour of patients is very difficult especially... among like the Arabic nationalities, we're facing more difficulties than other nationalities... They're not really convinced or you cannot convince them very easily to change their lifestyle and to change their diet and just to start exercising...” DIET1

Similarly, healthcare providers noted during the focus groups that the culture here allows unlimited involvement of the family in the patient care process. In fact, some families seize the patient's autonomy and disrupt the patient-provider relationship.

“Actually, here the issue with many Qatar families is that their family members they're more dominant than the patient. If we are on the board, we spend more time with the family than with the patient, because the family has so many questions and has so many inquiries, patient is okay, he is happy whatever you will ask, he will say okay, I will do, but the family does not agree, you have to convince them, "Okay, this is good for him...", they will say "No, no, no, this is not good for him", so it's a big problem.” PHY5

The interviewees acknowledged that the culture could influence the patient's confidence and comfort during healthcare interactions.

“Yeah, so in sense like in this culture, the kind of blame, the kind of scream, scolding, accusation, is a lot more in this part. But if, imagine if it was in a different part like if, imagine just an example, UK, in the clinic you respect the patient a lot, anyone in the healthcare setting would respect their patient and they will be treated him or her as a very important person, VIPs. But here, they know that there will be like situations even in the same hospital building people might treat you like disrespect, so people will be a bit scared to open up, to talk, to ask.” PHY3

Furthermore, some healthcare providers stated that some of the educational or assessment material adopted from other countries lack cultural sensitivity and compatibility.

“Different two cultures, yeah, make a difference because the question can be

accepted by one culture, but cannot be accepted by the second culture and coming also the religion is coming in between. So I have faced, I can say, a lot, a lot, a lot of patients coming with the paper to me in the station telling me "Sister, what kind of question is this? we are Muslims, we are not supposed to think like this, this is not acceptable", I said "And because it is not acceptable, you have to answer no, because what is happening, whatever you feel it is not logic to you, just reject it." N1

- **Psycho-cognitive function**

Forgetfulness: Some healthcare providers identified patient's forgetfulness as a barrier to health literacy. It hinders the patient's ability to retain health information and instruction provided by their healthcare professionals.

"...if I want to give them, I have to be really slow and clear and tell him, I show them the paper and tell him, Saturday you will take this dose, Friday you will take, for example, this dose, do you understand? is it clear? okay, repeat, tell me, really sometimes even though they are young..., no they could forget, ... one of them came today, we're asking how much you are taking, I don't know, okay tell us number of tablets, I think two or two and a half, I don't remember what I'm taking, what is the color of the tablet? I saw it, I saw the tablet, but I don't remember the color. I mean, he is young, and they forget easily, they confuse easily, I mean, it becomes very difficult to make them understand, no this is your regimen, you should keep this or that." PHAR2

Cognitive status: The interviewees noted the patient's cognitive status as a factor effecting the patient's level of health literacy. Impaired cognitive function, which increases with age, affects the healthcare provider's ability to communicate with the patient effectively and the ability of the patient understanding and comprehending the education and instructions.

"... cognitive level is the second barrier because we get, maybe, elderly people who have no medical background and sometimes like even if you want to communicate with them or like educate them, it's pointless, like the family members will tell you "No just talk to me and I will explain to him later" like he will not understand you, he will not, we will take care of his food, like he will not know how to, you know, apply your tips and things like that." DIET1

Understanding instructions: The patient's ability to understand instructions provided by the healthcare providers can contribute to their level of health literacy. Some healthcare providers identified the patient's ability to understand instructions as a factor affecting the communication and education between them and the patient.

"...today I have this issue and very frequent, when they refill, their medication is finished, so it's finished, they don't understand that they need to refill it, as a chronic medication, this is a simpler issue." PHAR1

"I worked with STEMI unit where I have usually young patients, most of them are workers, and usually they don't speak Arabic or English, most of them are workers, some nurses even though they speak their language or some sort of a

common language, sometimes they find it difficult to explain for them and they keep telling me I don't know he is not understanding, sometimes the nurses they become angry, "papa take this, this, this", even, I'm not talking their language, the nurse somehow speaks their language but she is telling I'm unable to make them understand... It's difficult for them to comprehend that they have to take this medication, they have this problem, they have to be adherent..." PHAR2

Psychological status: Some healthcare providers noted that the patient's psychological condition can affect their ability to communicate effectively with the patient and the ability of the patient to comprehend and understand health instructions.

"Depends on the mental status also, sometimes, some of their [patients] mental status, they can't understand you." PHAR7

One healthcare provider stated that the patient's psychological status can influence the extent to which they disclose to the patient discouraging health information.

"Of course, and we know that the psychology of the patient affects the whole management, so sometimes you have to just let it this way, but it's not that you lie, if the patient is dying you tell him you are okay, no... it depends from patient to patient. But sometimes it's helping, sometimes this might help, when you just go and tell the patients, like if he has pneumonia and he's improving, you don't need every time to say "you have a chest infection, we found a bacteria in your blood" this maybe it will just affect the patient negatively rather than you say "you have infection and you're responding to medication

we're giving you" and that's it. You have to know your patient, that's my point."

PHY1

4.2.2.2. *Theme 2: Healthcare provider skills, attitudes, and professionalism*

Healthcare provider skills, attitudes, and professionalism emerged as a theme associated with barriers and facilitators of health literacy in patients with CVDs. Several aspects emerged under this theme; these include the healthcare provider's skills, attitudes, and professionalism.

- Skills

Education and counseling: The education and counseling process is a major contributor to health literacy. The degree of effectiveness of the education and counseling provided by the healthcare provider to the patient is an important determinant of the degree to which the patient comprehends and utilizes the medical instructions and information. The healthcare providers identified their *counseling skills* and ability to *individualize patient care* as factors that can influence the communication with the patient and the patient's health literacy level.

"You have to individualize, like a patient who is young, educated, you have to tell him everything in details so that he understands his condition. However, if someone is really very elderly, sometimes it's not good to tell everything in details because they might take one simple thing from what you've said and they stuck it in their mind... You have to know your patient... Everything, the response of the patient, the patient, what he wants, some patients they don't

really want every detail.” PHY1

In addition, some healthcare providers identified the *amount of information* provided to the patient as a factor that can influence the patient’s comprehension and understanding of health information.

“When the patient is being discharged, I find many booklets with them, for example, Cardiac Rehabilitation, they have their own educational materials, surgery nurses, they provide educational materials about cleaning their wound. I [pharmacist] provide them with the warfarin book, and they have the appointment paper, and then they have the discharge summary, and then they have patient summary, and then they have the certificate, and then... I feel sometimes that they will not read my book of course.” PHAR2

Several healthcare providers noted that the patient education and counseling process lacks efficiency as the patient may interact with multiple healthcare providers, i.e. physician, nurse, pharmacist, etc., in a single visit, but there is no collaboration between these healthcare providers regarding the education and counseling provided. Therefore, the patient may end up being overwhelmed with the significant amount of information provided by each professional.

“The problem also arises from the, not from the patients only, also from ourselves, sometimes we, how many healthcare providers does a patient see? For example, in CCU, he sees the dietician, he sees the pharmacist, he sees the physician, he sees the social worker, he sees many individuals and everyone

gives him a new information about a new thing, so he cannot accumulate anything.” PHAR14

On the other hand, some healthcare providers stated that the lack of collaboration may lead patients to miss the education and counseling all together as each healthcare professional relies on another provider to deliver the education and counseling.

“And this is very good point actually and to give you some hint about something else, education is not starting from pharmacy side and maybe we ended up with the pharmacy is the final and the last place to educate. Maybe you miss the education from physician’s side, you should explain what is the diagnosis, what is the condition, and the nurse should explain what is triage and what happened to him, what about your blood pressure... your temperature, but sometimes we ended up with physician is not doing, nursing is not doing, so they ended up with pharmacy, we have to do all the education... We don't have the way to give him all the information with the proper way, because actually, we are specialists in medicine, we are not explaining the diagnosis, we are not explaining the triage, so sometimes it has been missed from the beginning.” PHAR4

Use of simple language: The use of clear and plain language by the healthcare providers helps the patients to understand and utilize the information and instructions provided. The use of simple language was identified by healthcare providers and patients as a facilitating factor for communication.

“That's a very valid point, because sometimes those patients, the Asia... with low level of education, I just give them just very simple points. I don't wanna overwhelm them with a lot of information, then they will get lost, so just very simple direct to the point, this one, take it regularly, don't stop it, this works here.” PHAR8

“Yeah, you have to simplify the language. For example, for me as a dietician, we try to overcome the... like we learned the keywords just to communicate with them...” DIET1

Use of medical jargon: The use of medical jargon ideally should be limited to communication among healthcare professionals. The use of medical jargon can cause confusion and diminish the understanding between the healthcare provider and the patient. Some healthcare providers and patients noted the inadvertent use of unexplained medical terminology as a barrier to communication.

“Sometimes, you see, these healthcare providers don't mean that they give this kind of information. Because, for example, if you say to the patient "you have stent" because you and I, we have encountered that "stent" too many times, we feel that everyone knows it... but the patient does not know what is stent. "You have three obstructions in one coronary artery", they don't know what's coronary artery, see, see the problem?” PHAR14

“Yeah, sometimes, they use, doctors use some medical word, but if we don't understand, we ask them, "what is that", then he tries to explain.” P1

One healthcare provider stated that the use of medical jargon is a common mistake among new healthcare providers.

“By mistake, it happens, telling the patient to take it, instead of saying twice daily, BID or TID or something. This happens sometimes, but I think by practice these things, maybe new staff only.” PHAR9

Patient empowerment: Patients who are actively involved in their disease management are thought to have higher health literacy as they seek to gain health information and knowledge to guide them in their decision-making. Some healthcare professionals recognized their role in patient empowerment as a mean to encourage patients to acquire and understand their disease condition.

“I try, not everyone might have this approach, but sometimes we need to empower them [the patients]. That this is your right to ask questions, this is your right to talk to us, we need to know, we need to hear from you...” PHAR4

- Attitudes

Pleasant staff: The healthcare provider’s approachability is a major factor that can influence the patient’s ability to interact and communicate comfortably with their healthcare providers. Some patients indicated that pleasant and friendly healthcare staff is an important factor for communication.

“Yeah, they are friendly, yes... Yes, I feel comfortable, no problem... I ask them and they are very helpful.” P7

- Professionalism

Multidisciplinary team: Healthcare providers at the Heart Hospital work in multidisciplinary teams comprising different professionals such as physicians, nurses, pharmacists, dieticians, physiotherapists, and social workers. The dynamic of these multidisciplinary teams can affect the patient management plan as well as the efficiency and the quality of the communication with the patient.

“Very often I would say, like on daily basis... but as they start joining the program, I think because they're getting support from different teams, we kind of reach like a good outcome. Now, I'm working as part of the Cardiac Rehabilitation team and in the Cardiac Rehab, we have multidisciplinary team and our intervention is mainly educational.” DIET1

4.2.2.3. Theme 3: Communication

This theme includes codes that are related to communication as expressed by both the patients and the healthcare providers who participated in the interviews and focus groups. These codes were divided into two categories, provider-patient interaction and linguistic factors.

- Provider – patient interaction

Rapport: The provider-patient interaction plays a pivotal role in the care of the patient and the provision of education and counseling. Building rapport between the patient and the healthcare provider is an important factor for understanding each other and effective communication. The participants noted that establishing rapport is necessary for

effective communication with the patients.

“the general way you present yourself to the patients is very important. You have to make the patient feel comfortable about your management and he trusts you. When he trusts you, he will not require every single detail, the patient who asks about single details, usually doesn't trust the physician... If you keep just telling him everything, this is not helpful.” PHY1

Preference for a single provider: Some participants indicated that seeing more than one healthcare provider for the same medical condition can create unnecessary confusion and poor communication. The patient prefers to continue care with the same providers who already have their full medical and medication history and have well established a good rapport.

“One thing more I would like to add about the clinics, sometimes you're covering clinics for another doctor, like a consultant... fellows sometimes do it, but I think we struggle a lot of the time with the patient, they're saying where is this specific doctor?... Suppose sometimes he is sick or for some reason he is not doing the clinic that day. So, I think that patients should be informed a day ahead that this physician is not going to come...” PHY5

“Ah, I don't know what is the difficulty. I understand your question but for me, to explain to him again, he has the report, of course, he reads it before he saw me, he reads the report and such, but maybe my discussions with the other doctor are not all there, so I have to answer the same questions again....” P3

Some patients stated that they would not be as comfortable interacting with a new or a substitute physician as they would be with their regular physician.

“Yeah, a substitute doctor, but it's fine because my case is with them in the system. But when I go to another doctor, I would not be psychologically comfortable because my doctor knows my condition well.” P2

- Linguistic factors

Language barrier: The language barrier between the patient and the healthcare provider was identified by most participants as a barrier to health literacy. The main languages spoken in Qatar are Arabic and English. However, healthcare providers often see patients who are unable to speak either Arabic or English, and some patients find it difficult to communicate.

“You will find catastrophic scenarios for the language barrier. Because actually, half of our patients... more than that, they are neither speaking English nor Arabic. So sometimes, because we are native Arabs and most of the people here are speaking English, so language barrier is a big issue, a big issue to deliver your message and to accept it from the other. But understanding, we are speaking about understanding of instruction, whatever this instruction is, medication, guidance, physician, admission, cashier, whatever, you will find the problem in understanding itself, so we are facing this.” PHAR4

“The most common barrier is the language, because most of our patients are

expats, most of them are South Asians, usually they don't speak English and of course they don't speak Arabic.” PHY1

“It is better to have a doctor who speaks Arabic, because you can understand more and ask questions. Most of the time, I go to Arabic doctors but sometimes the doctor is not there, maybe they have a vacation or something, so they put me with another doctor.” P6

The participants indicated that even different accents can cause a communication barrier. For example, if both the patient and the healthcare provider speak Arabic, but they have different accents, this can result in problems in understanding.

“Sometimes, the language and the accent also make a big difference, because I mean we all talk in Arabic, but still the accent makes a big difference. It's much better for the son or the daughter to translate to them in their own accent.” PHY7

Multilingual staff: The availability of staff with multilingual skills allows the healthcare providers to better communicate with the patients especially that Qatar hosts individuals with many different languages.

“But luckily, here, we have like when I worked in the HDU, most, majority of our physicians, they speak either Indian, Hindi, or speak Urdu or Persian. So that was not a big deal, and majority of our nurses can communicate this piece of information to the patient, so I think that's not one of the biggest problems.”

PHAR8

“Because here, you are working with multiple -nationalities, that one can be managed... for our peers, people, they will send us, they will send them to us, like Indian who doesn't speak English or Arabic will be sent to the nurse who speaks Hindi. so, language barrier, I think it's manageable here.” N3

“If the doctor doesn't speak Arabic, they bring a nurse who speaks Arabic and she helps to translate.” P2

Translation: Because healthcare providers often see patients who are unable to speak either Arabic or English, availability of translation services is important for communication. However, interviewed healthcare providers noted that the currently available methods of translation and interpretation are suboptimal.

“We will wait until they get translator, translator would be busy, will translate half and she will leave for the other clinic, it's a big major barrier. We do have Language Bank but it's not effective, if you request it ahead, it takes time to get the translators, it's not in the Heart Hospital, I think, somewhere else. There is hotline for Language Bank, they might translate over phone, but we need to wait also. The easiest way is to do it through the nurses, like, same nationality nurse, she will translate but it's not effective, it should be optimized. And this is not her duty, she's busy with something else....” PHY6

Some healthcare providers stated that they cannot always trust the translation

conducted by an individual that is not their duty to translate.

“Even with the assistance of, with the translation of our technician, the communication is difficult because you don't know what they are saying to each other.” PHAR9

“Nursing aide, nursing technician, they are, even you cannot trust the translation.” PHY4

4.2.2.4. Theme 4: Facility attributes

The characteristics of the hospital or healthcare facility itself can affect the patient's ability to navigate the hospital, their comfort level during the care process, and the efficiency of the care process. Several aspects are involved in the facility attributes; these include the physical condition, user-friendliness, and functionality.

- Physical condition

Small setting: Some participants noted that having a small hospital setting can facilitate the patient's ability to navigate the hospital easily.

“I think it's easy and I don't find it difficult, because actually, the outpatient setting is not a huge setting or a huge premise, it's only one floor and all are connected as clinics and the management desk and the pharmacy are in the same place. I don't think, I find it hard.” PHAR4

“The hospital is small, we don't have multiple outpatients, only one outpatient,

so it's easy for them [patients] to find it. When we send the patient, they easily find the place.” PHAR10

Small waiting area: Hospital visits usually involve a fair amount of waiting and the condition of the hospital waiting areas can influence the care process. Some healthcare providers, specifically pharmacists, noted that the small pharmacy waiting area causes challenges during the patient education and counselling.

“Sometimes, there is crowded waiting area, the waiting area is very small, distractions, especially if... you are counselling someone or the patient on the window and another staff or something come to call a number, to explain something else to another patient in the same window, this sometimes happens. So, the small area, the big number of patients, it's a lot of patients we have, with the most, I believe the most difficulty is in communication with the patient.” PHAR9

“If we're talking about the physical barriers... probably bigger location, the waiting area could be a bit bigger so again not lots of patients will be crowded in a very small area where the noise can be lower.” PHAR12

Pharmacy layout: The pharmacy design can either facilitate or hinder the communication between the pharmacist and the patient. Some healthcare providers noted that newer pharmacy designs with no windows and panels separating the pharmacist from the patients enhance the communication.

“Physical barrier in the pharmacy, there are no windows, no glass windows...

We don't have any physical barrier, I don't think...” PT1

Pharmacy counselling area: The lack of counselling areas in the pharmacy was identified by the interviewees as a barrier to effective communication with the patient because of the surrounding distractions in the open pharmacy.

“The other distractions we mentioned before, I think if we have, especially for the discharge patients, because after 02:00 we do the counselling for the discharge patients in the outpatient, if we have a counselling room, it will be very helpful for us, because we have a lot of distractions. Because the discharge counselling is done in window 4, window 4 is in the middle of the pharmacy in the corner, so we have the Qataris here, we have the non-GCC here, and this in the middle, so the counselling is very hard for us and a lot of medications.” PHAR9

One healthcare provider shared their experience from another country regarding the benefit of having a counselling area in the pharmacy.

“The US, there, usually we had like a booth, each pharmacist stays in a booth... like separate area, physically separated, and one patient comes to see the clinical pharmacist and the place where the other patients use to wait is different, is separated from this booth, and if the patient needs more consultation or more discussion or they feel that this patient needs more time, there's a separate room they can stay with the patient for longer time if he has

any issues or he needs more...” PHAR14

Satellite pharmacy: Some patients noted that launching several decentralized pharmacies within the hospital can minimize the strain on the main pharmacy and improve the patient’s encounter with the pharmacist.

“They should have more windows, maybe, like in Hamad General Hospital, outpatient, there are different pharmacies in different floors, it is much faster, but here we wait for a long time.” P5

- User-friendliness

Difficulty in differentiating care facilities: Healthcare providers observed that it is challenging for new patients to figure out the hospital location and differentiate it from other healthcare facilities within the medical corporation.

“When you say Heart Hospital, they always ask “Hamad?” I say, yes, Hamad, then at the end they say, “We are in Hamad, where are you?”, so they are in Hamad [Hamad General Hospital]. So, for them everything is Hamad, and if I say Heart Hospital is separate, then they say “That is Rumailah”... So, they only know that this is Rumailah, so they don't know actually precisely... If it is a first timer, then they really don't know where is the Heart Hospital, nobody will actually know where is Heart Hospital, they only know it's Hamad.” PHY3

Navigation: Healthcare providers and patients alike generally indicated that patients face difficulties while navigating inside healthcare facilities.

“Sometimes, the patient will come to you in the corridor, they will tell you like “this is the paper, you find out what I am supposed to do”. But sometimes I feel like they don't know where they are headed to, they just have a paper, they should go somewhere inside the Heart Hospital and that's it.” PHAR2

“The first time was hard to find the clinic, you should go to multiple places in different sides of the hospital before you go to the clinic. You go to registration, then cashier, then the tests, ECG, in different places, after all that, you go to the waiting area. At the start, it was not easy to find by myself, but I ask the nurses and security.” P4

Some healthcare providers and patients highlighted that the navigation difficulty is a result of the confusing layout of the hospital.

“The passages are confusing, number one, and even to give them directions, sometimes “Okay, go straight, don't take the first corridor. Second, not straight, straight, but there is a corridor you go in...”. Sometimes it is even so many corridors and different directions, even hard for us to give them the directions. One thing about the patients finding the room where they have the appointment... when they give them their number and they have to wait, the numbering is not like this, as a sequence... so the patient goes 16, 17, 18, 19, 20, and then suddenly he has to go back from the other side. Sometimes they look on our door, they cannot find the clinic next to us or before us, so the number or the clinic number is not clear sometimes, it does not go in a clear

sequence.” PHAR2

“It's very hard I believe, I face a lot of people asking for directions, because if you see at the layout, it's a circle, within a smaller circle. You feel you're running in the same place and you end up at the same point, what happened!”

DIET2

“At first, it was hard, it was confusing, and several times I go to a place, but I do not know how to go there the second time or the third time, it's a little bit confusing.” P6

- Functionality

Interruption and distraction: Surrounding distractions and interruption can lower the quality of communication between the patient and the healthcare providers. The participants reported environmental distractions within the hospital such as excessive noise and interruptions by others as a barrier to communication.

“Sometimes there is crowded waiting area, distractions, especially if you are counselling someone or the patient on the window and another staff or something come to call a number, to explain something else to another patient in the same window, this sometimes happen.” PHAR9

“The pharmacy is noisy, because there are a lot of patients all the times. So sometimes I need the pharmacist to raise their voice to be able to hear them.”

P6

Some healthcare providers noted that the level of interruption and distraction is different from one setting or department to another.

“Depends on the setting, where you are talking to the patient? So for example in the room, if it's an inpatient setting and you talk to the patient in the room, even the physical barriers can somehow be controlled, like if the TV is on, you can just simply ask him to lower the voice, but if we're talking about the outpatient pharmacy, for example, though there is a specific separate window, but sometimes it's very noisy around, maybe someone is shouting, someone is fighting, it's very noisy around the pharmacist, inside the pharmacy, due to the labels printing which creates a lot of noise in the background, people working, drawers being opened and closed. So, it depends actually on where are you trying to talk to the patient.” PHAR12.

“There are... areas that there will be noise, but in our clinics, when we get to see a patient, if you ask about outpatient, we are okay. Inpatient, of course, you expect that so much of action happens, not just doctors and patients, nurses, other nursing staff and assistance and things, there will be a lot of discussion going on, it cannot be like as quiet as we want it.” PHY3

“It depends on the area, for example, in the wards... ward A, B, we don't have a problem in the patients' room or the outpatient clinics, but the emergency, for example, it can be noisy sometimes and if you have... someone is coming to talk to the patient next to you and I'm giving education for my patient, you

can overhear everything... .” DIET1

Lack of privacy: The interviewed patients and healthcare providers stated that lack of privacy during the patient – provider interaction as a barrier to effective communication.

“Because we are in a class, sometimes when we're giving information that might be sensitive or particular to that person, so here we have a lot of privacy but on the exercise room, you don't have so much privacy, it's an open space. So sometimes maybe in that situation, not being isolated and being able to have the conversation one-to-one could be a barrier.” PHYSIO1

“Yeah, I feel this sometimes, that everyone can hear me talk to the pharmacist and the pharmacist talking to me, right, no privacy, sometimes I don't want others to hear about me, but we are used to this.” P11

4.2.2.5. *Theme 5: Care process*

This theme includes codes and categories related to the hospital processes and operations. The efficiency of the care process within the hospital can influence the quality of patient encounter with the healthcare provider and ultimately the level of the patient's health literacy.

- Workflow

Work scheduling: Healthcare providers, specifically clinical pharmacists, noted that sometimes they miss the opportunity to interact with, educate, and counsel discharged patients because of the nature of their shifts.

“Again, it depends on the setting. So if we are talking about inpatient setting, information should be concise and again depends on the situation but generally speaking... the inpatient time restraints are less than the outpatient setting where there is a queue of patients that you have to keep on moving but in the inpatient setting kind of, you can adjust your time which is not always the case. It's not 100%, sometimes patients might miss the education altogether, sometimes they miss the education from the clinical pharmacist, they get the education from the pharmacist who's dispensing... So, the time is different based on the setting.” PHAR12

Waiting time: The long waiting time that patients face when they go to the hospital may lead the patients to lose their patience and rush the interaction with the healthcare providers.

“Sometimes we check with them, okay this you take once daily...but they themselves because they waited too long, they are not ready to listen to any words you say, they're like "I know, I know, please finish". PHAR10

“Yes, it can take more than 2 hours, it wastes a lot of time, if you take an excuse to leave your work to go to the appointment, you want to go back as fast as possible. But if you need to wait for the registration, for the cashier, for the clinic and then for the pharmacy, it will take very long time before you can go back to work.” P4

Some healthcare providers and patients indicated that the long waiting time leads

some patients to become exhausted or even aggressive, which can hinder the communication, education, and counselling.

“And in... cases... if patients have to wait for one hour just to get enter into the clinic, the patient is then angry...” N2

“No, it’s fine, but the main problem with the pharmacy is the waiting time. It’s very long, people get tired while they are sitting and waiting for their medicine and the number of patients is very long.” P5

Appointments: The late appointment and suboptimal follow-up are barriers identified from both patients’ and healthcare providers’ perspectives. Participants indicated that there is a long lag time of over six months between follow-up appointments s During this time, the patient could forget health instructions and information and would not be able to contact their healthcare provider if they have any questions or need clarifications.

“The follow up period is 7 to 8 months, so patients are sometimes waiting for the appointment to ask questions because our follow-up is now getting more than 7 months. So, if a patient will forget something, he has to wait for 7 months to come back again to see the physician and talk to him.” PHY5

“Yeah, it’s enough, but the problem is that the appointments are very far, sometimes the doctor writes an appointment after 2 months, they say, the registration says there is no appointment before 4 or 6 months. It is long, especially if the condition is not stable, it’s very crowded here, the

appointments are very far sometimes.” P8

In addition, some patients do not stay in the country following their illness, thus, the providers do not have a way to follow-up with the patient.

“The fact that our patients, sometimes, don't really live in the country they don't stay for long after discharge, so you don't really have the luxury of again following up or reinforcing the information, of directly accessing patients, or calling them, for example.” PHAR12

- Others

Valuing quantity of work over quality: The interviewees indicated that the healthcare system recognizes only how much work is being done but does not acknowledge the quality of the work. This might lead some healthcare providers to perform the bare minimum to keep the flow going.

“But again, in order to raise this kind of behaviour among people [providers] who have been working in a kind of very hard system, we need to adapt a system that appreciates the human side of healthcare rather than how many patients have you seen? how many interventions have you documented?... and that's it, and they just submit your timesheet on time to get your salary. So, I'm very honest, ... I obviously need to feel satisfied, I need to feel that I can reach for a patient, that what I'm doing and the amount of effort I am spending here, 8 hours per day from my life, has an actual outcome, I don't want to see my patient coming back with stent thrombosis because probably he didn't

understand that he should take Aspirin and Plavix for a certain period of time...” PHAR12

Role of primary healthcare: Some healthcare providers noted that the primary healthcare system should have an active and leading role in improving patient health literacy.

“The other point, in the contribution to the patient literacy is the primary health system which is completely collapsing here. I mean, those are the places where patients should get their medications there, simply diabetes, hypertension and those chronic diseases.” PHY4

“I mean for us, yes, we have a very specific target, right, to me, my perception is a much bigger issue. It is something that needs to be dealt with at governmental policies and that needs to transfer down to population level. So, it's a general public health issue that needs to be more reinforced, can we do things about that? We do them on regular basis, we educate about exercise but, I think, we are talking about secondary prevention where this education will benefit, will serve in primary prevention so when the patient comes here, he is also more aware on why is exercise actually important, for example.”

PHYSIO1

Use of technology: It was pointed by the participants that information technology can be utilized by the hospital to improve the processes and flow inside the hospital.

“Role of technology in health literacy... So patient will choose his language from the application, say, for example, if there is HMC App, the patient himself will see his lab results in the App itself, if he will click on the disease that he has, he will get all the necessary information that he wants to understand, the physician advice, navigation through the hospital even, because I saw it somewhere in another hospital.” PHY4

“Applications, yes, he has today appointment in clinic number 4. So, he will click on the navigation system of this App, it will direct him take right, take left inside the hospital. What matters is the education, the literacy, so I have diabetes, click on diabetes, he will have all the information.” PHY4

4.2.2.6. Theme 6: Resources

This theme includes codes and categories related to resources that can affect patient-provider interactions, educational materials, and strategies and tools to improve health literacy.

- Administrative factors

Human resources: Several healthcare providers and patients pointed out that some departments in the hospital are understaffed which forces healthcare providers to interact with many patients in limited time.

“We see 500 patients per day in the outpatient and all staff is what 10, 15 staff and 4 of them are not dealing with the patients, only processing, maybe 6 or

something. So, the ones dealing with the patients, I think 7, 8, for 500 patients.”

PHAR9

“The main problem with the pharmacy here is the waiting, you wait a long time just to take your medicine... Waiting for one or one and half hours in the pharmacy. They should have more pharmacists, more windows to finish faster.” P10

Time constraint: Both patients and healthcare providers alike mentioned that time constrains limit the communication between the patient and healthcare provider and the amount of information and instructions provided.

“Also you need to spend more time with them actually, this is also one issue with us in the pharmacy, because sometimes you are instructing them some instruction, you should give them the time to understand, then they retrieve it back and take it back. But because how busy you are, sometimes you couldn't wait for a patient for 40 minutes to just give him understanding. So, we are depending on delivering the message and whatever the percentage he gets, he will get, and he will leave.” PHAR4

“When you get like back-to-back consultations and you try to squeeze yourself to give the patient all the information he needs to have or like to do the proper assessment and for us because we're giving them like a tailored meal plan so this kind of takes time. So yeah in the outpatient setting probably the time plays a major issue especially if you cannot control your clinic or like if you have

full, full time clinic.” DIET1

Home visits: Some healthcare providers indicated that implementing home visits to special patients, like elderly patients and patients with disabilities, can improve the quality of patient-provider interaction and yield optimal outcomes from the interaction.

“Patient is geriatric and bedridden or demented, they have stretcher that they bring. They will bring him but EMS have limited time so you have to finish fast and usually they are demented, there is no history and rarely they will get family with them. The bed-bound patient, bedridden, demented patient, their care is not optimum, it's better to do home visit rather than bring him here with the EMS stretcher, there is no benefit, will just look at him "male, no bed sore..." and send him back.” PHY6

- Educational resources

Written material: The availability of useful written materials to patients can facilitate the communication between the patient and healthcare providers and can improve patients’ understanding and retention of instructions and recommendations. Some healthcare providers noted that the currently available written materials and printed information are not optimal.

“Not everything is eye-friendly, sometimes it's lots of, like, tiny written sentences that someone has to go through, so I don't think it's really easy. Like someone who's really interested would be reading this, but if someone is not really interested, can be easily intimidated by some of the terms, will not find

it easy to follow, and again the fact that not all the conditions that the patient gets are, not all of them have leaflets that they can read and take home.”

PHAR12

“For us like as a dietician, I think leaflets, education materials, printed meal plans, these are the only tools I can give to the patients... .. We tend to give our feedbacks, we take feedbacks from the patients if they can understand it, if it's easy to understand, but yes there is always this problem, maybe that the booklets are overcrowded with the information, maybe the font is too small, it needs more pictures, maybe the pictures are not related to, so these has to do with the education materials itself... I think it helps but in order for it to be effective, you need to make it efficient and simple and clear.” DIET1

“Yeah, this can be good, to have more information or resources for trusted information, because if you read in the Internet, sometimes every website says something different, you can't know if this information is true or wrong. So, to get resources from the doctor is better, yeah... all the information, about the diagnosis, yeah, it can be good to have this information, you can read it anytime.” P7

In contrast, some patients stated that they prefer optimal verbal communication to written communication with the healthcare provider.

“I don't like reading, I prefer the doctor saying the information... It is not important, the verbal information is enough for me.” P6

On the other hand, some patients stated that written material is more useful when they first get the diagnosis or before a change in therapy as well as for additional information or optional to information provided verbally by the healthcare professional.

“I think written information is necessary at the beginning, when you first get the diagnosis, or before a surgery, or before a new treatment, but now I am continuing the same treatment. I already understand the condition, there are no changes now, the same treatment. So, yes, I think it is important for new patients or patients undergoing surgery.” P5

“No, I do not remember any printed information, no... It could provide more information, the doctor provides the main important information and additional details can be provided in printed material. More details about the condition, the causes, the things that could worsen or improve the condition, and the treatment, what the treatment does in the body.” P4

Online educational resources: Some patients indicated that online or electronic resources of information provided by the healthcare provider could be a convenient source of information.

“Even if they guided me to a specific reliable website or resource, it would be very good, excellent. The person sometimes search for the truth.” P3

In addition, some patients noted that online resources are better than printed material because you can access it many times.

“Yes, it was helpful, but it was long time ago, I don’t remember the information, you only read it one time and that’s it, maybe it’s better to have a website. If they develop a website where we can read all the information about our condition, or if they give us links to websites, reliable websites, to read information about the condition, it’s better than papers, papers you just read one time.” P10

Health literacy assessment tools: Health literacy assessment tools and questionnaires can be helpful for the healthcare provider to estimate the level of the patient’s health literacy and adjust their education and counselling accordingly.

“So, if there's any questionnaire, for example... or any interview can be done, earlier in the admission, that evaluates the health literacy of the patients so that gives the team an idea how to approach the patient. Probably, something you can suggest it in order to improve the process, so make everybody practice their things in easily way.” PHAR8

“Another thing that we started recently in the Cardiac Rehab Department, we're giving the patient like a set of questions or a questionnaire just to assess his knowledge about, you know, different subjects like diet or like physiotherapy or occupation therapy, and then we start our education, after we finish the education we ask them the same questions and like we mark the score, so if he maybe understands very well and gets like a high score, then like we don't do further intervention. DIET1

- Tools and strategies for improving health literacy

Teach back method: The teach-back method can be used by healthcare providers to confirm whether a patient understands what is being explained to him/her. Some patients and healthcare providers noted the use of teach-back method during the patient-provider interaction.

“Yes, “tell me back, what I said?” First, I find out if he is taking already the medication, I want to check “how you take this medicine, how you take this medicine” then, I explain if something is wrong... I tell them verbally, after that to repeat.” PHAR9

“Yeah, doctor is asking whether I have any question or not, or how I am feeling, if they are asking, then I explain, I try to explain to them. I explain back.” P1

Visual aid and pictograms: The use of visual aid, such as pictures, illustrations, graphs, or videos, can supplement verbal and written information to make the information more understandable by patients. Many healthcare providers noted the use of visual aids to improve communication and understanding.

“For me, to overcome communication problems, I usually use [visual aids], because in food and nutrition we have many products and you need to be aware of whatever is available to different socioeconomic status in Doha. So, especially things about oils and fats and ghee [clarified butter], I usually use like a pictorial that was developed by one of the dieticians. So that helps me

a lot to overcome, they are really happy to see pictures, patients are like "oh, yeah, yeah, I know this", so I start telling them "this is good", "this is not good". So pictinary, it helps me a lot, so I always carry stuff with me, you know, to show them." DIET2

"We have a Valve Clinic now, it's like two months. I proposed initially to have education through the TV, you know, we have TV in waiting areas. They did it in MitraClip clinic, short videos, education about mitral regurgitation and what is the procedure, each patient should go through it inside the clinics."

PHY8

Some healthcare providers indicated that the use of visual aids can assist in gathering data in relation to patient history and evaluating the patient's compliance.

"For us... when it comes to... when we interview the patient when they come in the first place, just to collect their medication history, sometimes quite challenging, so we have to bring them the booklet, show them the picture, if they've been taking this or no. So that's, we usually use these visual things for us, to help us understand if they are compliant with their medication or not, so we have been using these tools." PHAR8

Medication adherence enhancement tools: Medication adherence tools can be used by pharmacists and other healthcare providers to facilitate patients' understanding and comprehension regarding their medication schedules. These adherence enhancement tools include medication-scheduling tools, pillboxes, and pill-cards.

“For one of our patients, for example, who couldn't understand the warfarin regimen, we used the pillbox that we filled all the tablets because basically there are halves and different strengths... Schedule paper, we have the paper that has pictures of the tablets and days of the week, so we keep writing for them in case they forget or they don't understand, when we show them, they can read the numbers and see which tablet and the days of the week.” PHAR2

4.2.3. Quality assurance

The SRQR reporting guidelines were followed during the reporting of the qualitative phase of this study. A total of 18 items out of the 21-item SRQR checklist were described and addressed in this thesis. See **Appendix K** for SRQR checklist.

The researchers who conducted the focus groups and interviews had previous experience in conducting quantitative and qualitative research. A previous relationship was established between some of the participants (healthcare providers) and some of the research team members through previous professional interactions. The researchers have an interest in exploring strategies and interventions that could improve health literacy which can improve health outcomes among patients with CVDs. To ensure transparency, quality, and credibility, a peer-review process of the thematic analysis outcome (i.e. member checking) was conducted several times by the research team. Other measures of qualitative data quality, credibility, and trustworthiness were observed and we used SRQR to report what was achieved and what was not.

CHAPTER 5: DISCUSSION

5.1. Phase I: Evaluation of Health Literacy Skills among Patients with ACS and HF

5.1.1. *Discussions*

This phase of the study reported the levels of health literacy using S-TOFHLA and 3-item BHLS among patients with ACS and/or HF, as well as, the demographic and clinical characteristics of patients according to their health literacy levels. Up to our knowledge, this is the first study in the field of health literacy to be conducted in Qatar and the first to investigate health literacy among patients with CVDs in the Arab region. The S-TOFHLA was used to assess the functional health literacy of patients, whereas, 3-item BHLS helped assess the overall confidence of patients in health-related tasks. These two different health literacy assessment instruments were utilized for triangulation purposes.

The data analyzed was gathered from 300 participants. Their median (IQR) age was 55 (11) years and the majority were male (88%) and non-Qatari (94%). Clinically, 89% of the sample had ACS, while 21% had HF. The most commonly reported chronic comorbidities included hypertension (66%), diabetes (48%), and dyslipidemia (41%).

The study established that 36% of patients with ACS and/or HF had inadequate or marginal health literacy based on S-TOFHLA, while more than 50% had inadequate or marginal health literacy based on 3-item BHLS. These findings demonstrate an alarming low health literacy level among the study participants. These results are in line with a number of previous studies conducted to assess the prevalence of low health literacy. For instance, in the first extensive national adult literacy assessment conducted in United States with components meant to specifically measure health literacy among the adult

American population, it was found that 36% of adults had either below basic or basic health literacy [25]. In addition, only 12% of the adult population was proficient in health literacy [25]. However, the levels of health literacy specifically among patients with ACS and/or HF reported in the literature varied according to the region and the setting where the study was conducted. Based on one study conducted in the United States, the prevalence of low health literacy among patients with ACS was 34% [28]. Yet another study conducted in a similar setting indicated a prevalence rate of 44% among patients with ACS [29]. Moreover, a systematic review reported that the prevalence of low health literacy among HF patients varied greatly ranging from 17.5% to as high as 97%, with an average of 39% of study participants found to have low health literacy [27]. Therefore, our study results regarding the prevalence of low health literacy among patients with ACS or HF reaffirm the results reported by other studies conducted elsewhere.

These results indicate the need for strategies, tools, and interventions to assist healthcare professionals in improving health literacy among patients with ACS and HF, which can potentially improve health outcomes in this population [23]. With limited health literacy, patients as well as their family members cannot acquire the necessary knowledge and skills for participation in the healthcare process [121]. For effective self-management, ACS or HF patients' ability to read, assess and comprehend medical information has to be improved. Patients should be able to make informed decisions and recognize how to access appropriate healthcare when needed [16, 21]. Patient health literacy is an important element of effective health information sharing as well as self-management of chronic diseases [22]. Lack of skills in these areas caused by limited health literacy can undoubtedly restrict many ACS and HF patients in Qatar from being involved in effective self-care management

of their conditions. This is because patients with limited health literacy tend to let their healthcare providers make important decisions regarding their health without their input [22].

There were some differences between patients who have adequate health literacy and those who have inadequate or marginal health literacy in terms of some of their demographic characteristics including educational level, languages spoken, and socioeconomic status. These characteristics are widely recognized in the literature as factors associated with health literacy. This study found that 78% of the patients with undergraduate or postgraduate university education had adequate health literacy, while less than 10% had inadequate or marginal health literacy. The median (IQR) S-TOFHLA score for patients with high school education or less ranged from 16 (6) to 19 (9) as compared to 34 (4) to 35 (3) for patients with undergraduate or postgraduate university education. According to some scholars, the education background, as well as the patient's own knowledge and past experiences, are important factors that influence patients' capacity to look for and comprehend health information, specifically in identifying trusted sources of health information [81, 87]. However, other studies have also shown that attainment of high levels of education does not guarantee having high levels of health literacy [73, 75, 76, 78-81].

In concurrence with previous studies, this study established that patients who are not proficient in the main language of the country where they receive healthcare, in this case Arabic, tend to have lower levels of health literacy since the language barrier is a barrier for effective communication [73-75, 77, 78, 80, 82-86]. The median (IQR) S-TOFHLA scores differed significantly according to whether or not the patient speaks

Arabic, English, Hindi, Urdu, Malayalam, or other languages (p-values ranged from ≤ 0.001 to 0.035). In addition, 63% of patients who could read and write in Arabic (the official language in Qatar) had adequate health literacy, whereas 37% had inadequate or marginal health literacy. Conversely, of the sampled patients who could speak Hindi, 29% had adequate health literacy compared to 62% who had inadequate or marginal health literacy. Communication between patients and healthcare providers is an integral component of health literacy [77]. Patients would most likely face difficulty in understanding and communicating with healthcare providers due to language barriers. Previous studies have identified patients' spoken language as one of the main factors affecting communication and health literacy [73].

Patients' income level, which could be related to their occupation, was also found to be a contributing factor to health literacy [77-82]. While all of the participants who worked as drivers had inadequate or marginal health literacy, only about 7% of the participants who had managerial positions had inadequate or marginal health literacy. At the social level, lack of family support has been identified as a barrier for health literacy [73, 77-79, 81, 82, 85]. The study revealed some potential differences in health literacy levels based on marital status. The median (IQR) S-TOFHLA score was 19 (16) among single patients as compared to 31 (15) among married patients. A systematic review of the perspectives of healthcare providers and patients on health literacy found that the lack of family support is among the perceived barriers [78]. Jordan et al, also concluded that having a good support system, including family support, is associated with higher levels of health literacy [81].

One of Qatar's current national strategy targets is patient empowerment through knowledge and health literacy as well as active involvement of community in raising health awareness, promotion of healthy behaviors, and creation of a culture of public participation [66]. Therefore, it is important to identify the prevalence of limited health literacy and recognize the characteristics of patients with limited health literacy. This would be helpful to identify the segment of patients who may need targeted interventions the most.

5.1.2. Strengths and limitations

This study has several strengths and limitations that are noteworthy to mention; thus, the study findings should be carefully interpreted in light of these. To our knowledge, the study is the first to investigate the availability of generic and disease-specific tools used for the assessment of health literacy in the context of CVDs in general, including ACS and HF. It was clear that disease-specific instruments for the assessment of health literacy in CVD are very limited and in fact, there is no specific pharmacy or medication health literacy assessment tools. Furthermore, it is the first study to determine the prevalence of health literacy among patients with CVD (ACS and HF) in Qatar and the Middle East region, suggesting that inadequate health literacy is highly prevalent (36% – 54%). The findings highlight the need to develop interventions aimed at increasing the ability to improve health communication and health outcomes among patients with CVD and low health literacy. Therefore, it has served as a baseline platform for healthcare practitioners, policymakers, and regulatory body to consider strategies for improving health literacy in patients with CVD in general and ACS and HF in particular. The study has utilized two commonly used validated health literacy assessment tools (S-TOFHLA and the 3-item

BHLS) for the purpose of triangulation. This phase of the study utilized adequate sample size to maintain an adequate power for the study. Moreover, the psychometric measures of the Arabic versions of the instruments used in the study were tested in other Arabic-speaking populations [63, 64].

Conversely, this phase of the study has several limitations, the majority of which are inherent to its cross-sectional survey designs. First, although it was planned to include patients who speak common languages in Qatar including Arabic, English, Hindi, Urdu, Tamil, Tagalog, and Malayalam, the study included only patients who could speak Arabic or English. This is because the validity of the instruments in languages beside English and Arabic could not be established and due to the limitations in researchers' ability, who can speak Arabic and English only, to obtain consent from these patients. Therefore, participants whose native language was neither Arabic nor English or were unable to speak these languages were under-represented, subjecting the study to selection bias. Therefore, the findings may not be generalized to all patients with CVD in Qatar or the Arab world. Second, the findings were prone to social desirability bias as the measurement of the level of health literacy was through interviewer-administered technique. Third, this research used a convenience sample of individuals who were willing to complete the survey thus the possibility of having selection bias in this study. The participants were conveniently selected due to the absence of a reliable sampling frame. Finally, the health literacy assessment tools used (S-TOFHLA and BHLS), although widely used, are not disease-specific and do not take into consideration pharmacy/medication health literacy issues specifically.

5.1.3. Recommendations for future studies

The current study has identified a high prevalence of inadequate health literacy in a cohort of CVD patients in Qatar and demonstrated a lack of available CVD-specific health literacy assessment instruments. Therefore, we suggest future studies in the following areas where there are still clear gaps:

- To replicate the study using a more comprehensive sample who can speak all commonly available languages in Qatar, including, but not restricted to commonly spoken Asian languages (Malayalam, Hindi, Urdu, Tamil etc.). And to pursue with this study, we will need a big multidisciplinary team of faculty, hospital personnel and research assistants who are fluent in these languages.
- To assess the prevalence of health literacy and/or medication literacy among other CVD patients (other than ACS and HF) in Qatar, GCC countries, and the Middle East and North Africa (MENA) region.
- To develop and validate CVD-specific health literacy assessment instruments and potentially with a focus on pharmacy/medication health literacy issues.
- To assess the knowledge, skills, and competencies of healthcare professionals on health literacy assessment in the CVD context.
- To design studies that assess tools and interventions for the improvement of health communication and health outcomes among patients with CVD and low health literacy; these studies should investigate and evaluate the impact

of improving literacy on health outcomes of patients with CVDs.

- To assess pharmacy and other healthcare professional education curricula in terms of content related to health literacy.

5.1.4. Conclusion

Health literacy is a critical component of healthcare. This study contributed to the existing body of knowledge by establishing the level of health literacy and determining the prevalence of limited health literacy among patients with ACS and/or HF as well as comparing the characteristics of the patients with limited health literacy versus those with adequate health literacy.

Three hundred patients participated in the health literacy assessment. All participants had a diagnosis of either ACS, HF, or both and received care at the Heart Hospital. The study revealed that 36% of patients with ACS and/or HF have inadequate or marginal health literacy according to S-TOFHLA while over half (54%) have inadequate or marginal health literacy according to 3-item BHLS. Moreover, analysis of demographic characteristics showed some differences between patients with adequate health literacy and those with inadequate or marginal health literacy patients. These characteristics included: education level, languages spoken, and socioeconomic status.

Finally, health literacy scores observed among patients in this study were low. This indicates that many patients would struggle to understand various health related information and instructions needed to manage their health conditions. Healthcare providers should take extra care when educating patients taking into consideration their limited health literacy. In addition, appropriate strategies and interventions should be

developed and implemented to address health literacy issues. These could include utilizing patient-centered communication, improving educational materials, training healthcare providers, and employing a multilingual staff.

5.2. Phase II: Identification of the Facilitators of and Barriers to Health Literacy among Patients with ACS and HF in Qatar

5.2.1. *Discussions*

The overall aim of this phase of the study was to determine the factors related to limited health literacy among patients with ACS and HF in Qatar and to identify potential tools and strategies for the improvement of health literacy skills among this population. To our knowledge, it is the first study conducted in the Middle East region to investigate health literacy barriers and facilitators. Since the themes generated from the perspectives of patients and healthcare providers were similar in context, the results are presented together to give an overall understanding of the barriers and facilitators to health literacy.

Studies investigating health literacy generally identified many patient-related aspects and sociodemographic characteristics as factors for low health literacy [73-86]. Similarly, the present study identified certain sociodemographic characteristics that play a role in health literacy from both patients' and healthcare providers' perspectives. This study has been found that gender differences between the patient and the healthcare provider could be a barrier to health literacy, as females may often find it difficult to discuss sensitive issues with male healthcare providers. On the contrary, Clouston et al. found that females tend to have higher levels of health literacy that could be attributed to increased practice of reading and interpreting medication labels among females [122]. Qatar is a

Muslim country with a relatively conservative society. Female patients might feel embarrassed to discuss their health-related information with male healthcare providers. The difference in cultural and religious norms between Qatar and USA explains the difference in study results between this study and that of Clouston et al.

This study found that even though gender differences could affect the communication between patients and providers, old age could be a more critical factor in hindering health literacy. This was partly explained, by healthcare providers, by the inability of elderly patients to express their educational needs in terms of understanding and comprehending provided information. Besides, elderly patients may experience impairment in cognitive function, which could also affect the health literacy. Liu et al. reported that older adults even with mild cognitive impairment may have inadequate or marginal levels of health literacy [123]. Clouston et al. also noted that the cognitive decline, especially in males, during the later stages of life, was directly related to poorer health literacy [122].

The present study, as reported by the interviewees, found that the psychological status of the patient could also be related to his or her decreased levels of health literacy. McKenna et al. showed that psychological issues including stress, anxiety, and shock of coping with the diagnosis could negatively affect the ability of patients to understand health-related information [124].

In addition to old age and psycho-cognitive issues, this study found that physical disability caused by visual or hearing disability and mobility impairment can hinder health literacy, partly due to decrease in the time that patients may spend with healthcare professionals. However, this finding could be further explored as the literature shows

mixed findings. For instance, Nguyen and Gilbert reported that people with disabilities may not experience health literacy difficulties as compared to the people without disabilities [125], whereas Hahn et al. reported that higher health literacy is associated with better mobility, and disabilities, such as stroke, spinal cord injury, and traumatic brain injury, could decrease health literacy [126].

The study findings showed that the level of education and functional literacy of the patients can influence the level of understanding and the extent of details provided by the healthcare professionals, thereby, influencing the level of health literacy. McKenna et al. asserted that literacy skills are useful in making sense of information and knowledge within the patients' own social and healthcare context[124]. In this regard, a study found that decreased levels of health literacy are associated with poorer general literacy and knowledge [127]. Therefore, the literacy and educational attainment of patients could be considered as essential factors in improving the health literacy of patients. However, it should be noted that the evidence from the literature indicates that low health literacy is not only limited to patients with low level of education [73, 75, 76, 78-81].

Further aspects related to patient characteristics were generated from the present study. For instance, socioeconomic status has been found to be a factor related to patient health literacy. This is also supported by the findings of the study conducted by Stormacq et al., according to whom disadvantaged socioeconomic conditions contribute to lower levels of health literacy [128]. One of the reasons behind the decrease in health literacy is that poor socioeconomic status could negatively affect the confidence of the patients in getting information. Moreover, according to Lambert et al., low income can interfere with a patient's ability to absorb or comprehend health information and convert knowledge into

action [77]. In contrast, it was reported that even if the patient has the ability to seek, understand, and utilize health information, i.e. the patient is health literate, socioeconomic circumstances can hinder the process of acquisition of health information [81].

Furthermore, the different attributes of the patients, such as those related to self-confidence, misconceptions, patient reluctance, and the ability to identify and use reliable information sources, have been reported among the most critical factors affecting the patient's health literacy. The importance of self-confidence and control has also been reported by McKenna et al., where it was noted that an increase in patients' self-confidence could help in increasing the engagement of patients with health-related issues [124].

Additional patient-related factors, namely cultural norms and caregiver emerged from this study as critical attributes to health literacy. In this study, it has been found that culture is involved in different ways in affecting the level of health literacy. For example, it is often difficult to change the autonomy, confidence, and comfort of patients in relation to healthcare. Levin-Zamir et al. also provided a detailed explanation regarding the importance of cultural norms and interpersonal relationships in a family in the development of health literacy [129]. They noted that in many cultures such as the Chinese culture a hierarchy exists in which healthcare providers are considered to have the highest rank and asking questions to healthcare providers could be an impolite practice [129]. The same aspect has been found in several Chinese societies, including Taiwan, Hong Kong, and Chinese communities in United States [129]. Considering the importance of cultural norms, it is imperative to start interaction with patients while utilizing culturally-friendly or culturally-appropriate approaches in improving health literacy. Moreover, the study found that caregivers, including family members and friends, play an important role in patients'

health literacy. Devraj and Gupchup also provided evidence that caregivers may contribute to health literacy, especially when the caregiver rather than the patient is provided health information and education [86].

As stated by Jordan et al., health literacy is not limited to the capacities and abilities of a patient, but is also dependent on the relationship between patient's capacities, healthcare providers, and the healthcare system [81]. The healthcare professionals and the healthcare system play a major role in supporting patients to build knowledge and skills about their health [77]. Therefore, apart from patients' attitude and attributes, some of the healthcare providers' skills and attitudes also play an important role in the health literacy of patients. These attributes include skills related to education or counseling and patient empowerment by the healthcare provider. This study also shows that the education and counseling process could be considered among the most important contributors to health literacy. Anderson et al., conducted a patient survey to assess the effectiveness of group counseling in improving understanding among patients with limited health literacy [130]. The investigators found that teamwork among patients, staff, healthcare providers, and community members, and provider-coordinated behavioral counseling are critical in improving health literacy and the quality of life of patients [130]. The importance of teamwork, including the involvement of the multidisciplinary team, has also been found in this study to contribute to improvement of health literacy. Moreover, healthcare providers who participated in this study indicated that their role in patient empowerment is critical to improve patient health literacy. In relation to this, McKenna et al. found that patients' ability to be proactive in interactions with healthcare providers is important regarding issues such as requesting referrals or second opinions and questioning medication use

[127].

Along with teamwork, the attitudes and behavior of healthcare providers, such as having a pleasant and friendly attitude, were found in this study to be important contributors to health literacy. Bahramian et al. also asserted that positive attitude of healthcare providers could improve the health literacy skills of patients [131]. In this regard, healthcare providers should take into consideration patients' problems, and should have pleasant, friendly and empathic attitudes when interacting with patients. This would develop patients' rapport and improve their level of understanding [132]. Patients who have high health literacy demands, such as patients with an initial diagnosis of CVD, will have lower levels of health literacy knowledge and skills and if not properly supported through their encounters with healthcare professionals they will have limited opportunities to build their health literacy skills leading to undesirable health outcomes [77].

Communication has also been found as an important theme in this study, including the interaction between patients and healthcare providers, and linguistic factors. The interaction between patients and healthcare providers could facilitate in developing rapport between the two and in improving the patients' understanding. McKenna et al. further reported that the improvement in interactions not only helps in increasing the level of patients' knowledge but also can enhance patients' confidence which in turn can eventually upscale the communicative or interactive level of health literacy [124]. The language barrier between patients and healthcare providers was identified in this study as a significant barrier to health literacy, especially in Qatar where people speak many languages. Similarly, Rajah et al. concluded that language barrier is perceived as one of the main barriers toward health literacy [78]. In the development of positive interactions, not

only the language is important but also the accent of patients and healthcare providers. However, this finding of the present study is contrary to those of Anderson et al who reported that the language preference was not a significant barrier in improving health literacy and in helping patients in meeting health-related goals [130]. This difference in findings could be attributed to the dissimilarities between countries and the degree to which language barriers are present in each country. Nevertheless, in order to improve health literacy and bypass linguistic factors, it is suggested to involve multilingual staff or medical interpreters.

Besides patients' and healthcare providers' characteristics and attributes, the facilities' characteristics were found to contribute to patients' health literacy. Some of the properties of a facility, such as the physical condition of the area, user-friendliness of the care facilities, and functionality and privacy provided through the facility, are also considered as factors affecting health literacy. In this regard, some interventions, such as implementing a sufficiently wide waiting area associated with the pharmacy, adding a counseling area for pharmacists, and executing the newer types of pharmacy layout with no separating panels between the patients and pharmacists could increase patients' health literacy. Moreover, adding satellite pharmacies could decrease the burden on the central pharmacy and could help in optimizing pharmacists' encounters with patients and improve patients' health literacy. These findings are very useful as the research on the impact of pharmacy design and layout on patients' health literacy is scarce.

The processes of the healthcare system, such as those related to workflow, quality of care, and use of technology, have also been found to play an important role in health literacy. However, as mentioned by Jordan et al., the healthcare system functions in a way

that assumes that all patients have adequate health literacy [81]. Therefore, the healthcare system fails to recognize and meet the needs of patients with inadequate health literacy. The healthcare workflow may include proper scheduling of healthcare providers, especially clinical pharmacists, and optimizing appointment times. These in turn can affect health literacy. Prolonged time between appointments, such as a six-month gap, could result in patients forgetting the previous instructions and health-related information and can lead to patients having uncertainties and unanswered questions. In this regard, Dowdy et al. also asserted that the problems in follow-up appointments, such as missed follow-ups in primary care could lead to several adverse clinical effects and patient-level risk factors [133]. These adverse clinical effects could be worsened in case patients have a low level of health literacy [133].

Apart from appropriate appointment schedules, technology is also crucial for improved health literacy. In this study, it has been found that information technology could assist in increasing access to health-related information and streamlining the workflow and processes related to health practices. In this regard, Manganello et al. conducted a study to determine the association of digital technology for health-related information with health literacy [134]. They found that although technology can help in health literacy, public healthcare organizations and agencies have to consider patients' specific needs and preferences concerning digital technology [134]. For instance, some people may use search engines, while others would use social networking platforms and phone apps as sources of health-related information [134]. Therefore, any suggested improvement in technology should target different platforms or apps depending on patients' preferences

Along with technological resources, there are also other resources that can improve

health literacy. These resources may include administrative resources (such as human resources, time, and home visits), educational resources (such as written educational materials and online educational resources), and health literacy strategies and tools (such as visual aids and pictograms, teach-back methods, and medication-scheduling tools) available to the healthcare providers. In terms of resources, a study conducted by Rajah et al. on Malaysian pharmacists, physicians, and nurses, showed that the perceived lack of human resources and time constraints are among the major health literacy barriers [90]. Regarding written educational materials, Shaw et al., found that patients consider verbal communication as their first preference and written communication as their second preference and [88], which is similar to the views of patients in the present study. In terms of tools and strategies, Mendoza conducted a study on the effectiveness of the teach-back method in improving patients' literacy and adherence. They noted that the teach-back technique is an evidence-based tool that can be used as an intervention in improving patients' health literacy [135]. While using health literacy assessment measures could assist healthcare providers in tailoring health information to patients' needs and could help them in identifying areas for the development of interventions [81]. there is a lack of easy-to-use health literacy assessment instruments [86].

5.2.2. Strengths and limitations

Similar to Phase I, this is the first study to explore the potential barriers and facilitators for health literacy among patients with ACS or HF in Qatar and the Middle East. One of the most important strengths of this study is that it is based on qualitative data, allowing a detailed examination of the factors related to health literacy and the

development of health literacy. In addition, the integration of patients' and healthcare providers' perspectives would allow the generation of an in-depth understanding and trustworthy conclusions regarding the topic in this population. This also serves as a mean for data triangulation. The qualitative data generated from the participants (patients and healthcare providers alike) has provided greater insights into the issue based on stakeholders' beliefs and experiences, which may not be easily investigated through quantitative study designs. Furthermore, we have utilized best practices for conducting and ensuring quality and trustworthiness of the qualitative research. The credibility of the study was strengthened through interviewing participants of diverse sociodemographic and professional characteristics to ensure variability in the study sample and comprehensiveness of addressing the research questions from different perspectives. Through the in-depth interviews and the focus groups, we have identified the facilitators of and the barriers to health literacy in patients with CVDs, which can guide policymakers in improving health services.

Conversely, Phase II of the study had some limitations that may be inherent to all qualitative research. First, the use of purposive sample could be an important source of bias beyond the awareness of the investigators. Second, the interviewer's or researcher's perspective could affect transparency and reflexivity. Third, the study is limited to only one setting within Hamad Medical Corporation (i.e. the Heart Hospital) and may not be generalizable to other hospitals within Qatar or in other countries. However, it is noteworthy that qualitative research studies are exploratory and are not meant to draw generalization; therefore, external validity is not an issue in this phase of the study. Moreover, due to the qualitative nature of this investigation, the causal links between the

factors and the health literacy of the patients could not be established. Despite that several potential strategies and interventions could be suggested, further large-scale quantitative studies, such as randomized controlled trials, should be considered to assess the effectiveness of these interventions in the future.

5.2.3. Recommendations for future studies

The findings of this phase of the study provide the basis for future research. Further research studies are warranted in the following areas:

- To explore the potential barriers and facilitators for health literacy among patients with CVDs from the perspective of caregivers (e.g. family, friends etc.) and health policymakers.
- To conduct a similar study in other Middle East and Arabic-speaking countries so as to determine if the barriers and facilitators are similar across these countries.
- To include a more representative sample of patients who can speak all commonly available languages in Qatar, mostly patients from Southern Asia.
- To explore the impact of cultural competencies and diversities among healthcare providers and patients on health and medication literacy.
- To utilize the barriers and facilitators determined in designing intervention programs for optimizing health communication and literacy among patients with CVDs. These interventions could focus on patient education,

healthcare provider training, system optimization, or a combination to yield the most improvement in patient understanding and health literacy.

5.2.4. Conclusion

This study contributed to the existing body of knowledge through an in-depth understanding of the facilitators and barriers to health literacy in patients with CVDs, specifically ACS and/or HF, in Qatar. Factors related to health literacy are very complex and multifactorial in nature, thus, to be adequately addressed they require a lot of attention.

Results from this study suggest that there are six main aspects that play a role in the patient's health literacy: the patients themselves, healthcare providers, healthcare facility, care process, resources, and communication aspects. Many of the barriers identified in this study were directly related to patients' preparedness and ability to understand and comprehend health-related information and knowledge. However, there were also barriers related to the society such as cultural norms and attitudes of family members. On the other hand, healthcare providers identified barriers relating to their own ability to provide effective education and counseling and to empower patients to be more proactive in their care, as well as, related to the efficiency of the multidisciplinary team in enhancing the patients' health literacy. The language barrier between the patient and the healthcare providers emerged as a significant player toward health literacy. Therefore, interventions that address the language barrier such as methods for interpretation and translation are needed to address health literacy issues among an undeniable proportion of the population. In addition, lack of resources and time constraints can hinder the process of building health literacy among patients.

Finally, the findings from this study provide extensive exploration of the barriers and facilitators to health literacy among patients with CVDs, thereby, pave the way for interventions to improve health literacy and consequently health outcomes. Moreover, future research should target other perspectives influencing health literacy such as policymakers and caregivers.

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APPENDIX A: Ethics Approval Letters

4/26/2018



APPROVAL LETTER
MEDICAL RESEARCH CENTER
HMC, DOHA-QATAR

Dr. Sumaya Mehdar Al Saadi Director of Pharmacy Department of Pharmacy HH- HMC		Date: 19th April 2018
Protocol No.	MRC-02-17-087	
Study Title:	Evaluating Health Literacy and Its Barriers among Patients with Cardiovascular Diseases in Qatar: A Mixed Method Study	
Team Member List:	Dr. Ahmed Awaisu , Dr. Daniel Rainkie , Dr. Nadir Kheir , Mr. Ahmed Sobhy Hassan Ghonim Mahfouz , Ms. Fatima Basheir Hassan Hamou , Ms. Marwa Elbashir Elbashir , Ms. Muna Said Mohd Al Ismaaial , Ms. Sumaya Mehdar A Al-Saadi Al Yafei	
IRB Review Type:	Expedited	
IRB Decision:	Approved	
IRB Approval Period:	28 January 2018 - 27 January 2019	
Hospitals/ Facilities Approved:	Heart Hospital (HH)	

The above titled research proposal submitted to the Medical Research Center has been approved to be conducted in HMC provided that the continuing approval from HMC Institutional Review Board(IRB) is renewed as per the committee terms.

This research study should be conducted in full accordance with all the applicable sections of the Rules and Regulations for Research at HMC and you should notify the Medical Research Center immediately of any proposed changes in study conduct that may affect the resource utilization at HMC. It is the Principal Investigator's responsibility to obtain review and continued approval if there is any modification to the approved protocol.

Please always ensure that you are only using the stamped approved versions of the documents for your research. These documents are always accessible through Abhath.The investigator/ research team must ensure the study progress is updated in the MRC online system 'ABHATH'.

We wish you all success and await the results in due course.

Thank you

Prof. William John Mckenna
Institutional Officer for Research
HMC

Date:19 April 2018

1/2

4/26/2018

William McKenna

Prof. William John McKenna
Chief Executive Office & Medical Director
Hamad Hospital - HMC
038438





Qatar University Institutional Review Board
QU-IRB

June 28, 2018

Dr. Ahmed Awaisu
College of Pharmacy
Qatar University
Tel.: 4403-5596
Email: aawaisu@qu.edu.qa

Dear Dr. Ahmed Awaisu,

Sub.: Research Ethics Review Exemption
Ref.: Project titled, "Evaluating Health Literacy and Barriers among patients with Cardiovascular Diseases in Qatar"

We would like to inform you that your application along with the supporting documents provided for the above proposal, is reviewed and having met all the requirements, has been exempted from the full ethics review.

Please note that any changes/modification or additions to the original submitted protocol should be reported to the committee to seek approval prior to continuation.

Your Research Ethics Approval No. is: **QU-IRB 955-E/18**

Kindly refer to this number in all your future correspondence pertaining to this project.

Best wishes,

Dr. Khalid Al-Ali
Chairperson, QU-IRB



Evaluating Health Literacy and Its Barriers among Patients with Cardiovascular Diseases in Qatar

<p>Diagnosis (please choose all that apply):</p> <p><input type="checkbox"/> Heart Failure (HF)</p> <ul style="list-style-type: none"> <input type="radio"/> NYHA Class I <input type="radio"/> ACC/AHA Stage A <input type="radio"/> NYHA Class II <input type="radio"/> ACC/AHA Stage B <input type="radio"/> NYHA Class III <input type="radio"/> ACC/AHA Stage C <input type="radio"/> NYHA Class IV <input type="radio"/> ACC/AHA Stage D <p><input type="checkbox"/> Acute Coronary Syndrome (ACS)</p> <ul style="list-style-type: none"> <input type="radio"/> STEMI <input type="radio"/> NSTEMI <input type="radio"/> Unstable Angina <p>Duration since diagnosis of HF:</p> <p>Duration since diagnosis of ACS:</p> <p>Comorbidities (please choose all that apply):</p> <p><input type="checkbox"/> Diabetes mellitus <input type="checkbox"/> Renal dysfunction</p> <p><input type="checkbox"/> Hypertension <input type="checkbox"/> Liver disease</p> <p><input type="checkbox"/> Hyperlipidemia <input type="checkbox"/> Atrial fibrillation</p> <p><input type="checkbox"/> Other (Please specify)</p> <p>Total number of comorbid chronic diseases:</p> <p>Current Medications (please indicate medication, route, and dosage regimen):</p> <p><input type="checkbox"/> Beta Blockers:</p> <p><input type="checkbox"/> Antiplatelets:</p> <p><input type="checkbox"/> Statins:</p> <p><input type="checkbox"/> ACEI/ARB:</p> <p><input type="checkbox"/> CCB:</p> <p><input type="checkbox"/> Diuretics:</p> <p><input type="checkbox"/> Other (Please specify)</p> <p>Total number of prescribed oral medications for chronic conditions:</p> <p>Cigarette smoking:</p> <p><input type="checkbox"/> Current smoker</p> <p><input type="checkbox"/> Former smoker</p> <p><input type="checkbox"/> Never smoker</p>	<p style="text-align: center;"><u>Last available data</u></p> <p>Weight (kg):</p> <p>Height (cm):</p> <p>BMI (kg/m²):</p> <p>SBP (mmHg):</p> <p>DBP (mmHg):</p> <p>HR (BPM):</p> <p>Total cholesterol (mmol/L):</p> <p>LDL (mmol/L):</p> <p>HDL (mmol/L):</p> <p>TG (mmol/L):</p> <p>HbA1c:</p> <p>Charlson comorbidity index:</p> <table border="1"> <thead> <tr> <th>Disease</th> <th>Weight</th> <th></th> </tr> </thead> <tbody> <tr><td>Myocardial infarction</td><td rowspan="10">1</td><td></td></tr> <tr><td>Congestive heart failure</td><td></td></tr> <tr><td>Peripheral vascular disease</td><td></td></tr> <tr><td>Cerebrovascular disease</td><td></td></tr> <tr><td>Dementia</td><td></td></tr> <tr><td>Chronic pulmonary disease</td><td></td></tr> <tr><td>Connective tissue disorder</td><td></td></tr> <tr><td>Peptic ulcer disease</td><td></td></tr> <tr><td>Mild liver disease</td><td></td></tr> <tr><td>Diabetes without complication</td><td></td></tr> <tr><td>Diabetes with complications</td><td rowspan="4">2</td><td></td></tr> <tr><td>Paraplegia or Hemiplegia</td><td></td></tr> <tr><td>Moderate or severe renal disease</td><td></td></tr> <tr><td>Cancer</td><td></td></tr> <tr><td>Moderate or severe liver disease</td><td>3</td><td></td></tr> <tr><td>Metastatic cancer</td><td rowspan="2">6</td><td></td></tr> <tr><td>AIDS</td><td></td></tr> </tbody> </table>	Disease	Weight		Myocardial infarction	1		Congestive heart failure		Peripheral vascular disease		Cerebrovascular disease		Dementia		Chronic pulmonary disease		Connective tissue disorder		Peptic ulcer disease		Mild liver disease		Diabetes without complication		Diabetes with complications	2		Paraplegia or Hemiplegia		Moderate or severe renal disease		Cancer		Moderate or severe liver disease	3		Metastatic cancer	6		AIDS	
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Evaluating Health Literacy and Its Barriers among Patients with Cardiovascular Diseases in
Qatar: A Mixed Method Study – MRC-02-17-087

Patient Code: -----

S-TOFHLA

Reading Comprehension



1

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PASSAGE A

Your doctor has sent you to have a _____ X-ray.

- a. stomach
- b. diabetes
- c. stitches
- d. germs

You must have an _____ stomach when you come for _____.

- | | |
|-----------|--------|
| a. asthma | a. is. |
| b. empty | b. am. |
| c. incest | c. if. |
| d. anemia | d. it. |

The X-ray will _____ from 1 to 3 _____ to do.

- | | |
|---------|-----------|
| a. take | a. beds |
| b. view | b. brains |
| c. talk | c. hours |
| d. look | d. diets |



THE DAY BEFORE THE X-RAY.

For supper have only a _____ snack of fruit, _____ and jelly,

- | | |
|-----------|-----------|
| a. little | a. toes |
| b. broth | b. throat |
| c. attack | c. toast |
| d. nausea | d. thigh |

with coffee or tea.

After _____, you must not _____ or drink

- | | |
|--------------|----------|
| a. minute, | a. easy |
| b. midnight, | b. ate |
| c. during, | c. drank |
| d. before, | d. eat |

anything at _____ until after you have _____ the X-ray.

- | | |
|---------|--------|
| a. ill | a. are |
| b. all | b. has |
| c. each | c. had |
| d. any | d. was |



THE DAY OF THE X-RAY.

Do not eat _____.

- a. appointment.
- b. walk-in.
- c. breakfast.
- d. clinic.

Do not _____, even _____.

- | | |
|-----------|------------|
| a. drive, | a. heart. |
| b. drink, | b. breath. |
| c. dress, | c. water. |
| d. dose, | d. cancer. |

If you have any _____, call the X-ray _____ at 616-4500.

- | | |
|---------------|---------------|
| a. answers, | a. Department |
| b. exercises, | b. Sprain |
| c. tracts, | c. Pharmacy |
| d. questions, | d. Toothache |



PASSAGE B

I agree to give correct information to _____ if I can receive Medicaid.

- a. hair
- b. salt
- c. see
- d. ache

I _____ to provide the county information to _____ any

- | | |
|----------|--------------|
| a. agree | a. hide |
| b. probe | b. risk |
| c. send | c. discharge |
| d. gain | d. prove |

statements given in this _____ and hereby give permission to

- a. emphysema
- b. application
- c. gallbladder
- d. relationship

the _____ to get such proof. I _____ that for

- | | |
|-----------------|----------------|
| a. inflammation | a. investigate |
| b. religion | b. entertain |
| c. iron | c. understand |
| d. county | d. establish |

Medicaid I must report any _____ in my circumstances

- a. changes
- b. hormones
- c. antacids
- d. charges



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within _____ (10) days of becoming _____ of the change.

- | | |
|----------|----------|
| a. three | a. award |
| b. one | b. aware |
| c. five | c. away |
| d. ten | d. await |

I understand _____ if I DO NOT like the _____ made on my

- | | |
|---------|---------------|
| a. thus | a. marital |
| b. this | b. occupation |
| c. that | c. adult |
| d. than | d. decision |

case, I have the _____ to a fair hearing. I can _____ a

- | | |
|-----------|------------|
| a. bright | a. request |
| b. left | b. refuse |
| c. wrong | c. fail |
| d. right | d. mend |

hearing by writing or _____ the county where I applied.

- a. counting
- b. reading
- c. calling
- d. smelling

If you _____ TANF for any family _____, you will have to

- | | |
|----------|--------------|
| a. wash | a. member, |
| b. want | b. history, |
| c. cover | c. weight, |
| d. tape | d. seatbelt, |



_____ a different application form. _____, we will use

- a. relax
- b. break
- c. inhale
- d. sign

- a. Since,
- b. Whether,
- c. However,
- d. Because,

the _____ on this form to determine your _____.

- a. lung
- b. date
- c. meal
- d. pelvic

- a. hypoglycemia.
- b. eligibility.
- c. osteoporosis.
- d. schizophrenia.



Evaluating Health Literacy and Its Barriers among Patients with Cardiovascular Diseases in
Qatar: A Mixed Method Study – MRC-02-17-087

Patient Code: -----

Health Literacy Screening Questions

Please circle the answer that best represents your response.

1. How often do you have someone help you read hospital materials?
 1. All of the time
 2. Most of the time
 3. Some of the time
 4. A little of the time
 5. None of the time

2. How often do you have problems learning about your medical condition because of difficulty understanding written information?
 1. All of the time
 2. Most of the time
 3. Some of the time
 4. A little of the time
 5. None of the time

3. How confident are you filling out medical forms by yourself?
 1. Not at all
 2. A little bit
 3. Somewhat
 4. Quite a bit
 5. Extremely



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تقييم المعرفة والممارسة الصحية وحواجزها بين المرضى الذين يعانون من أمراض القلب والأوعية الدموية في قطر : دراسة
باستخدام إجراءات مختلطة - MRC-02-17-087

Patient Code: -----

يملأ هذا الجزء من الاستمارة ذاتياً

استطلاع



MRC-02-17-087 Validity: 28 01 2018 - 27 01 2019 E-stamped 14 March 2018

1

المقطع أ:

الاسئلة المتعلقة بالمقطع أ: ضع دائرة حول الكلمة الصحيحة لإكمال الجملة

طلب طبيبك منك القيام بتنظيف _____ .

- أ. القولون
- ب. للسكري
- ج. للقطب
- د. للبكتيريا

عليك ان _____ عند المجيء لاجراء _____ .

- أ. تكون قد اصبت بالربو
- ب. تكون اتبعت نظام غذائي خاص
- ج. تكون قد تعرضت لسفاح القرية
- د. تكون قد اصبت بفقر الدم
- أ. الفعل
- ب. أنا
- ج. اذا
- د. ه

لاجراء تنظيف القولون _____ من ١ الى ٣ _____ .

- أ. يلزمك
- ب. تشاهد
- ج. تتكلم
- د. تنتظر
- أ. اسرة
- ب. عقول
- ج. ساعات
- د. حميات



في اليومين الذين يسبقان تنظيف القولون:

يمكنك _____ تناول السوائل، والحساء المصفى كوجبة خفيفة مع القهوة أو الشاي .

- | | |
|-----------|------------------|
| أ. فقط | أ. اصابع القدم |
| ب. البطيخ | ب. حنجرة |
| ج. مواجهة | ج. الماء والعصير |
| د. غثيان | د. فخذ |

في _____، عليك التوقف عن _____ أو شرب اي شيء _____ الى ان _____ تنظيف القولون.

- | | | | |
|----------------|------------|------------|---------|
| أ. دقيقة | أ. السهولة | أ. مرض | أ. تكون |
| ب. يوم التنظيف | ب. اكلت | ب. اطلاقاً | ب. قمت |
| ج. خلال | ج. شربت | ج. كل | ج. تجري |
| د. قبل | د. اكل | د. اي | د. كانت |

في اليوم المحدد للتنظيف لا تأكل _____.

- أ. الموعد
- ب. المجيء بلا موعد
- ج. الفطور الصباحي
- د. العيادة

لا _____، حتى _____ في آخر ٣ ساعات قبل التنظيف.

- | | |
|---------|------------|
| أ. تقود | أ. القلب |
| ب. تشرب | ب. النفس |
| ج. تلبس | ج. المياه |
| د. كمية | د. السرطان |



إذا كان لديك _____ ، اتصل _____ على الرقم المسجل.

- | | |
|--------------|-----------|
| أ. بالمرض | أ. اجابات |
| ب. فكش | ب. تمارين |
| ج. بصيدلية | ج. حقل |
| د. وجع اسنان | د. اسئلة |



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أل مقطع ب :

الاسئلة المتعلقة بالمقطع ب: ضع دائرة حول الكلمة الصحيحة لإكمال الجملة

إذا كنت _____ من التأمين الخاص، يمكنك _____ مباشرة إلى مكتب المحاسبة.

- | | |
|------------|-----------|
| أ. شعر | أ. التقدم |
| ب. ملح | ب. بيت |
| ج. مكفول | ج. مريض |
| د. الأوجاع | د. إذا |

تُعطي أمين الصندوق بطاقة _____ و _____ منه _____ على _____ الذي تريد أن تخضع له.

- | | | | |
|------------|------------|-------------|-----------------|
| أ. التأمين | أ. الخطر | أ. مكافحة | أ. إخفاء |
| ب. خطر | ب. المرارة | ب. أخذ | ب. إنتفاخ الرئة |
| ج. خروج | ج. خروج | ج. المراقبة | ج. الفحص |
| د. ورقة | د. تطلب | د. الموافقة | د. علاقة |

_____ شركات التأمين يمكن _____ لها إلكترونياً من مكتب _____ .

- | | | |
|---------------|-----------|-------------|
| أ. في | أ. نادرا | أ. الرئيس |
| ب. معظم الوقت | ب. الوصول | ب. الطالب |
| ج. هذه | ج. أبداً | ج. المحاسبة |
| د. هناك | د. عندما | د. هناك |

أمين الصندوق سيتحقق إلكترونياً إذا كانت شركة تأمينك توافق على الفحص أم لا. إذا كانت شركة التأمين

التي _____ إليها لا تغطي الفحص، فوجب عليك _____ الكافة بنفسك.

- | | |
|-----------|--------------|
| أ. التحري | أ. نفع |
| ب. تسلي | ب. الهرمونات |
| ج. تنتمي | ج. كتابة |
| د. تؤسس | د. تغييره |



إذا لم يستطع أمين الصندوق _____ شركة التأمين إلكترونياً، يطلب منك التوجّه إلى مندوب

- | | |
|----------------|----------|
| أ. سوف | أ. تحديد |
| ب. أبداً | ب. توافق |
| ج. دائماً | ج. فهم |
| د. بعض الاوقات | د. بلد |

شركة التأمين _____ في الطابق الأول في حرم مستشفى الجامعة الأمريكية

- أ. المستقبل
- ب. ماضي
- ج. المتواجدة
- د. سابقاً

عندما _____ إلى هناك _____ الفحص إلى _____ في المكتب.

- | | | |
|---------|-----------|------------|
| أ. اتصل | أ. إشتراك | أ. المندوب |
| ب. يصل | ب. إخفاء | ب. القائد |
| ج. فحص | ج. تعطي | ج. الضابط |
| د. فصل | د. تلغي | د. المهندس |

سوف _____ المندوب عن بطاقة تأمينك و _____ .

- | | |
|----------|--------------|
| أ. يسأل | أ. عائلية |
| ب. يصرخ | ب. هويتك |
| ج. يجادل | ج. غير شخصية |
| د. بيت | د. عالمية |



مندوب شركة التأمين سوف يرسل الفحص إلى الشركة عبر الفاكس للحصول على _____ .

- أ. شركة
- ب. العمل
- ج. شخصية
- د. الموافقة



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تقييم محور الأمية الصحية وحواجزها بين المرضى الذين يعانون من أمراض القلب والأوعية الدموية بدولة قطر: دراسة
مختلطة المنهج - MRC-02-17-087

رمز المريض:-----

أسئلة فرز محور الأمية الصحية

يرجى وضع دائرة حول الإجابة التي تمثل الرد الأمثل بالنسبة لك .

1. ما هي وتيرة أن يكون لديك شخص يساعدك على قراءة مواد المستشفى؟

1. طوال الوقت

2. طوال الوقت تقريباً

3. أحياناً

4. قليل من الوقت

5. على الإطلاق

2. ما هي وتيرة أن يكون لديك مشاكل في معرفة حالتك الطبية بسبب صعوبة فهم المعلومات المكتوبة؟

1. طوال الوقت

2. طوال الوقت تقريباً

3. أحياناً

4. قليل من الوقت

5. على الإطلاق

3. لأي درجة تشعر بالثقة وأنت تكمل نماذجك الطبية بنفسك؟

1. غير واثق على الإطلاق

2. قليلاً

3. إلى حد ما

4. بعض الشيء

5. واثق جداً



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APPENDIX C: Additional Results from Phase I

Clinical characteristics based on S-TOFHLA category					
Variable	Adequate (n=192)		Inadequate or marginal (n=108)		P-value
	n (%)	Median (IQR)	n (%)	Median (IQR)	
Diagnosis					
HF only	22 (11.5)		10 (9.3)		0.545 [†]
ACS only	148 (77.1)		89 (82.4)		
HF and ACS	22 (11.5)		9 (8.3)		
NYHA classification**					
I	11 (25.6)		2 (10.5)		0.176 [†]
II	23 (53.5)		8 (42.1)		
III	7 (16.3)		7 (36.8)		
IV	2 (4.7)		2 (10.5)		
ACS type**					
STEMI	52 (36.6)		38 (44.7)		0.339 [†]
NSTEMI	69 (48.6)		39 (45.9)		
UA	21 (14.8)		8 (9.4)		
HF duration (years)		2.0 (1.8)		1.5 (1.0)	0.504 [§]
ACS duration (years)		2.8 (5.0)		2.0 (3.0)	0.690 [§]
Comorbidities*					
Diabetes	92 (47.9)		53 (49.1)		0.847 [†]
Hypertension	133 (69.3)		66 (61.1)		0.151 [†]
Dyslipidemia	90 (46.9)		33 (30.6)		0.006 [†]
Renal dysfunction	10 (5.2)		8 (7.4)		0.441 [†]
Liver dysfunction	1 (0.5)		1 (0.9)		1.000 [‡]
AF	14 (7.3)		4 (3.7)		0.311 [‡]
Other	53 (27.6)		25 (23.1)		0.398 [†]
Number of comorbidities		3.0 (2.0)		3.0 (2.0)	0.037 [§]
Medications*					
Beta-blocker	168 (87.5)		97 (89.8)		0.549 [†]
Antiplatelet	177 (92.2)		104 (96.3)		0.218 [‡]
Statin	174 (90.6)		100 (92.6)		0.561 [†]
ACEI/ARB	150 (78.1)		81 (75.0)		0.537 [†]
CCB	41 (21.4)		28 (25.9)		0.366 [†]
Diuretic	57 (29.7)		28 (25.9)		0.488 [†]
Other	134 (69.8)		86 (79.6)		0.064 [†]
Number of oral medications		6.0 (3.0)		6.0 (3.0)	0.075 [§]
Smoking status					
Never	106 (55.2)		63 (58.3)		0.823 [†]
Former	47 (24.5)		26 (24.1)		
Current	39 (20.3)		19 (17.6)		
Weight (kg)		83.0 (18.2)		75.0 (18.8)	≤0.001 [§]
Height (cm)		171.0 (9.0)		166.0 (9.0)	≤0.001 [§]

Clinical characteristics based on S-TOFHLA category (Cont.)

BMI (kg/m ²)	28.4 (6.4)	27.4 (6.3)	0.012 [§]
SBP (mmHg)	127.0 (29.0)	130.5 (27.0)	0.702 [§]
DBP (mmHg)	77.5 (13.0)	77.5 (14.0)	0.539 [§]
HR (bpm)	72.0 (14.0)	70.0 (16.0)	0.199 [§]
Total cholesterol (mmol/L)	3.5 (1.4)	3.7 (1.6)	0.225 [§]
LDL (mmol/L)	1.8 (1.1)	2.0 (1.3)	0.091 [§]
HDL (mmol/L)	1.0 (0.4)	1.0 (0.3)	0.174 [§]
TG (mmol/L)	1.3 (1.1)	1.5 (0.8)	0.074 [§]
HbA1c (%)	6.2 (1.6)	6.1 (2.0)	0.373 [§]

*Items are not mutually exclusive

**Missing values

†P-values were calculated using Chi-square test

‡P-values were calculated using Fisher's Exact test

§P-values were calculated using Mann Whitney test

APPENDIX D: Additional Results from Phase I

Health literacy characteristics based on S-TOFHLA category

Variable	Adequate (n=192)		Inadequate or marginal (n=108)		P-value
	n (%)	Median (IQR)	n (%)	Median (IQR)	
S-TOFHLA score*		34.0 (5.0)		17.0 (7.0)	≤0.001‡
BHLS score†		10.0 (3.0)		7.0 (2.0)	≤0.001‡
BHLS category					
Adequate (10 – 12)	132 (68.8)		7 (6.5)		≤0.001§
Inadequate or marginal (0 – 9)	60 (31.3)		101 (93.5)		

*S-TOFHLA scores range from 0 to 36

†BHLS scores ranges from 0 to 12

‡P-values were calculated using Mann Whitney test

§P-values were calculated using Chi-square test

APPENDIX E: Additional Results from Phase I

Demographic characteristics based on BHLS category

Variable	Adequate (n=139)	Inadequate or marginal (n=161)	P-value [†]
	n (%)		
Age			
<60 years	106 (76.3)	120 (74.5)	0.730
≥60 years	33 (23.7)	41 (25.5)	
Gender			
Male	127 (91.4)	138 (85.7)	0.128
Female	12 (8.6)	23 (14.3)	
Marital status			
Single	9 (6.5)	18 (11.2)	0.210
Married	129 (92.8)	143 (88.8)	
Divorced/widowed/separated	1 (0.7)	0 (0.0)	
Nationality			
Qatari	6 (4.3)	11 (6.8)	0.347
Non-Qatari	133 (95.7)	150 (93.2)	
Education level			
None	0 (0.0)	1 (0.6)	≤0.001
Primary school	0 (0.0)	7 (4.3)	
Middle school	3 (2.2)	24 (14.9)	
High school	2 (1.4)	82 (50.9)	
College/diploma	7 (5.0)	14 (8.7)	
University	113 (81.3)	31 (19.3)	
Post-graduate	14 (10.1)	2 (1.2)	
Languages spoken*			
Arabic	87 (62.6)	74 (46.0)	0.004
English	134 (96.4)	132 (82.0)	≤0.001
Hindi	40 (28.8)	82 (50.9)	≤0.001
Urdu	31 (22.3)	72 (44.7)	≤0.001
Tamil	2 (1.4)	1 (0.6)	0.598 [‡]
Tagalog	4 (2.9)	10 (6.2)	0.272 [‡]
Malayalam	14 (10.1)	25 (15.5)	0.161
Other	21 (15.1)	39 (24.2)	0.049

Demographic characteristics based on BHLS category (Cont.)

Occupation			
Unemployed	1 (0.7)	20 (12.4)	≤0.001
Management	20 (14.4)	7 (4.3)	
Finance/accounting	17 (12.2)	3 (1.9)	
Medical/healthcare	12 (8.6)	0 (0.0)	
Driving	0 (0.0)	20 (12.4)	
Retail salesperson	2 (1.4)	11 (6.8)	
Retired	7 (5.0)	10 (6.2)	
Administration	16 (11.5)	8 (5.0)	
Engineering	28 (20.1)	1 (0.6)	
Teaching	4 (2.9)	2 (1.2)	
Labor	4 (2.9)	35 (21.7)	
Cashier	0 (0.0)	2 (1.2)	
Secretary	1 (0.7)	1 (0.6)	
Others	27 (19.4)	41 (25.5)	
Health information source*			
Physician	126 (90.6)	154 (95.7)	0.083
Pharmacist	111 (79.9)	123 (76.4)	0.471
Physiotherapist	19 (13.7)	10 (6.2)	0.029
Nurse	96 (69.1)	104 (64.6)	0.413
Dietician	7 (5.0)	9 (5.6)	0.831
Person in charge of medications (at home)			
Self	137 (98.6)	161 (100.0)	0.214 [‡]
Spouse/partner	2 (1.4)	0 (0.0)	

*Items are not mutually exclusive

[†]P-values were calculated using Chi-square test

[‡]P-values were calculated using Fisher's Exact test

APPENDIX F: Additional Results from Phase I

Clinical characteristics based on BHLS category					
Variable	Adequate (n=139)		Inadequate or marginal (n=161)		P-value
	n (%)	Median (IQR)	n (%)	Median (IQR)	
Diagnosis					
HF only	15 (10.8)		17 (10.6)		0.874 [†]
ACS only	111 (79.9)		126 (78.3)		
HF and ACS	13 (9.4)		18 (11.2)		
NYHA classification**					
I	8 (28.6)		5 (14.7)		0.149 [†]
II	15 (53.6)		16 (47.1)		
III	5 (17.9)		9 (26.5)		
IV	0 (0.0)		4 (11.8)		
ACS type**					
STEMI	43 (41.7)		47 (37.9)		0.527 [†]
NSTEMI	45 (43.7)		63 (50.8)		
UA	15 (14.6)		14 (11.3)		
HF duration (years)		2.0 (1.5)		1.9 (1.0)	0.743 [§]
ACS duration (years)		2.5 (4.0)		2.0 (4.0)	0.653 [§]
Comorbidities*					
Diabetes	65 (46.8)		80 (49.7)		0.613 [†]
Hypertension	95 (68.3)		104 (64.6)		0.493 [†]
Dyslipidemia	64 (46.0)		59 (36.6)		0.099 [†]
Renal dysfunction	8 (5.8)		10 (6.2)		0.868 [†]
Liver dysfunction	1 (0.7)		1 (0.6)		1.000 [‡]
AF	10 (7.2)		8 (5.0)		0.418 [†]
Other	37 (26.6)		41 (25.5)		0.820 [†]
Number of comorbidities		3.0 (2.0)		3.0 (2.0)	0.309 [§]
Medications*					
Beta-blocker	119 (85.6)		146 (90.7)		0.172 [†]
Antiplatelet	129 (92.8)		152 (94.4)		0.569 [†]
Statin	125 (89.9)		149 (92.5)		0.421 [†]
ACEI/ARB	109 (78.4)		122 (75.8)		0.588 [†]
CCB	31 (22.3)		38 (23.6)		0.790 [†]
Diuretic	37 (26.6)		48 (29.8)		0.540 [†]
Other	96 (69.1)		124 (77.0)		0.120 [†]
Number of oral medications		6.0 (2.0)		6.0 (3.0)	0.102 [§]
Smoking status					
Never	79 (56.8)		90 (55.9)		0.655 [†]
Former	36 (25.9)		37 (23.0)		
Current	24 (17.3)		34 (21.1)		
Weight (kg)		81.8 (18.8)		79.0 (20.0)	0.039[§]
Height (cm)		171.3 (9.1)		167.0 (8.2)	≤0.001[§]

Clinical characteristics based on BHLS category (Cont.)

BMI (kg/m ²)	27.7 (6.4)	28.3 (6.7)	0.902 [§]
SBP (mmHg)	126.0 (28.0)	130.0 (27.0)	0.324 [§]
DBP (mmHg)	78.0 (14.0)	77.0 (13.0)	0.893 [§]
HR (bpm)	73.0 (15.0)	70.0 (15.0)	0.067 [§]
Total cholesterol (mmol/L)	3.5 (1.5)	3.6 (1.6)	0.407 [§]
LDL (mmol/L)	1.8 (1.0)	1.9 (1.3)	0.684 [§]
HDL (mmol/L)	1.0 (0.40)	1.0 (0.3)	0.603 [§]
TG (mmol/L)	1.3 (0.9)	1.5 (1.1)	0.007[§]
HbA1c (%)	6.1 (1.4)	6.3 (2.1)	0.084 [§]

*Items are not mutually exclusive

**Missing values

†P-values were calculated using Chi-square test

‡P-values were calculated using Fisher's Exact test

§P-values were calculated using Mann Whitney test

APPENDIX G: Additional Results from Phase I

Health literacy characteristics based on BHLS category

Variable	Adequate (n=139)		Inadequate or marginal (n=161)		P-value
	n (%)	Median (IQR)	n (%)	Median (IQR)	
S-TOFHLA score*		35.0 (4.0)		21.0 (13.0)	≤0.001‡
S-TOFHLA category					
Adequate (23 – 36)	132 (95.0)		60 (37.3)		≤0.001§
Inadequate or marginal (0 – 22)	7 (5.0)		101 (62.7)		
BHLS score†		11.0 (2.0)		7.0 (2.0)	≤0.001‡

*S-TOFHLA scores range from 0 to 36

†BHLS scores ranges from 0 to 12

‡P-values were calculated using Mann Whitney test

§P-values were calculated using Chi-square test

APPENDIX H: Additional Results from Phase I

Differences in BHLS scores across different demographic characteristics			
Variable	n (%)	Median (IQR)*	P-value
Age			
<60 years	226 (75.3)	9.0 (4.0)	0.433 [‡]
≥60 years	74 (24.7)	9.0 (5.0)	
Gender			
Male	265 (88.3)	9.0 (4.0)	0.089 [‡]
Female	35 (11.7)	8.0 (5.0)	
Marital status			
Single	27 (9.0)	8.0 (4.0)	0.075 [§]
Married	272 (90.7)	9.0 (4.0)	
Nationality			
Qatari	17 (5.7)	9.0 (3.0)	0.746 [‡]
Non-Qatari	283 (94.3)	9.0 (4.0)	
Country of origin			
Qatar	17 (5.7)	9.0 (3.0)	≤0.001[§]
Egypt	46 (15.3)	10.0 (3.0)	
Palestine	8 (2.7)	11.0 (3.0)	
Lebanon	4 (1.3)	11.0 (1.0)	
Syria	12 (4.0)	10.0 (3.0)	
Sudan	14 (4.7)	10.0 (3.0)	
Jordan	9 (3.0)	10.0 (3.0)	
India	78 (26.0)	8.0 (4.0)	
Pakistan	25 (8.3)	9.0 (4.0)	
Sri Lanka	11 (3.7)	8.0 (5.0)	
Nepal	5 (1.7)	8.0 (2.0)	
Bangladesh	31 (10.3)	7.0 (2.0)	
Philippines	12 (4.0)	9.0 (5.0)	
Iran	2 (0.7)	10.0 (0.0)	
Others	26 (8.7)	12.0 (2.0)	
Education level			
Primary school	7 (2.3)	5.0 (2.0)	≤0.001[§]
Middle school	27 (9.0)	7.0 (2.0)	
High school	84 (28.0)	7.0 (2.0)	
College/diploma	21 (7.0)	9.0 (4.0)	
University	144 (48.0)	11.0 (2.0)	
Post-graduate	16 (5.3)	11.5 (2.0)	
Languages spoken [†]			
Arabic			0.018[‡]
Yes	161 (53.7)	10.0 (3.0)	
No	139 (46.3)	9.0 (4.0)	

Differences in BHLS scores across different demographic characteristics (Cont.)

English			
Yes	266 (88.7)	9.5 (4.0)	≤0.001[‡]
No	34 (11.3)	8.0 (3.0)	
Hindi			
Yes	122 (40.7)	8.0 (4.0)	≤0.001[‡]
No	178 (59.3)	10.0 (3.0)	
Urdu			
Yes	103 (34.3)	8.0 (4.0)	≤0.001[‡]
No	197 (65.7)	10.0 (3.0)	
Tamil			
Yes	3 (1.0)	11.0 (-)	0.414 [‡]
No	297 (99.0)	9.0 (4.0)	
Tagalog			
Yes	14 (4.7)	8.5 (4.0)	0.451 [‡]
No	286 (95.3)	9.0 (4.0)	
Malayalam			
Yes	39 (13.0)	8.0 (4.0)	0.318 [‡]
No	261 (87.0)	9.0 (4.0)	
Other			
Yes	60 (20.0)	8.0 (6.0)	0.209 [‡]
No	240 (80.0)	9.0 (4.0)	
Occupation			
Unemployed	21 (7.0)	6.0 (3.0)	≤0.001[§]
Management	27 (9.0)	11.0 (3.0)	
Finance/accounting	20 (6.7)	10.5 (1.0)	
Medical/healthcare	12 (4.0)	12.0 (0.0)	
Driving	20 (6.7)	7.0 (2.0)	
Retail salesperson	13 (4.3)	6.0 (5.0)	
Retired	17 (5.7)	9.0 (4.0)	
Administration	24 (8.0)	10.0 (2.0)	
Engineering	29 (9.7)	11.0 (2.0)	
Teaching	6 (2.0)	10.5 (4.0)	
Labor	39 (13.0)	7.0 (2.0)	
Cashier	2 (0.7)	8.0 (-)	
Secretary	2 (0.7)	8.0 (-)	
Others	68 (22.7)	9.0 (3.0)	
Health information source [†]			
Physician			
Yes	280 (93.3)	9.0 (4.0)	0.038[‡]
No	20 (6.7)	10.5 (4.0)	
Pharmacist			
Yes	234 (78.0)	9.0 (4.0)	0.215 [‡]
No	66 (22.0)	9.0 (5.0)	

Differences in BHLS scores across different demographic characteristics (Cont.)

Physiotherapist			
Yes	29 (9.7)	10.0 (3.0)	0.033[‡]
No	271 (90.3)	9.0 (4.0)	
Nurse			
Yes	200 (66.7)	9.0 (4.0)	0.361 [‡]
No	100 (33.3)	9.0 (4.0)	
Dietician			
Yes	16 (5.3)	9.0 (4.0)	0.460 [‡]
No	284 (94.7)	9.0 (4.0)	
Person in charge of medications (at home)			
Self	298 (99.3)	9.0 (4.0)	0.103 [§]
Spouse/partner	2 (0.7)	11.5 (-)	

*BHLS scores range from 0 to 12

[†]Items are not mutually exclusive

[‡]P-values were calculated using Mann Whitney test

[§]P-values were calculated using Kruskal Wallis test

APPENDIX I: Additional Results from Phase I

Differences in BHLS scores across different clinical characteristics			
Variable	n (%)	Median (IQR)*	P-value
Diagnosis			
HF only	32 (10.7)	9.0 (4.0)	0.880 [‡]
ACS only	237 (79.0)	9.0 (4.0)	
HF and ACS	31 (10.3)	9.0 (4.0)	
NYHA classification**			
I	13 (21.0)	10.0 (5.0)	0.361 [‡]
II	31 (50.0)	9.0 (4.0)	
III	14 (22.6)	8.0 (6.0)	
IV	4 (6.5)	7.0 (3.0)	
ACS type**			
STEMI	90 (39.6)	9.0 (4.0)	0.372 [‡]
NSTEMI	108 (47.6)	9.0 (4.0)	
UA	29 (12.8)	10.0 (4.0)	
Comorbidities[†]			
Diabetes			
Yes	145 (48.3)	9.0 (4.0)	0.972 [§]
No	155 (51.7)	9.0 (4.0)	
Hypertension			
Yes	199 (66.3)	9.0 (4.0)	0.511 [§]
No	101 (33.7)	9.0 (4.0)	
Dyslipidemia			
Yes	123 (41.0)	10.0 (3.0)	0.039[§]
No	177 (59.0)	9.0 (4.0)	
Renal dysfunction			
Yes	18 (6.0)	8.5 (4.0)	0.957 [§]
No	282 (94.0)	9.0 (4.0)	
Liver dysfunction			
Yes	2 (0.7)	9.0 (-)	0.957 [§]
No	298 (99.3)	9.0 (4.0)	
AF			
Yes	18 (6.0)	10.0 (3.0)	0.603 [§]
No	282 (94.0)	9.0 (4.0)	
Other			
Yes	78 (26.0)	9.0 (5.0)	0.837 [§]
No	222 (74.0)	9.0 (4.0)	
Smoking status			
Never	169 (56.3)	9.0 (4.0)	0.486 [‡]
Former	73 (24.3)	9.0 (4.0)	
Current	58 (19.3)	9.0 (4.0)	

*BHLS scores range from 0 to 12

**Missing values

[†]Items are not mutually exclusive

[‡]P-values were calculated using Kruskal Wallis test

[§]P-values were calculated using Mann Whitney test

APPENDIX J: Additional Results from Phase I

Differences in BHLS scores across different health literacy characteristics

Variable	n (%)	Median (IQR)*	P-value[†]
S-TOFHLA category			
Adequate (23 – 36)	192 (64.0)	10.0 (3.0)	≤0.001
Inadequate or marginal (0 – 22)	108 (36.0)	7.0 (2.0)	
BHLS category			
Adequate (10 – 12)	139 (46.3)	11.0 (2.0)	≤0.001
Inadequate or marginal (0 – 9)	161 (53.7)	7.0 (2.0)	

*BHLS scores range from 0 to 12

[†]P-values were calculated using Mann Whitney test

APPENDIX K: SRQR Checklist

Reporting Item		Check-box	
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	x
Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	✓
Introduction			
Problem formulation	#3	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	✓
Purpose or research question	#4	Purpose of the study and specific objectives or questions	✓
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale.	✓
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	✓
Context	#7	Setting / site and salient contextual factors; rationale	✓

Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	✓
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	✓
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	✓
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	✓
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	✓
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization / deidentification of excerpts	✓
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	✓
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	✓
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include	✓

		development of a theory or model, or integration with prior research or theory	
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	✓
Discussion			
Integration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	✓
Limitations	#19	Trustworthiness and limitations of findings	✓
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	x
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	x

APPENDIX L: Scholarly Output

- Research article publication:
 - Elbashir M, Awaisu A, El Hajj MS, Rainkie DC. Measurement of health literacy in patients with cardiovascular diseases: A systematic review. *Research in Social and Administrative Pharmacy*. 2019 Dec;15(12):1395-1405. doi: 10.1016/j.sapharm.2019.01.008.

- Research Grants:
 - Awaisu A, Elbashir M. Evaluating Health Literacy and Its Barriers among Patients with Cardiovascular Diseases in Qatar. Awarded by Qatar University: Internal Student Grant. 2017.

- Poster Presentations:
 - Elbashir M, Awaisu A, El Hajj MS, Rainkie DC. Measurement of health literacy in patients with cardiovascular diseases: A systematic review (Poster). 7th Annual Research Forum, College of Pharmacy, Qatar University, Doha, Qatar. 24 May 2017.