

HEALTH LITERACY IN PATIENTS WITH NCDs

HEALTH LITERACY IN PATIENTS WITH NCDs

AMERICAN UNIVERSITY OF BEIRUT

EXPLORING HEALTH LITERACY IN PATIENTS
WITH NON-COMMUNICABLE DISEASE IN SOUTH LEBANON

by
HANADI ALI SAAD

A project
submitted in partial fulfillment of the requirements
for the degree of Master of Science in Nursing
Community and Public Health Nursing
to the Hariri School of Nursing
at the American University of Beirut

Beirut, Lebanon
January 2019

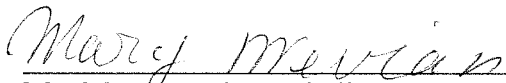
HEALTH LITERACY IN PATIENTS WITH NCDs

AMERICAN UNIVERSITY OF BEIRUT

EXPLORING HEALTH LITERACY IN PATIENTS
WITH NON-COMMUNICABLE DISEASE IN SOUTH LEBANON

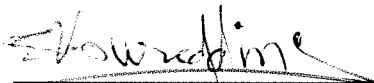
by
HANADI ALI SAAD

Approved by:



Mrs Mary Arevian Bakalian
Clinical Associate Professor
Hariri School of Nursing

First Reader



Dr. Samar Nouredine
Professor
Hariri School of Nursing

Second Reader

Date of project presentation: January, 25 2019

AMERICAN UNIVERSITY OF BEIRUT

THESIS, DISSERTATION, PROJECT RELEASE FORM

Student Name: Saad Hanadi Ali
Last First Middle

Master's Thesis Master's Project Doctoral Dissertation

I authorize the American University of Beirut to: (a) reproduce hard or electronic copies of my thesis, dissertation, or project; (b) include such copies in the archives and digital repositories of the University; and (c) make freely available such copies to third parties for research or educational purposes.

I authorize the American University of Beirut, to: (a) reproduce hard or electronic copies of it; (b) include such copies in the archives and digital repositories of the University; and (c) make freely available such copies to third parties for research or educational purposes after:

One --- year from the date of submission of my thesis, dissertation, or project.

Two --- years from the date of submission of my thesis, dissertation, or project.

Three years from the date of my thesis, dissertation, or project.

H. Saad,

Signature

February 1-2019

Date

ACKNOWLEDGMENTS

I would like to express my deepest gratitude and respect to Mrs. Arevian Bakalian & Dr. Nouredine for their vision, teaching, supervision, constructive guidance, support, encouragement, and critical appraisal of this work.

I am grateful to Dr. Nouredine for her guidance in grouping the variables and in writing the statistical findings.

I would like to extend my gratitude to the following individuals:

- Ms Hana'a Abdul Salam for her encouragement, support and help throughout my study and in accomplishing my project.
- Mr. Taher Faour, Mrs. Manal Akkoush & Ms. Ahlam Abdul Kareem for their help in the translation of scales.
- Mr. Nabih Murad for his support.

I would like to thank my family for their great support, patience, understanding and encouragement and not to forget my colleagues, and friends.

AN ABSTRACT OF THE PROJECT OF

Hanadi Ali Saad for Master of Science in Nursing
Major: Nursing

Title: Exploring Health Literacy in Patients with Non-Communicable Disease in South Lebanon

Patients' health literacy has a significant effect on both their self-care and health care outcomes. Low health literacy among patients has been associated with poor self-management and consequently more disease complications. There are limited data regarding this issue in Lebanon, which impacts negatively the health policy plan and imposes risk on health outcomes, thus making the topic vital to investigate.

The purpose: is to explore health literacy level in South of Lebanon among adult patients suffering from non-communicable diseases, in order to detect areas that need to be elaborated in planning health education instructions and awareness campaigns.

Methods: A cross sectional descriptive correlational study design was used to determine the level of health literacy among adult patients suffering from non-communicable diseases. A convenience sample of 120 adult patients ages 40 to 80 years diagnosed with chronic non-communicable diseases were recruited from four primary health care centers, consented to take the survey. *Instrument:* composed of two sections; socio-demographic information and All Aspects of Health Literacy Scale (AAHLS) with three subscales (functional, communication, and critical scale). Patients were recruited in coordination with the staff of the centers. After informed consent was secured; interview was conducted in a private room in the center, which lasted 5-10 minutes.

Results: Significant association at bivariate analysis, was found between socio-demographic characteristics: employment, nationality, educational level, and income with functional and communication health literacy level, except for diabetes mellitus which was not significantly associated with communication. The critical health literacy was significantly associated with only employment and educational level. Multivariate linear regression held significance only with educational level and income.

Implications: significant for health care providers and policy makers to improve quality of patient care

Conclusion: Further research is needed on national level to explore the level of health literacy and improve individual's health performance and abilities.

CONTENTS

	Page
ACKNOWLEDGEMENTS	V
ABSTRACT	VI
LIST OF TABLES	VIII
Chapter	
I. INTRODUCTION.....	1
II. REVIEW OF LITERATURE.....	7
III. METHODOLOGY.....	12
IV. RESULTS.....	20
<u>V.</u> DISCUSSION.....	31
REFERENCES.....	41

TABLES

Table	Page
4.1 Demographic characteristics by selected variables	22
4.2 Health Literacy Scale results	24
4.3 Significant associations between health literacy scale and demographic variables	25
4.4 Significant associations between health literacy scale and education and income	26
4.5 Regression analysis for the functional health literacy	27
4.6 Regression analysis for the communication health literacy	28
4.7 Regression analysis for the critical health literacy	29

CHAPTER I

INTRODUCTION

The health care system has grown at a fast pace and has transformed into a sophisticated system. Moreover, non-communicable diseases (NCDs), which include cardiovascular disease, cancer, diabetes mellitus and chronic respiratory diseases, constitute the leading cause of mortality and morbidity in the Eastern Mediterranean Region (World Health Organization [WHO], 2018). Non-communicable diseases (NCDs) are the major causes of death and disability worldwide as reported by WHO (2014) and need cost effective interventions to decrease mortality and burden of the diseases. Patients with NCDs need to manage multiple medications and undergo many lifestyle changes, which necessitate sophisticated knowledge. NCDs are also estimated to account for 85% of deaths in Lebanon (WHO, 2014). Moreover, the declaration of the 9th Global conference on health promotion in Shanghai in 2016 has highlighted “*the need for people to be able to control their own health -to be in position to make healthy lifestyle choices...and health literacy improving health*” (WHO, 9th Global conference, 2016).

NCDs require a lot of self-care management on the part of patients and their families. This necessitates that patients, in particular older adults, play an active role in their health care management and be able to navigate the complex health care system during their illness trajectory. Hence, patients need to have the cognitive abilities and skills to read, understand, comprehend and follow complex health care recommendations and instructions to ensure better health care outcomes (Cavanaugh et al., 2010; Price-Haywood et al., 2009; Rubinelli et al., 2009). Moreover, patients with NCDs need to comprehend and implement life style changes and acquire skills to manage their health (Baker, 2006). Consequently, inadequate knowledge of their

HEALTH LITERACY IN PATIENTS WITH NCDs

condition and decreased capability to search for information pose a major barrier to the patients' performance and subsequent achievement of positive health outcomes (Ringsberg et al., 2018; Edwards et al., 2012).

In Lebanon, Ramia and colleagues (2017) carried out a survey of 921 patients taking on average ≥ 5 medications /day. They reported inadequate knowledge of the medications and their adverse drug reactions, in addition to decreased patients' interaction with their health care providers (Ramia et al., 2017). The deficiency in data regarding the willingness of adults with non-communicable disease to learn about their disease and the preventive measures they need to take in Lebanon makes it worthy to assess the health literacy level among patients with non-communicable diseases. Health literacy according to Nutbeam (2009) is considered to have two elements: one is the ability to read and write, and second is the knowledge to find out information and skill to follow health instructions. Hence, the purpose of this study is to explore the level of health literacy among a convenience sample of 120 patients diagnosed with NCDs visiting four primary health care centers in South of Lebanon.

A. Background

Health literacy remains a controversial subject for researchers who aim to unfold the parameters that increase people's awareness and knowledge of health problems. The concept has originated from a basic ability to fulfill health related tasks that need reading and writing skills, in addition to cognitive skills that guide the analysis and processing of the acquired health information (Edwards, 2012). In 1986, the World Health Organization (WHO) has considered health literacy (HL) as one of ten future social health promotion challenges. HL was considered a pivot to promote community health and improve people's well-being. Thereafter, the subject of HL was a major subject in subsequent WHO conferences in Nairobi (2009), Helsinki (2013), and

HEALTH LITERACY IN PATIENTS WITH NCDs

Shanghai's declaration (2016) (www.who.int). Moreover, the plan of health in 2020 and the Marmot Commission report considered the subject of HL as a significant social determinant of health equity among communities (Ringsberg et al., 2018). Also, the Institute of Medicine addressed the need for cultural competence in health education for diverse racial/ethnic groups, based on studies that noted differences between the groups and documented the negative effects of limited health literacy that lead to poor health outcomes and decreased appreciation of health information (Lie et al., 2012; Kronfol, 2012; Rubinelli et al., 2009). Furthermore, in spite of the growing health information and internet accessibility, people with limited health literacy may not possess the skills they need to access and process this information (Gutierrez et al., 2013).

Studies in Western countries have shown high prevalence of risky health behaviors and serious disease sequelae and outcomes of non-communicable diseases (NCDs) among those with lower education (Romneike et al., 2016). On the other hand, Nair et al. (2016) assessed the health literacy in the Eastern and Middle-Eastern cultures as the concept of health literacy has proliferated rapidly due to its importance as a determinant of health. Better patient health literacy translated into better adherence to: medications, health instructions, and comprehension of well-formed healthy behaviors that contribute to better health outcomes, autonomy and fewer complications. A review by Kronfol (2012) revealed the presence of social inequalities and health inequalities between rural and urban Arab regions between various income, gender and ethnic groups. He pointed out that the risk of neonatal mortality of an illiterate mother is increased three times as compared to that of a mother of secondary or higher level of education (Kronfol, 2012).

Nutbeam (2009) extended the health literacy definition to include social, communication, and critical skills in order to improve the quality of life (Edwards, 2012). Many tools were

HEALTH LITERACY IN PATIENTS WITH NCDs

developed to study health literacy such as the Test of Functional Health Literacy in Adults (TOFLA). The TOFLA test focuses on the ability to read and comprehend health instructions given, and it consists of 50-item reading comprehension and 17-item numerical ability test. It takes up to 22 minutes to administer (Parker et al., 1995). Another tool is the Rapid Estimate of Adult Learning (REALM) that stresses on the evaluation of reading ability. It consists of 66-item word recognition. It assesses the adult's ability to read common medical words and spoken lay terminology of body parts and diseases (Davis et al., 1991). However, due to the longer time needed to complete health literacy assessment using these tools, they were modified and shortened to enhance screening. Still the short versions of these scales are limited to assessing comprehension of medical and health related words presented by the researcher to the patients. Furthermore, The Health Activities Literacy scale (HALS) (Chew et al., 2004), which measures health promotion, protection, disease prevention, and health care maintenance and navigation, was developed; but it was a long tool consists of 191 questions and takes up to one hour to be completed (Nutbeam, 2009; Edwards et al., 2012). Chinn and MacCarthy (2013) developed a 13-item shortened version of the HALS called the All Aspects of Health Literacy scale (AAHLS) that addresses patient's need for help in understanding health information and their information seeking behavior and communication with health care providers.

Studies have revealed a significant relation between decreased health literacy and negative health outcomes. Low health literacy was consistently correlated with decreased health care outcomes and inappropriate self-care management (Edwards et al., 2012; Gutierrez et al., 2013; Nair et al., 2016; Nutbeam, 2009; Zuhle & Engel, 2013;).

To date, there is no evidence of published research about HL in Lebanon. The purpose of the study was to explore the level of health literacy in South Lebanon among adult patients

HEALTH LITERACY IN PATIENTS WITH NCDs

suffering from non-communicable diseases, in order to detect areas that need to be elaborated on in planning health education programs and awareness campaigns.

B. Significance

Patient's health literacy affects health care outcomes directly and indirectly (Omachi et al., 2012). Studies have shown that low educational level of patients is significantly associated with their perceived ambiguity and misunderstanding of the health instructions provided by health care professionals (Schillinger et al., 2003). Moreover, health literacy levels were found to be different in various cultural and ethnic groups (Chow et al., 2013; Persell et al., 2007; Romeike et al., 2016; Shaw et al., 2009).

Many investigators have found a direct association between low health literacy level and decreased practice of well-known healthy habits and disease preventing measures (Wolf et al., 2012; Zuhlke, & Engel, 2013). Since optimal patient health literacy increases the ability of patients with NCDs to cope with lifestyle changes and take the preventive measures needed to improve their quality of life and decrease adverse health events, it was worth studying the aspects of health literacy among patients with non-communicable diseases.

Exploring the level of health literacy among the primary health care clients will set the foundation for developing an educational health program to fill the gap in knowledge of NCDs and their management (Lie et al., 2012). Therefore, the purpose of this project was to explore the level of health literacy among adult patients suffering from NCDs in primary health care centers in South Lebanon, to detect areas that need to be elaborated in planning health education initiatives and awareness campaigns. The findings of this study may have implications for policy makers in designing strategies to impact the overall burden of NCDs in Lebanon.

HEALTH LITERACY IN PATIENTS WITH NCDs

C. Purpose

The purpose of the study was to explore health literacy level in South Lebanon among a convenience sample of adult patients suffering from non-communicable diseases at four primary health care centers in South Lebanon.

The research questions were:

1. What is the level of health literacy in adults with non-communicable diseases who visit primary health care centers in South Lebanon?
2. What are the demographic and clinical variables associated with the level of health literacy among these adults?

CHAPTER II

REVIEW OF LITERATURE

Health literacy is a basic but complex concept that is defined in many ways. Yet, all the definitions converge on the concept of the cognitive ability (Baker, 2006; Nair et al., 2016). The concept is defined as: *“the capacity of an individual to obtain, interpret, and understand basic health information and services in ways that are health enhancing”* (Chinn, & McCarthy, 2013, p. 248).

In a review of studies in the field, Nutbeam (2009) has suggested measuring health literacy using two major elements: task based and skill based. Task based literacy relates to the capacity of the person to read and write short simple sentences. On the other hand, skill based literacy emphasizes the critical thinking needed to process information in order to accomplish a required task. Those two elements are needed to enable people to acquire the knowledge needed to enhance their share in society and improve their health outcomes (Nutbeam, 2009).

Globally, studies have shown that low patient health literacy is prevalent in under-developed countries, as well as well developed countries (Gu et al., 2002; Ringsberg et al., 2017). Chow et al. (2013) conducted a cross sectional study to investigate awareness, treatment and control of hypertension in rural and urban communities in countries of different income levels. The findings revealed that only 46.5% of the hypertensive participants were aware of their diagnosis and out of these, 32.5% had controlled blood pressure on treatment. The findings suggested that substantial improvement was possible in the diagnosis and treatment of hypertension and could be achieved with increased patient literacy (Chow et al., 2013).

HEALTH LITERACY IN PATIENTS WITH NCDs

Moreover, a study that was conducted in 2007 to assess the relationship between the level of health literacy and recall of antihypertensive medications and the medical record documentation in 119 participants with diagnosed hypertension attending three primary care clinics in Michigan State. The investigators detected that 31% of the participants who had limited health literacy were unable to name any of their antihypertensive drugs or recognize the medications that were documented in their medical record. The study had shown that low health literacy hypertensive patients are more likely to be prescribed \geq two antihypertensive drugs ($p=0.004$) than patients with higher literacy levels. Though, there were no association between the health literacy and the number of antihypertensive medications that patients recalled they are taking ($p=0.35$) (Persell et al., 2007).

In addition, Todd and Hoffman-Goetz (2010) found that decreased health literacy was correlated with limited comprehension ability and intentions to understand health information about colon cancer when not presented in their mother-tongue language among older Chinese immigrants women to Canada (Todd & Hoffman-Goetz, 2010). Wolf et al., (2012) conducted a cross sectional study in Chicago where they investigated the association between cognitive abilities on health literacy and functional health performance. Correlations between cognitive ability (processing speed, working memory, inductive reasoning, long term memory, prospective memory, fluid cognitive ability, and crystallized cognitive ability) and literacy measures (TOFLA, REALM, the Newest Vital Sign [NVS]) were statistically significant at $p < 0.001$. They found that lower health literacy was associated with decreased performance in healthcare tasks, which include and are not limited to reading and numeracy at a p value <0.001 . Thus, the authors suggested to further study all the cognitive demands faced by the patients in their health self-management and not only the skills of reading and calculation.

HEALTH LITERACY IN PATIENTS WITH NCDs

On the other hand, in 2010, Cavanaugh and colleagues found in their prospective cohort study of patients with renal failure in the United States of America, that increased mortality of patients with advanced kidney disease was strongly correlated with low health literacy. Cox proportional hazard regression analysis in the study of 480 incident chronic hemodialysis patients in 77 dialysis clinics, between 2005 and 2007 who were followed up till 2008, revealed significant risk of death 54% higher than those with adequate literacy skills (hazard ratio [HR], 95% [CI]: 1.54 [1.04 to 2.28]; P = 0.031). Thus, increasing the patient health information about end stage renal disease may be associated with decreased mortality in these patients (Cavanaugh et al., 2010).

Few studies have used the All Aspects of Health Literacy scale (AAHLS) to measure the level of patient's literacy. One was, through an online survey in which Barsell et al. (2018) studied the factors that contribute to positive or risky health behaviors. They examined the associations between the health literacy, self-efficacy, and health behaviors among 147 undergraduate college students from different ethnic groups with chronic conditions at a mid-Atlantic US university. They highlighted that health literacy and self-efficacy are potential prerequisites to maintain healthy behaviors (Barsell et al., 2018). They adopted the All Aspects of Health Literacy Scale to measure functional, communicative, and critical health literacy, The Chronic Disease Self-Efficacy Scales with 10 different subscales to measure self-efficacy, and the Health Behaviors Questionnaire to examine general behaviors, wellness maintenance, and general substance use. They reported that higher levels of health literacy and self-efficacy were significantly associated with general health behaviors and wellness maintenance and fewer substance use in college students diagnosed with chronic conditions (Barsell et al., 2018). Another study where the AAHLS scale was used to examine the functional, communicative, and

HEALTH LITERACY IN PATIENTS WITH NCDs

critical health literacy on foodborne diseases and HL effects on self-rated health was conducted in Accra, Ghana among individuals who live in an area that fits the United Nations definition of slum area. A mixed-method design was used by Gupta et al (2018) who administered a self-reported survey questionnaire (AAHLS) for 401 residents in Accra, Ghana and carried 30 in-depth interviews to selected participants from the sample who filled the questionnaire. A high mean score of the functional health literacy was significantly associated with higher educational level and higher social status. Although, the associations between the communicative and critical health literacy scores were not statistically significant with education, both the quantitative questionnaires and qualitative interviews indicated increased possibility that participants with higher educational level questioned more their health providers about their health conditions and health care. Moreover, the self-rated health of respondents was positively associated with overall health literacy. The authors concluded that an evident direct positive linkage exists between higher education and functional health literacy, which may translate into a positive relationship between health literacy and health status (Gupta et al., 2018).

Studies on health literacy in the Middle East region are limited. One survey was done in the United Arab Emirates and India simultaneously. The purpose of the study was to develop a questionnaire to assess health literacy within the context of the region's culture (Nair et al., 2016). The investigators developed and tested a short simple tool to check the ability of the patient who visits the primary health centers to read, understand and follow simple instructions (Nair et al., 2016). The internal consistency of the tool was measured and a Cronbach's α reliability coefficient for all the items of the final scale was high 0.85 (Nair et al., 2016).

A newly published cross-sectional study that was carried out by Ramia et al. (2017) in Lebanon between March and May 2016 assessed the outpatients' knowledge about the use of

HEALTH LITERACY IN PATIENTS WITH NCDs

their medications regardless of their diagnosis, and the medications' side effects. The investigators concluded that 56% of the sample showed sub-optimal knowledge of their medications, with the main deficiency in knowing about the adverse drug reactions. In addition, the study revealed insufficient communication between patients and health care providers (Ramia et al., 2017).

Optimal health is attained through an adequate level of health literacy, which has a positive impact on the patient's performance to self- manage their symptoms and improve their potentials, in order to decrease morbidity rate and out of pocket health expenses. The literature suggests inadequate health literacy to be prevalent (Stableford & Mettger, 2007). The complexity of the subject and its importance to the clients' health performance make the topic worth investigating in Lebanon, where the limited empirical evidence suggests that the problem does exist.

In summary, better health literacy level may improve patient's perception and adherence to health instructions provided, as he/she appreciates more the health outcomes that could be attained with primary and secondary health preventive measures. Increased health literacy level has a positive impact on the patient's health outcomes and decreased economic burden at the personal and public level. To our knowledge, this subject was not investigated in the country, which makes it an attractive subject to cover and explore.

CHAPTER III

METHODOLOGY

The purpose of this study was to explore the level of health literacy among a convenience sample of adult patients suffering from non-communicable diseases (NCD) in South Lebanon, who visit one of four primary health care centers in Saida and its surroundings. Another aim was to identify factors associated with health literacy in the sample.

A. Setting

The study was conducted at four centers in the South of Lebanon, namely Saida and its surroundings that are designated by the Lebanese Ministry of Public Health as primary health care centers. On average, each center serves approximately 30-35 patients per day, diagnosed with NCD(s) and who usually belong to low to middle income class. At the center(s) patients are followed up medically and receive monthly supply of medications for their chronic health condition(s).

B. Design

A cross-sectional descriptive correlational study design was used with survey methodology to explore the health literacy level in South Lebanon. A convenience sample of adult patients with non-communicable disease(s) was recruited from four primary health care centers in Saida and its surroundings, in order to determine the level of health literacy and its correlates. This design was appropriate to answer the research question since the aim was to investigate associations between study variables. The independent categorical variables included demographic and some illness related variables whereas the dependent variable included the health literacy level.

C. Sample

The target population was accessed through a convenience sample of 150 clients who came from various regions and with various nationalities (Lebanese, Syrians and Palestinians) to the four primary health care centers in Saida and its surroundings. They were low to middle class income patients diagnosed with NCDs. Patients who had two previous visits to the primary health care center within the last year were eligible to participate in the survey.

Given that no investigator has used the AAHLS as it was originally developed, we based the sample size calculation for this study on the formula by Polit & Beck (2008). Based on an alpha of 0.05, power of 80% and moderate effect size ($R^2 = 0.13$) and 7 predictors, the sample size needed $N = L/\sqrt{f^2} + k + 1$. L is the tabled value for the desired α and power; f^2 is the estimated effect size ($R^2/1-R^2$) and K is the number of predictors. In case of moderate effect size, $f^2 = 0.13/0.87 = 0.149$. Thus, the sample size needed is at least 104 participants. Considering a 20% refusal rate, we will recruit 124 participants to get our sample size

The study's inclusion and exclusion criteria were as follows.

1. Inclusion criteria

- Arabic speaking adults between the ages of 40 to 80 years
- Non-communicable disease diagnosis (chronic respiratory disease, diabetes mellitus, cancer, or/and cardiovascular disorders)
- Lebanese, Syrian, or Palestinian nationality
- The patient is cognitively intact, as evidenced by a score of 9/9 on the General Practitioner Assessment of Cognition (GPCOG)

HEALTH LITERACY IN PATIENTS WITH NCDs

2. Exclusion criteria

- All other persons who are not diagnosed as non-communicable disease (diabetes mellitus, hypertension, chronic respiratory disorders, cancer, or/and cardiovascular disorders) patients
- Those who are diagnosed with non-communicable disease and did not have two previous visits.
- People with mental disorder or hearing loss as this hinders their ability to be interviewed.

Out of 150 patients approached, 120 patients voluntarily consented to participate in the study, 30 from each center.

D. Recruitment and Ethical Considerations

Ethical approval to conduct the study was obtained from the American University of Beirut's Institutional Review Board. A letter was sent to the directors (Appendix A) of the four centers and meetings with the directors were done to arrange with them for the date and time availability at the centers and administrative approval of the chief executive of each of the four centers was secured before conduction of the study. An independent Collaborative Initiative Training Initiative (<https://www.citiprogram.org/>) certified person, Hanadi Ali Saad, a registered nurse and AUB MSN student, who is not employed at any of the four centers, reported to each center on the assigned time agreed on with the centers' managers. The participants were recruited upon registration of their visit by the nurse or the clerk at the center, who informed them about the study and invited them to participate. Those who agreed to participate were approached by the researcher after being invited by the nurse or clerk.

HEALTH LITERACY IN PATIENTS WITH NCDs

To determine eligibility for inclusion in the study, the researcher first did a quick cognitive assessment for the patients by asking the five questions of the general practitioner assessment of cognition (GPCOG) (Appendix B [English form] Appendix C for Arabic form) (Iatraki et al., 2017, Rashedi et al., 2018). The participant is told three words and asked to repeat them after few minutes. Then, he is asked five questions: 1) what is the date? 2) Please mark all the numbers to indicate the hours of a clock; 3) Please mark in hands to show 10 minutes past eleven o'clock (11:10); 4) Can you tell me something that happened in the news recently?; and 5) Repeat for me the name and address that I gave you 4 minutes before. The score ranges between 0 and 9. If the five questions are answered correctly (score = 9), the participant was considered eligible to participate and so the researcher then explained the aim of the survey, clarified any concerns or questions and provided with an informed consent. This eligibility screening was all done in a private room. Participants were asked to sign the consent form. For those who were illiterate, a witness who was a nurse or a family member was asked to sign as a witness the informed consent form.

The consent form (Appendix D [English form]) (Appendix E [Arabic form]) included the purpose of the study and the importance of the adults' responses to help understand the literacy level in order to use the information for promoting their health, in addition to a description of the research question, recruitment and study procedures, risks and benefits of participation. A copy of the consent form was provided to each participant. The participants were assured anonymity and confidentiality, and that deciding not to participate in the study will not affect them in anyway, as participation in the study is completely voluntary. To ensure confidentiality, data was reported in aggregate form. There was minimal to no risk to the participants. The information collected was kept in a secured location accessible only to the investigator.

E. Instruments

The independent categorical variables measured by self-report were age, gender, marital status, educational level, type of work, work setting, nationality, income, family relation to health personnel, comorbidities, years of diagnosis, and regular follow up. We thought that the work setting and having a relative who is a health professional might influence the patient's resource of health information. The dependent variable was health literacy with its three dimensions functional, communication, and critical health literacy.

1. All Aspects of Health Literacy Scale (AAHLS)

Patient health literacy is defined as: *“the capacity of an individual to obtain, interpret, and understand basic health information and services in ways that are health enhancing”* (Chinn, & McCarthy, 2013, p.247; Price-Haywood et al., 2009). Health literacy was measured using the *All Aspects of Health Literacy Scale (AAHLS)* (Chinn, & McCarthy, 2013), which is a 13-item self-report scale, which encompasses three subscales. It evaluates functional health literacy by asking how often do you need help to read health information given by the health professional, communicative health literacy by asking if the patient asks questions or explanation about his condition, and critical health literacy by asking if they question the information given or try to verify them by research (Appendix F [English form]) (Appendix G [Arabic form]). The first and third questions in the AAHLS scale were reverse-coded with a 3-point scale (often as one and rarely as three) where in the second question often was represented by number three and rarely represented by number one. On the other hand, questions 4-11 of the AAHLS scale had the number three to represent often and the number 1 to represent rarely. The higher the scores the higher the health literacy. Ishikawa et al. (2008) who developed the diabetes specific health

HEALTH LITERACY IN PATIENTS WITH NCDs

literacy scale, which consisted of the same set of questions as the AAHLS functional scale, similarly did reverse coding of the functional questions to get a higher score to indicate higher functional health literacy level (Ishikawa et al., 2008). The last three items are coined empirical items. One of them asks participants whether there are plenty of ways to have a say in what the government does about health rated as often, sometimes and rarely. The last two questions were dichotomous. One question asked whether or not participants did anything to affect the health of their family or community, and the other asked the participants what do they think is most important for their health. The AAHLS was used as a measure of the health literacy in primary health care settings (Chinn & MacCarthy, 2013). A mean score is obtained for the whole scale and the subscales namely functional, communicative and critical health literacy. Higher scores represented higher health literacy level (Barsell et al., 2018; Gupta et al., 2018).

The developers of the AAHLS reported a satisfactory internal consistency evidenced by an overall Cronbach's alpha coefficient = 0.74 (Chinn, & McCarthy, 2013). Reliability testing of the health literacy scale in this study showed Cronbach alpha coefficient value of 0.67 overall, with values of 0.39 for the functional scale, 0.58 for the communication subscale, and 0.54 for the critical subscale. Spearman Rho correlation coefficient was used to examine the associations among the three health literacy subscales. A significant moderate positive correlation was found between the communication and functional scores ($r = 0.43$, $P < 0.001$). A significant weak positive correlation was found between the critical and the functional scores ($r = .23$, $P = 0.01$). In addition, a moderate positive correlation was noted between the critical and communication scores ($r = 0.34$, $P < 0.001$).

The author of the AAHLS was contacted for usage of the scale and permission for translation to Arabic was secured (Appendix H). As for the GPCOG cognition scale, it was

HEALTH LITERACY IN PATIENTS WITH NCDs

available publicly online. Translation of both scales to Arabic was done by a bilingual professional followed by back-translation by a bilingual professional who was independent of the research team and not familiar with the study. The two Arabic versions were examined by an expert in the field, who evaluated the original and back translated versions as equivalent, so there was no need to do further modifications of the AAHLS (Appendix G [Arabic form]).

F. Pre-testing the Measures

To ensure face validity prior to data collection, the clarity of the phrases and meaningfulness of the survey items were pre-tested by four patients with NCD diagnosis, one from each center. No adjustments were needed and the questionnaire (Appendix H [English form]) was used in its original Arabic form (Appendix I [Arabic form]).

G. Data Collection

The researcher conducted the interviews with the eligible clients, after securing their informed consent. Data were collected using interview rather than giving the questionnaire to be self-administered since based on prior experience with community samples of the age group of this study, anecdotal evidence points to the preference of people to be interviewed rather than fill questionnaires. Moreover, the participants in the current study were of low to middle socioeconomic class, and thus interviews were more appropriate. The interview took at most 10 minutes. Data were collected over a 30-day period between the month of October and first week of November 2018.

H. Statistical analyses

Statistical Product and Services Solutions (SPSS) version 23 was used to analyze the data. Some of the demographic data were recoded. The marital status was collapsed to married

HEALTH LITERACY IN PATIENTS WITH NCDs

and not married, the nationality variable into Lebanese and non-Lebanese, while in the educational level baccalaureate and bachelor levels were collapsed into secondary level and above, and the category less than 6th grade was replaced by elementary, and brevet level by intermediate. The subscales mean scores of functional, communicative and critical health literacy were computed.

Descriptive statistics, namely frequencies and percentages were used to describe the demographic characteristics of the respondents. The overall and subscale health literacy scores were analyzed using means and standard deviation to answer the first research question.

To answer the second research question, independent sample t tests and Analysis of Variance (ANOVA) were used to analyze the associations between the level of health literacy, demographic and clinical variables. Independent samples t-test was used to study the relationship between the health literacy scores and gender, employment, nationality and diabetes mellitus status. ANOVA was performed to compare group means of the health literacy subscales against income, and level of education. The statistical significance level was set at 0.05. Multiple linear regression analyses were conducted to predict the three types of health literacy (Functional, Communicative and Critical) using the variables significantly correlated at the bivariate level of analysis with the health literacy scores. Variables significantly associated with health literacy at the bivariate level of analysis and relevant ones were entered into the multiple linear regression models in order to determine the significant predictors of functional, communicative and critical health literacy.

CHAPTER IV

RESULTS

In this chapter, description of the demographic characteristics of the sample is presented, in addition to the results of the descriptive, inferential statistics and regression findings.

The research questions of this study are:

1. What is the level of health literacy in adults with non-communicable diseases who visit primary health care in South Lebanon?

2. What are the demographic and clinical variables associated with the level of health literacy among these adults?

A. Sample Characteristics

The sample was equally distributed as 30 participants from each of the four centers. A total of 150 patients who met the inclusion criteria were invited to participate during the study period but only 120 patients (80%) voluntarily consented to participate in the study.

Table 1 presents the demographic characteristics of the participants. More than half of the study respondents were females (54.2%), while around half of them (47.5%) were between the ages of 51 and 65 years. The majority (77.5%) were married. Almost all the participants (84.2%) were Lebanese while the rest were either Syrians or Palestinians. More than half (54.2%) of the sample had a level of education less than elementary and 20% had high school and above education. More than two thirds (75.8%) were diagnosed with NCD since more than two years, and 14.2% were diagnosed since less than one year. The most frequent NCD diagnoses of the respondents were hypertension (61.7%), diabetes mellitus (48.3%), dyslipidemia (40%), other heart problems (33.3%) such as tachycardia and heart failure, coronary artery disease (30.8%),

HEALTH LITERACY IN PATIENTS WITH NCDs

respiratory problems (6.7%) and renal problems (4.2%). The time since the last doctor's visit ranged between one month and four months ago for 60.8 % of respondents, while 20% had the most recent visit to their doctor five to eight months ago. Around one third (34.2%) were employed, of whom more than two thirds (72.5%) had a monthly income less than 750,000LL, whereas 17.5% had their monthly income between 800,000LL and 1000,000 LL. Around one fifth (18.3%) of the participants had a relative who is a health care professional; out of those, 22.7% were the patient's son or daughter and 13.6% were the patient's spouse (Table 1).

Table 1. Demographic characteristics by selected variables (N=120)

Variables	Frequency	Percent
Gender		
Male	55	45.8
Female	65	54.2
Age (years)		
40-50	34	28.3
51-65	57	47.5
66-80	29	24.2
Marital status		
Married	93	77.5
Nationality		
Lebanese	101	84.2
Level of education		
Up to elementary	65	54.2
Intermediate	31	25.8
High school and above	24	20.0
Time since NCD diagnosis		
< 1 year	17	14.2
2 years	12	10.0
> 2 years	91	75.8
Non-communicable disease		
CAD	37	30.8
Other heart problems	40	33.3
HTN	74	61.7
DM	58	48.3
Dyslipidemia	48	40.0
Respiratory problems	8	6.7
Renal problems	5	4.2
Last visit to the doctor		
1 month – 4 months	73	60.8
5 months – 8 months	24	20.0
9 months – 12 months	11	9.2
> 1 year	12	10.0
Employment		
Yes	41	34.2
Monthly income		
< 750,000 LL	87	72.5
800,000 – 1,000,000 LL	21	17.5
> 1,000,000 LL	12	10.0
Has a relative in health profession	22	18.3

NCD=Non-communicable disease, CAD=coronary artery disease, HTN=hypertension, DM=diabetes mellitus.

B. Findings

1. Research question 1

What is the level of health literacy in adults with non-communicable diseases who visit primary health care in South Lebanon?

Table 2 shows the frequency of responses to the questions of the AAHLS tool. The mean functional scale score was 2.04, standard deviation (SD) 0.76. Over one third (35.8%) mentioned that they frequently needed someone to read health information given to them while 41.7% rarely needed help. Over one half (53.4%) of those who needed help had frequent access to assistance, whereas 27.4% answered sometimes. Moreover, almost half (41.7%) said that they frequently required help to fill an official document.

The mean communication scale score was 2.35 (SD 0.53). Two third of the participants (66.7%) said they frequently give health providers all the health information needed, whereas 25.8% said sometimes. Over half (55.8%) stated that they frequently ask questions to the health care providers versus 27.5% who sometimes asked. One-third (30.8%) ascertained that they understood everything given to them, while 43.3% said they sometimes understood.

The mean critical scale score was 2.13 (SD 0.53). Over two thirds (67.5%) frequently expressed interest in finding out information about their health. Moreover, only one fifth (28.3% and 23.3%, respectively) reported questioning the reliability and credibility of the information supplied to them by the health providers and thinking it was well trusted. In addition, 40% reported rarely investigating information given by health care providers.

For the empirical questions, 60% of the respondents thought that they rarely have an influence on what the government does about health. Most participants (80%) did not take any

HEALTH LITERACY IN PATIENTS WITH NCDs

action during the last 12 months toward a problem that affected their family or community's health. Moreover, 59.2 % considered the healthy habitat, education and decent work as the most important aspects for every one's health versus 40.8 % who considered health information and healthy lifestyle the most important aspects.

Table 2. Health Literacy Scale Results (N = 120)

Questions	Rarely n (%)	Sometimes n (%)	Frequently n (%)
FQ1: How often do you need someone to help you when you are given information to read by your doctor, nurse/pharmacist?	50 (41.7)	27 (22.5)	43 (35.8)
FQ2: When you need help, can you easily get hold of someone to assist you?*	14 (19.2)	20 (27.4)	39 (53.4)
FQ3: Do you need help to fill in official documents?	47 (39.2)	23 (19.2)	50 (41.7)
Functional Scale (Mean, SD)		2.04 (0.76)	
Com Q1: When you talk to a doctor or nurse, do you give them all the information they need to help you?	9 (7.5)	31 (25.8)	80 (66.7)
Com Q2: When you talk to a doctor or nurse, do you ask the questions you need to ask?	20 (16.7)	33 (27.5)	67 (55.8)
Com Q3: When you talk to a doctor or nurse, do you make sure they explain anything that you do not understand?	31 (25.8)	52 (43.3)	37 (30.8)
Communication Scale (Mean, SD)		2.35 (0.53)	
Cr1: Are you someone who likes to find out lots of different information about your health?	17 (14.2)	22 (18.3)	81 (67.5)
Cr2: How often do you think carefully about whether health information makes sense in your particular situation?	24 (20)	62 (51.7)	34 (28.3)
Cr3: How often do you try to work out whether information about your health can be trusted?	54 (45)	38 (31.7)	28 (23.3)
Cr4: Are you the sort of person who might question your doctor or nurse's advice based on your own research?	48 (40)	34 (28.3)	38 (31.7)
Critical Scale (Mean, SD)		2.13 (0.53)	
Emp1: Do you think that there are plenty of ways to have a say in what the government does about health?	72 (60)	33 (27.5)	15 (12.5)

Legend: FQ = functional question, Com Q = communication question, Cr = critical, Emp = empirical. * This question had a not applicable option that was coded as missing, thus we lost 47 cases from the total count on this item

HEALTH LITERACY IN PATIENTS WITH NCDs

2. Research question 2

What are the demographic and clinical variables associated with the level of health literacy among these adults? Table 3 presents significant results of the independent sample t-test for the associations between health literacy and the demographic variables. The employed had higher functional, communication and critical scores ($p = 0.033$, $p = 0.005$ and 0.009 , respectively) than the unemployed. The Lebanese had higher functional and communication scores ($p = 0.048$, $p < 0.001$) than the non-Lebanese. Patients with diabetes mellitus had lower functional health literacy than the non-diabetics ($p = 0.048$). Females had lower functional score than males (1.92 vs. 2.18) but the difference was not significant ($p = 0.064$). Having a health professional relative was marginally associated with higher functional (2.31 vs. 1.98, $p = 0.063$)

Table 3. Significant Associations between Health Literacy and Demographic Variables (N = 120)

Variables	Mean (SD)	P-value
Diabetes Status		
<i>Functional score</i>		
Diabetes	1.90 (0.76)	0.048
No diabetes	2.17 (0.73)	
Employment		
<i>Functional Score</i>		
Not employed	1.93 (0.75)	0.033
Employed	2.24 (0.74)	
<i>Communication score</i>		
Not employed	2.25 (0.52)	0.005
Employed	2.55 (0.49)	
<i>Critical score</i>		
Not employed	2.04 (0.52)	0.009
Employed	2.31 (0.52)	
Nationality		
<i>Functional Score</i>		
Lebanese	2.09 (0.77)	0.048
Non-Lebanese	1.75 (0.63)	
<i>Communication score</i>		
Lebanese	2.22 (0.49)	< 0.001
Non-Lebanese	1.96 (0.59)	

Legend: SD=Standard deviation

HEALTH LITERACY IN PATIENTS WITH NCDs

Table 4 presents the significant results of ANOVA for the association between health literacy scores, education and income levels. Higher education levels were noted with higher levels of literacy for the three subscales; p values were < 0.001 for both the functional and communication scales and p= 0.002 for the critical scale. Higher income was associated with higher levels of functional, communication and critical health literacy (p = 0.003, p = 0.003 and 0.048, respectively). No other significant associations were found between health literacy scores and age, time since NCD diagnosis, marital status, type of NCD, and time since the last visit to the doctor.

Table 4. Significant Associations between Health Literacy, Education and Income (N=120)

Variables	Mean (SD)	P-value
Educational level		
<i>Functional Score</i>		
Elementary	1.63 (0.07)	< 0.001
Intermediate	2.35 (0.12)	
High school and above	2.74 (0.10)	
<i>Communication Score</i>		
Elementary	2.19 (0.51)	< 0.001
Intermediate	2.41 (0.59)	
High school and above	2.69 (0.31)	
<i>Critical Score</i>		
Elementary	1.98 (0.54)	0.002
Intermediate	2.26 (0.45)	
High school and above	2.38 (0.48)	
Income		
<i>Functional Score</i>		
<750,000	1.88 (0.73)	0.003
800,000-1,000,000	2.45 (0.63)	
>1000000	2.51 (0.72)	
<i>Communication Score</i>		
<750,000	2.25 (0.55)	0.003
800,000-1,000,000	2.60 (0.34)	
>1,000,000	2.64 (0.44)	
<i>Critical score</i>		
<750,000	2.07 (0.52)	0.048
800,000-1,000,000	2.22 (0.49)	
>1,000,000	2.44 (0.56)	

Legend: SD=Standard deviation

HEALTH LITERACY IN PATIENTS WITH NCDs

Three separate multiple linear regression analyses were conducted to determine the predictors of the functional, communication and critical health literacy subscales. Dummy variables were created for education and income since each one of them had three levels.

For the functional health literacy, the variables entered were gender, employment, nationality, education, income and diabetes status. Table 5 shows the results of the multiple regression for the functional health literacy. The model explained 43% of the variance in functional health literacy ($F_{(8,119)} = 10.25, p < 0.001$). As shown in table 5, the significant predictors were education such that intermediate and higher education predicted higher functional health literacy than elementary education, and income such that middle and higher income predicted higher functional health literacy than low income.

Table 5. Regression Analysis for Functional Health Literacy (N = 120)

Variable	B	SE of B	Beta	95% CI		P value
				Lower bound	Upper bound	
Gender	-0.08	0.13	-0.05	-0.33	0.17	0.527
Employment	-0.14	0.14	-0.09	-0.42	0.14	0.331
Nationality	-0.03	0.16	-0.01	-0.33	0.28	0.867
Income: Reference						
Low income						
Middle income	0.35	0.15	0.18	0.05	0.65	0.024
High income	0.29	0.20	0.12	-0.02	0.68	0.142
Education: Reference						
Elementary education						
Intermediate	0.65	0.14	0.38	0.39	0.92	0.000
High School	0.99	0.16	0.53	0.62	1.30	0.000
Diabetes	-0.20	0.11	-0.14	-0.42	0.02	0.068

Legend: SE = Standard Error; CI = confidence interval

HEALTH LITERACY IN PATIENTS WITH NCDs

For the communication health literacy, the variables entered in the regression analysis were employment, nationality, education and income. Table 6 presents results of the regression for the communication health literacy. The model explained 24% of the variance in communication health literacy ($F_{(6,119)} = 5.93, p < 0.001$). As noted in the table, nationality and having at least high school education were significant predictors of communication health literacy. Being Lebanese and having at least high school education predicted higher communication health literacy than having other nationality or lower education levels, respectively. Having middle income did not reach statistical significance ($p = 0.088$) yet it predicted higher communication health literacy versus having low income.

Table 6. Regression Analysis for Communication Health Literacy (N = 120)

Variable	B	SE of B	Beta	95% CI		P value
				Lower bound	Upper bound	
Employment	0.15	0.10	0.14	-0.05	0.35	0.129
Nationality	-0.35	0.12	-0.24	-0.59	-0.10	0.006
Income: Reference						
Low income						
Middle income	0.21	0.12	0.15	-0.03	0.45	0.088
High income	0.16	0.16	0.09	-0.15	0.47	0.298
Education: Reference						
Elementary education						
Intermediate	0.12	0.11	0.10	-0.09	0.34	0.251
High School	0.30	0.13	0.22	0.04	0.55	0.022

Legend: SE = standard error; CI = confidence interval

For the critical health literacy, the variables entered were employment, income and education. Table 7 shows results of the regression analysis for critical health literacy. The model explained 13% of the variance in critical health literacy. ($F_{(5,119)} = 3.51, p = 0.006$). As noted in

HEALTH LITERACY IN PATIENTS WITH NCDs

the table the only predictor was having at least high school education, as this variable predicted significantly higher critical level of health literacy than having elementary education. Having intermediate education approached significance in predicting higher critical health literacy ($p = 0.056$) than elementary education.

Table 7. Regression Analysis for critical Health Literacy (N = 120)

Variable	B	SE of B	Beta	95% CI		P value
				Lower bound	Upper bound	
Employment	0.15	0.11	0.13	-0.06	0.36	0.156
Income: Reference						
Low income						
Middle income	0.04	0.13	0.03	-0.22	0.29	0.779
High income	0.22	0.16	0.13	-0.10	0.55	0.181
Education: Reference						
Elementary education						
Intermediate	0.22	0.11	0.18	0.00	0.45	0.056
High School	0.28	0.13	0.21	0.02	0.54	0.036

Legend: SE = standard error; CI = confidence interval

In summary, more than half of the respondents were females and almost half of them were between the ages 51 and 65. The majority were married, Lebanese and diagnosed with NCD for more than two years, with a monthly income less than 750,000 LL. In addition, more than half had elementary educational level and visited the health care provider within the past four months. The mean score of the sample on the health literacy scales were for the functional scale 2.04, the communication scale 2.35, and the critical scale 2.13. Unadjusted significant associations were found between: a- the functional health literacy scale score and employment, nationality, educational level, income and diabetes status; b- the communication scale score and

HEALTH LITERACY IN PATIENTS WITH NCDs

employment, nationality, educational level, and income; and c- the critical scale score and employment, educational level, and income. Multiple linear regression analyses showed that education and income predicted functional health literacy, whereas income and nationality predicted communication literacy, and only education predicted critical health literacy.

CHAPTER V

DISCUSSION

The aims of the study were to explore the level of health literacy in South Lebanon among a convenience sample of adult patients suffering from non-communicable diseases at four primary health care centers in Saida and its surroundings, and to identify factors associated with health literacy in the sample. This chapter includes discussion of the study findings in relation to those present in the literature. The discussion is organized according to the findings, followed by directions for future research. Limitations of the study, recommendations and conclusions are included in this chapter.

Overall, the sample included mostly middle aged married Lebanese patients who were equally distributed by gender and of low socioeconomic status. The health literacy scores ranged between 2.04 for the functional scale and 2.35 for the communication scale. Important predictors of health literacy in this sample included mostly socioeconomic status (education and income), in addition to nationality for the functional and communication scales.

The following section presents the discussion according to the research questions.

A. **Research question 1**

What is the level of health literacy in adults with non-communicable diseases who visit primary health care center in South of Lebanon?

The findings of the study revealed that around half of the patients who are diagnosed with NCDs are middle-aged (47.5%), females (54.2%) and at the elementary education level (54.2%). The mean subscale score of: functional HL 2.04 (SD 0.76), communicative HL 2.35 (SD 0.53), and critical HL 2.13 (SD 0.53) were obtained in this study. Similar findings were reported by Barsell et al.,

HEALTH LITERACY IN PATIENTS WITH NCDs

(2018), Gupta et al. (2018), and Sykes and Wills (2018), respectively. Barsell et al. (2018) reported in college students with chronic conditions the following scores: functional HL 1.79 (SD 0.46), communicative HL 2.6 (SD 0.50), and critical HL 2.12 (SD 0.56). Lower scores among the college students may be accounted for by their limited exposure to health care, as opposed to our older sample. Gupta et al., (2018) has calculated the mean score for the subscales of the AAHLS and had some similar findings to ours. Gupta et al did not report the age in the demographic data and the participants did not have a chronic disease. The inclusion criteria were those with food borne diseases. Sykes and Wills explored the processes to build the critical health literacy using the AAHLS but they reported their results by the frequencies of rarely, sometimes, or often participants' response to each question in the scale as pre and post-intervention assessment (Sykes & Wills, 2018).

A real reflection of the Lebanese apathetic role toward the hazards that endanger their health and the community is obvious in the responses where more than half of the sample did not believe that they have a say in what the government does for health, and the majority did not take any action to solve a health problem in their community. In addition, almost two thirds believed that healthy habitat, education and decent work is more important than healthy lifestyle or health information. Thus, one needs to deeply study such responses as how the general low socioeconomic condition in the society is affecting the values of the people and their beliefs.

At the bivariate association analysis, diabetes mellitus was significantly associated with the level of functional health literacy ($p=0.048$). However, adjusted analysis showed no significant difference, which may be accounted for by the small sample size. Nevertheless, the decreased functional HL level in those diagnosed with diabetes mellitus (52% versus 32% did not have diabetes) is of high concern in the practice field as low functional literacy levels were

HEALTH LITERACY IN PATIENTS WITH NCDs

shown to be correlated to increased incidence of diabetic complications. It is worth noting that diabetes mellitus does not exist as a disease entity by itself. It is always associated with comorbidities as we noticed in our study, where 69% of the diabetics had hypertension vs. 41% and the association was almost significant ($p=0.053$), in addition to other co-morbidities as dyslipidemia, CAD and high risk of developing cardiovascular problems. Many studies have shown a direct relationship between low health literacy and critical health outcomes in diabetic patients (Ishikawa et al., 2008; Vandenbosch et al., 2018), in addition to Barsell's (2018) statement about the negative effect of low health literacy on the health consequences and the management of chronic conditions (Barsell et al., 2018). Thus, as the number of people who are diagnosed with diabetes mellitus is high in Lebanon and the study reveals low health literacy in this group, increased attention and more care are needed for this group if diabetic complications are to be attended to and decreased.

The findings of our study coincide with one study by Ramia et al. (2016). Ramia et al. found that better medication knowledge is positively associated with higher education level ($p=0.035$), comorbidities ($p=0.026$) and increased patient-health provider interaction ($p=0.012$). As a conclusion to their study, they raised a concern about studying patient's ability to read and process the written information given to them in order to really understand the benefits and risks of their ordered medication (Ramia et al., 2016). Another study carried out by Todd & Hoffman-Goetz who found out that 50% of the English-as-a-second-language Chinese women studied had an inadequate comprehension of colon cancer prevention information when they were offered the information in English as compared to 7.5% of the Chinese women who were offered the information in the Chinese language (Todd & Hoffman-Goetz, 2011).

HEALTH LITERACY IN PATIENTS WITH NCDs

Furthermore, the level of education also had a positive association with the communication and critical scale score where increased level of health literacy correlated with increased level of education. Most of the studies have identified the significant association of the health literacy level and the level of education in the way patient communicated their needs and their practice in medication reconciliation, and ability to make proper health decisions and self-efficacy (Wolf et al., 2012). Investigators of a study of medication reconciliation in an ambulatory care center concluded that 30.5 % of participants, who had high school or general equivalency diploma, attained marginal/adequate health literacy as compared to only 7.3% of participants who had less than 8th grade completion (Persell et al., 2007). It is worth noting, the results of the survey that investigated the association of health literacy and exacerbation of outcomes in chronic obstructive pulmonary disease (COPD), which concluded that those with decreased educational level had lower functional health literacy level and decreased self-efficacy management (Omachi et al., 2012; Gupta et al., 2018). Omachi et al. (2012) assessed the health literacy by the 3 item questionnaire developed by Chew and colleagues which assessed the reading and writing abilities.

Furthermore, higher functional, communication and critical health literacy was associated with being employed, which is logical and meets the findings of Gupta et al. (2018), where the employed participants owned better communication and decision making skills. This could be explained by the necessity of the employed to own better negotiation skills and need to analyze the situations they face in their daily life encounters at work, and possibly having more resources to get help in understanding health information. Edwards et al. (2012) who analyzed the type of the profession as a variable in a longitudinal qualitative study that explored how health literacy skills affect the way patients seek information and play an active role in sharing the decision in

HEALTH LITERACY IN PATIENTS WITH NCDs

their care among 18 patients. The authors concluded that those with some knowledge about their condition were actively involved in seeking information and had assertive communication skills with the health provider in a manner to enlighten them about their condition and negotiation of treatment options (Edwards et al., 2012). Nevertheless the association with employment lost its significance in the multiple regression analysis, possibly because of the interaction between employment and the level of education, where only 20% of those with elementary education being employed versus 45.2% and 58.3% of those with intermediate and high school education ($\chi^2 = 13.70, p = 0.001$).

In addition, the findings showed that Lebanese participants had higher functional and communication score. Many investigators have pointed out how the cultural, ethnic and social differences and beliefs impact the level of health literacy and health practice in many different countries (Romeike et al., 2016; Vandenbosch et al., 2018). Shaw et al. (2009) have examined the cultural influences on health literacy, cancer screening, and disease outcomes as they are an integral part that allows the patient to perceive the proper healthy behavior needed to understand, motivate and take appropriate health actions in an attempt to improve own health. The authors concluded that any program that does not consider these parameters is unlikely to meet the needs of the targeted population (Shaw et al., 2009). Another research has investigated what do health literacy and cultural competence have in common. The disparities in health literacy levels among the various ethnic groups within the American population drew the attention of the scientists to the need to shift their attention from supplying health services to preparing health professionals who are culturally competent educators, in order to enhance patients' health literacy level and achieve better health with cost containment (Lie et al., 2012). The significant association with nationality did not hold at the multiple regression, possibly since the majority of the sample

HEALTH LITERACY IN PATIENTS WITH NCDs

(84.2%) were Lebanese who were significantly more educated than the non-Lebanese (intermediate education 83.9 vs. 16.1% and high school and above 100 vs. 0%, $\chi^2 = 6.10$, $p = 0.047$).

The functional, communication, and critical health literacy scores were all positively associated to the monthly income of the individual. These results are in line with the previous studies that had similar findings (Shaw et al., 2008; Omachi et al., 2012; Kronfol, 2012; Chow et al., 2013; Vandenbosch et al., 2018; Zuhle & Engel, 2013). The increased health literacy level correlated with high income, which is significantly associated with higher level of education (people earning above 1 million L.L. per month included 4.6% with elementary education, 9.7% with intermediate education, and 25% with high school and above ($\chi^2 = 15.06$, $p = 0.005$). This finding indicates higher cognitive capabilities that enables the person to use critical thinking in analyzing and better utilize the given information. This will enable the person to exercise optimal control over his health life course. The reduction in predictive power of income on health literacy in the multiple regression is explained by interaction with the level of education.

B. Research question 2

Which demographic and clinical variables associated with the level of health literacy among these adults.

No significant correlation was noted between health literacy and age, marital status, type of the diagnosis or the number of comorbidities, and time since last visit. Thus, these variables do not necessarily have any impact on the level of health literacy in this sample. Gupta et al. (2018) and Vandenbosch et al. (2018) had similar findings (Gupta et al., 2018; Vandenbosch et al., 2018). Moreover, no significant correlation was found between the interval since diagnosis,

HEALTH LITERACY IN PATIENTS WITH NCDs

co-morbidities (except for diabetes) and health literacy level, which contradicted the findings of one study (Edwards et al., 2012) where the findings suggested that health literacy advances in long-term health conditions. Patients build up knowledge about the condition and improve the self- management through frequent encounters and negotiation of their case with their health providers (Edwards et al., 2012). It is worth noting that in this study there was a repeated complaint by most patients that they were not given enough time to discuss issues during their encounter with their health care provider.

Significant correlations were noted respectively between functional health literacy and diabetes diagnosis, employment, nationality, income, and educational level at the bivariate level of analysis while borderline correlation was noted between functional HL and gender. Females had lower functional HL less than males. The findings are comparable to those of Omachi et al. (2012) where higher health literacy level was correlated to higher educational level and higher income ($p < 0.001$). In addition, Wolf et al. (2012) found that lower health literacy was associated with less education and lower income. He used three measures to assess the health literacy level. They were the Rapid Estimate of Adult Literacy in Medicine (REALM), Test of Functional Health Literacy in Adults (TOFLA), and Newest Vital Signs (NVS). In another study that used the Rapid Estimate of Adult Literacy in Medicine, the authors found that 32% of the sample who were $< 9^{\text{th}}$ grade reading level had limited health literacy compared to 68% with $\geq 9^{\text{th}}$ grade reading level who had adequate health literacy level (Cavanaugh et al., 2010). In the multiple regression, the level of education persisted as the significant predictor of all types of health literacy, despite interaction with other covariates.

C. Limitations

The study has several limitations. The major limitation of this study is that the obtained health literacy level is a self-report measure (soft measure). Furthermore, data collection was through interview, which might lead to the interviewer's bias. It is also possible that patients did not report all the diagnoses they had and may not have been aware of them, as the information were not validated against the patient's file. The comorbidities were just what the patient has reported. In addition, the results of this study can only be generalized to a setting that is similar to the health care centers where the study was conducted, which are not representative of all primary health care centers in Lebanon. Finally, Cronbach alphas of the scale were low (below 0.7), which could be another limitation.

This study was a preliminary research to look at the health literacy level among adult Lebanese diagnosed with NCDs in South Lebanon.

D. Directions for future research

1. Further testing of the AAHLS tool is needed in the Lebanese population. We recommend consultation with experts in health education and cognitive interviewing to revise and adapt this scale to the Lebanese population, followed by psychometric testing in a sufficiently large sample.
2. Patients need to be supported throughout their life span to develop their health literacy and to know the skills they need to develop, in an effort to maintain optimal health and better health outcomes. Thus, measuring health literacy level of the population establishes the ground for successful patient education and provides policy makers with the information to establish strategies that will attract and support the patient, while containing cost and health

HEALTH LITERACY IN PATIENTS WITH NCDs

complications. Future studies must examine health literacy in relation to patient outcomes, such as quality of life and satisfaction with health care.

3. 3. Replication of the study on a national basis across primary health care centers in order to generalize the results and set up a national agenda to improve health literacy level is recommended. Research will guide community stakeholders to set educational health programs that aim to change attitudes toward health and not only change behaviors based on future studies of health literacy level of the Lebanese population.
4. It is recommended to have the source of the health information as one of the dependent variables.

E. Implications for primary health care center nurses

1. Encourage community nurses to assess the health literacy of their patients in order to identify gaps and try to fill them. For instance, we know from experience that in Lebanon many people get their health information from the neighbor or the pharmacist, which may not be appropriate.
2. Pay increased attention to those clients with diabetes mellitus regarding health literacy, in an attempt to prevent serious diabetic complications.
3. Set strategies to build educational programs regarding NCDs based on the health literacy level in order to decrease the negative effects and unwanted disease outcomes by continuing education courses, continuous evaluation of adults' adherence to instructions and assessment of attitude toward the information supplied.
4. Allow more time for communication with patients and improve patient-health care provider relationship, as it is underexplored.

HEALTH LITERACY IN PATIENTS WITH NCDs

5. Health providers should refrain from medical jargon and use repeat instructions with all patients whatever their health literacy level to ensure patient safety and better quality of care.

F. Conclusion

In conclusion, in this sample of middle-aged chronically ill patients with low education and low income, the level of health literacy seemed reasonable. The major positive predictors were education, income and nationality with its attendant socioeconomic characteristic; these predictors are determinants of health. Improving the social conditions of this population may be one step towards improving its health literacy.

HEALTH LITERACY IN PATIENTS WITH NCDs

References

- Baker, D. W. (2006). The meaning and the measure of health literacy. *Journal of General Internal Medicine*, 21(8), 878-883.
- Barsell, D. J., Everhart, R. S., Miadich, S. A., & Trujillo, M. A. (2018). Examining Health Behaviors, Health Literacy, and Self-efficacy in College Students With Chronic Conditions. *American Journal of Health Education*, 49(5), 305-311.
- Cavanaugh, K. L., Wingard, R. L., Hakim, R. M., Eden, S., Shintani, A., Wallston, K. A., ... & Ikizler, T. A. (2010). Low health literacy associates with increased mortality in ESRD. *Journal of the American Society of Nephrology*, 21(11), 1979-1985. DOI 10.1681/ASN.2009111163
- Chew, L. D., Bradley, K. A., & Boyko, E. J. (2004). Brief questions to identify patients with inadequate health literacy. *health*, 11, 12.
- Chinn, D., & McCarthy, C. (2013). All Aspects of Health Literacy Scale (AAHLS): developing a tool to measure functional, communicative and critical health literacy in primary healthcare settings. *Patient education and counseling*, 90(2), 247-253
- Chow, C. K., Teo, K. K., Rangarajan, S., Islam, S., Gupta, R., Avezum, A., ... & Kazmi, K. (2013). Prevalence, awareness, treatment, and control of hypertension in rural and urban communities in high-, middle-, and low-income countries. *Journal of the American Medical Association*, 310(9), 959-968. DOI 10.1001/jama.2013.184182
- Davis, T. C., Crouch, M. A., Long, S. W., Jackson, R. H., Bates, P., George, R. B., & Bairnsfather, L. E. (1991). Rapid assessment of literacy levels of adult primary care patients. *Family medicine*, 23(6), 433-435.
- Edwards, M., Wood, F., Davies, M., & Edwards, A. (2012). The development of health literacy in patients with a long-term health condition: the health literacy pathway model. *BMC Public Health*, 12(1), 130.
- Gu, D., Reynolds, K., Wu, X., Chen, J., Duan, X., Muntner, P., ... & He, J. (2002). Prevalence, awareness, treatment, and control of hypertension in China. *Hypertension*, 40(6), 920-927. DOI10.1161/01.HYP.0000040263.94619.D5

HEALTH LITERACY IN PATIENTS WITH NCDs

- Gupta, S., Tutu, R. A., Boateng, J., Busingye, J. D., & Elavarthi, S. (2018). Self-reported functional, communicative, and critical health literacy on foodborne diseases in Accra, Ghana. *Tropical medicine and health, 46*(1), 15.
- Gutierrez, N., Kindratt, T. B., Pagels, P., Foster, B., & Gimpel, N. E. (2014). Health literacy, health information seeking behaviors and internet use among patients attending a private and public clinic in the same geographic area. *Journal of Community Health, 39*(1), 83-89. DOI 10.1007/s10900-013-9742-5
- Harnett, S. (2017). Health literacy tool shed: A source for validated health literacy instruments. *Journal of Consumer Health on the Internet, 21*(1), 78-86.
- Iatraki, E., Simos, P. G., Bertias, A., Duijker, G., Zaganas, I., Tziraki, C., ... & THALIS Primary Health Care Research Team/Network. (2017). Cognitive screening tools for primary care settings: examining the 'Test Your Memory' and 'General Practitioner assessment of Cognition' tools in a rural aging population in Greece. *European Journal of General Practice, 23*(1), 172-179.
- Ishikawa, H., Takeuchi, T., & Yano, E. (2008). Measuring functional, communicative, and critical health literacy among diabetes patients. *Diabetes care.*
- Kronfol, N. M. (2012). Access and barriers to health care delivery in Arab countries: a review. *Eastern Mediterranean Health Journal, 18*(12), 1239.
- Lie, D., Carter-Pokras, O., Braun, B., & Coleman, C. (2012). What do health literacy and cultural competence have in common? Calling for a collaborative health professional pedagogy. *Journal of Health Communication, 17*(sup3), 13-22. DOI 10.1080/10810730.2012.712625
- Nair, S. C., Satish, K. P., Sreedharan, J., & Ibrahim, H. (2016). Assessing health literacy in the eastern and middle-eastern cultures. *BMC Public Health, 16*(1), 831. Doi 10.1186/s12889-016-3488-9
- Nutbeam, D. (2009). Defining and measuring health literacy: what can we learn from literacy studies? *Int J Public Health (2009) 54:303-305* DOI 10.1007/s00038-009-0050-x

HEALTH LITERACY IN PATIENTS WITH NCDs

- Omachi, T. A., Sarkar, U., Yelin, E. H., Blanc, P. D., & Katz, P. P. (2013). Lower health literacy is associated with poorer health status and outcomes in chronic obstructive pulmonary disease. *Journal of General Internal Medicine*, 28(1), 74-81. DOI 10.1007/s11606-012-2177-3
- Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of functional health literacy in adults. *Journal of general internal medicine*, 10(10), 537-541.
- Persell, S. D., Osborn, C. Y., Richard, R., Skripkauskas, S., & Wolf, M. S. (2007). Limited health literacy is a barrier to medication reconciliation in ambulatory care. *Journal of General Internal Medicine*, 22(11), 1523-1526. DOI 10.1007/s11606-007-0334-x
- Price-Haywood, E. G., Roth, K. G., Shelby, K., & Cooper, L. A. (2010). Cancer risk communication with low health literacy patients: a continuing medical education program. *Journal of General Internal Medicine*, 25(2), 126-129. DOI 10.1007/s11606-009-1211-6
- Polit, D. F., & Beck, C. T. (2008). *Nursing research: Generating and assessing evidence for nursing practice* (9th ed.) Philadelphia, PA: Lippincott Williams & Wilkins.
- Ramia, E., Zeenny, R. M., Hallit, S., & Salameh, P. (2017). Assessment of patients' knowledge and practices regarding their medication use and risks in Lebanon. *International Journal of Clinical Pharmacy*, 39(5), 1084-1094.
- Rashedi, V., Foroughan, M., Nazari, H., Seeher, K., & Brodaty, H. (2018). Validity and reliability of the Persian version of general practitioner assessment of cognition (P-GPCOG). *Aging & mental health*, 1-5.
- Ringsberg, K. C., Olander, E., Tillgren, P., Thualagant, N., & Trollvik, A. (2018). Concerns and future challenges of health literacy in the Nordic countries—From the point of view of health promotion practitioners and researchers. *Scandinavian Journal of Public Health*, 46(20_suppl), 107-117.
- Romeike, K., Abidi, L., Lechner, L., Vries, H., & Oenema, A. (2016). Similarities and differences in underlying beliefs of socio-cognitive factors related to diet and physical

HEALTH LITERACY IN PATIENTS WITH NCDs

- activity in lower-educated Dutch, Turkish, and Moroccan adults in the Netherlands: a focus group study. *BMC Public Health*, 16(1), 813. DOI 10.1186/s12889-016-3480-4
- Rubinelli, S., Schulz, P. J., & Nakamoto, K. (2009). Health literacy beyond knowledge and behaviour: letting the patient be a patient. *International journal of public health*, 54(5), 307. DOI 10.1007/s00038-009-0052-8
- Schillinger, D., Piette, J., Grumbach, K., Wang, F., Wilson, C., Daher, C., ... & Bindman, A. B. (2003). Closing the loop: physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine*, 163(1), 83-90.
- Shaw, S. J., Huebner, C., Armin, J., Orzech, K., & Vivian, J. (2009). The role of culture in health literacy and chronic disease screening and management. *Journal of Immigrant and Minority Health*, 11(6), 460-467. DOI 10.1007/s10903-008-9135-5
- Stableford, S., & Mettger, W. (2007). Plain language: a strategic response to the health literacy challenge. *Journal of Public Health Policy*, 28(1), 71-93. DOI 10.1057/palgrave.jphp.3200102
- Sykes, S., & Wills, J. (2018). Challenges and opportunities in building critical health literacy. *Global health promotion*, 25(4), 48-56.
- Todd, L., & Hoffman-Goetz, L. (2011). Predicting health literacy among English-as-a-second-language older Chinese immigrant women to Canada: Comprehension of colon cancer prevention information. *Journal of Cancer Education*, 26(2), 326-332. DOI 10.1007/s13187-010-0162-2
- Vandenbosch, J., Van den Broucke, S., Schinckus, L., Schwarz, P., Doyle, G., Pelikan, J., ... & Terkildsen-Maindal, H. (2018). The impact of health literacy on diabetes self-management education. *Health Education Journal*, 77(3), 349-362.
- Wolf, M. S., Curtis, L. M., Wilson, E. A., Revelle, W., Waite, K. R., Smith, S. G., ... & Deary, I. C. (2012). Literacy, cognitive function, and health: results of the LitCog study. *Journal of General Internal Medicine*, 27(10), 1300-1307. DOI 10.1007/s11606-012-2079-4
- Zühlke, L. J., & Engel, M. E. (2013). The importance of awareness and education in prevention and control of RHD. *Global Heart*, 8(3), 235-239. doi.org/10.1016/j

HEALTH LITERACY IN PATIENTS WITH NCDs

WHO, (2016). The 9th Global Conference on Health Promotion: Global Leaders Agree to...The Shanghai Declaration on Health Promotion. Retrieved from:
<http://www.who.int/mediacentre/news/releases/2016/conference-health-promotion/en/>

Lebanon-WHO-NCD Country Profiles, (2014). Retrieved from:
http://www.who.int/nmh/countries/lbn_en.pdf?ua=1

WHO, (2015). Facing the facts-WHO. The Impact of Chronic Disease in Lebanon. Retrieved from: http://www.who.int/chp/chronic_disease_report/media/impact/lebanon.pdf?ua=1
<http://www.who.int/healthpromotion/conferences/9gchp/shanghai-declaration/en/>

Appendix A

جانب ادارة مركز الرعاية الصحية الاولية

الموضوع: دراسة بحثية لتقييم و استكشاف محو الامية الصحية عند المرضى الذين يعانون من الامراض المزمنة غير المعدية المعرفة والاهتمام والرغبة في معرفة المريض لتشخيص مرضه ومخاطره. أيضا ، للعثور على كيفية تحديد موقع معلومات حول عملية المرض والتحقق من صحتها.

بالاشارة الى الموضوع اعلاه،

يتعلق هذا البحث بتقييم مدى المعرفة عند المريض الذي شخص بمرض غير معدي وعمره ما بين 40 و 80 عاما والاهتمام والرغبة في معرفة تشخيص مرضه ومخاطره. أيضا ، للعثور على طرق كيفية محاولة شخص تحديد موقع معلومات حول عملية المرض والتحقق من صحتها. وذلك بهدف اقتراح الية تتناسب مع احتياجات المريض لتزويده بالمعلومات.
نحيطكم علماً:

انه تم الموافقة من مجلس المراجعة الاجتماعية والعلوم السلوكية في الجامعة الاميركية على البحث واليته.

لذا نطلب منكم اذن الموافقة على تواجدنا في المركز لتعبئة استمارة البحث.
نتمنى عليكم التعاون لانجاح هذه الرسالة لما فيه من فائدة علمية و صحية للمجتمع.
شكرا لتعاونكم

ربطاً: ورقة الموافقة المستنيرة التي سيقع عليها المريض قبل البدء بملء الاستمارة

HEALTH LITERACY IN PATIENTS WITH NCDs

Appendix B

GPCOG

1. "I am going to give you a name and address. After I have said it, I want you to repeat it. Remember this name and address because I am going to ask you to tell it to me again in a few minutes: John Brown, 42 West Street, Kensington". (Allow a maximum of 4 attempts).		
	Correct	Incorrect
2. What is the date? (exact only)		
3. Please mark all the numbers to indicate the hours of a clock (correct spacing required)		
4. Please mark in hands to show 10 minutes past eleven o'clock (11:10)		
5. Can you tell me something happened in the news recently> (recently = in the last week. If a general answer is given, e.g. "war", "lots of rain", ask for details. Only specific answers scores)		
6. What was the name and address I asked you to remember?		
John		
Brown		
42		
West Street		
Kensington		
Total Correct (score out of 9)		

AppendixC

Arabic version of the GPCOG assessment

- 1- سوف اعطيك اسم وعنوان و عليك ان ترددهم من بعدي. بعد بضع دقائق ساطلب منك ان تقولهم لي. الاسم والعنوان: احمد النقوزي، 42، دوار المرجان، صيدا.
- 2- ما هو تاريخ اليوم؟
- 3- ارجو ان ترسم لي ساعة؟ على ورقة بيضاء لو سمحت ارني بالعقارب الساعة احدى عشر وعشر دقائق.
- 4- هل تستطيع ان تخبرني عن حدث وقع حديثا (خلال الاسبوع الفائت مثل حرب، مطر....)
- 5- ما هو الاسم والعنوان الذي اعطيتك اياه منذ دقائق؟

خطأ	صح	السؤال
		1- سوف اعطيك اسم وعنوان و عليك ان ترددهم من بعدي. بعد بضع دقائق ساطلب منك ان تقولهم لي. الاسم والعنوان: احمد النقوزي، 42، دوار المرجان، صيدا.
		2- ما هو تاريخ اليوم؟
		3- ارجو ان ترسم لي ساعة؟ على ورقة بيضاء لو سمحت ارني بالعقارب الساعة احدى عشر وعشر دقائق.
		4- هل تستطيع ان تخبرني عن حدث وقع حديثا؟
		5- ما هو الاسم والعنوان الذي اعطيتك اياه منذ دقائق؟ أ. احمد ب. النقوزي ت. 42 ث. دوار المرجان ج. صيدا
		المجموع العام

Appendix D

American University of Beirut

Hariri School of Nursing

Study Title: Exploring Health Literacy in Patients with Non-Communicable Disease

Investigative team: Mary Arevian Bakalian, Principal Investigator

Co-Investigators: Mrs. Hanadi Saad; Dr.Samar Nouredine

Consent document

Dear Sir/ lady

You are kindly invited to participate in a **research study**. The purpose of the study is to assess the knowledge, interest and willingness to know about their disease in people who have non- communicable diseases. We also want to find out how people try to locate information about their disease and how do they validate the received information.

You were selected as a possible candidate to participate because you are Arabic speaking (Lebanese, Syrian, or Palestinian) adult and your age is between 40 to 80 years who is diagnosed with a non-communicable disease (chronic respiratory disease, diabetes mellitus, cancer, or/and cardiovascular disorders).

Please read the following information carefully and feel free to ask any questions that you may have.

- This informed consent document is applicable for use only in the present study.
- The direct recruitment approach in relation to inviting subjects directly to participate in the study was approved by the ethics committee of the American University of Beirut.
- Your participation is completely anonymous. No one will be able to link the information you provide to you.
- If consented the interview will take place in a private room.
- You will receive a copy of the consent form you sign.

A. Project Description

You will be first asked 5 questions and if answered you will be asked to:

1. Please read the first page and sign it if you decide to take part in the study.
2. You are among 120 Arabic speaking Lebanese, Syrian, Palestinian patients aged 40-80 years and diagnosed with NCD's who are being recruited from 4 primary health care centers in Saida and its surroundings through the nurse in the center.
3. All what we require is that we do an interview with you, asking you questions about how you deal with information about your disease, from health care providers, family and

HEALTH LITERACY IN PATIENTS WITH NCDs

other sources. We will also ask some questions about your health problem and social status. We expect the interview to take at most 10 minutes of your time.

B. Voluntary Participation

Participation in this study is voluntary; there are no penalties of any kind for declining to take part or for not answering all the questions in the survey. Not taking part in the survey or answering an incomplete questionnaire will in no way affect your relationship with the center or with the American University of Beirut.

C. Privacy

Your participation in this survey is completely anonymous. There is no way anyone will be able to link your answer to your identity, not since we will not include identifying information on the questionnaire. Data will be reported in aggregate only, so none of the information you will provide will be used in a way that could identify you.

D. Confidentiality

I would like to assure you that all the information you provide will be used for research purposes and that format of the study results will not allow the identification of any study participant. To secure the confidentiality of your responses, we will not include any identifying information on the questionnaires. All questionnaires and data will be kept in a locked drawer in a locker room at the Hariri School of Nursing at the American University of Beirut. The data will be analyzed on a password-protected computer in a secure office at the Hariri School of Nursing. Data access is limited to the Principal Investigator and researchers working directly on this project. Records will be monitored and may be audited without violating confidentiality. All data will be destroyed responsibly after the required retention period (3 years.)

Risks and Benefits

Your participation in this study does not involve any physical risk or emotional risk to you beyond the risks of daily life. You have the right to withdraw your consent or discontinue participation at any time for any reason. Your decision to withdraw will not involve any penalty or loss of benefits to which you are entitled. Discontinuing participation does not affect your relationship with any primary health care center.

You will receive no direct benefits from participating in this research; however, your participation will help researchers better understand the level of literacy of the patients with non-communicable disease.

D. Contact Information

1) If you have any questions or concerns about the research, you may contact the principal investigator, Mrs. Mary Arevian Bakalian, American University of Beirut, Riad El Solh 1107 2020; PO Box: 11 0236; Beirut, Lebanon
Tel.: (961) 1-350000, Ext. 5972,
Fax.: (961)1-744476
e-mail: mb00@aub.edu.lb

HEALTH LITERACY IN PATIENTS WITH NCDs

2) If you have any questions, concerns, or complaints about your rights as a participant in this research, you can contact the following office at AUB:
Social & Behavioral Sciences Institutional Review Board, American University of Beirut.
Telephone: (961)1350000-extension 5454; email: irb@aub.edu.lb

AppendixE

الجامعة الأمريكية في بيروت

مدرسة رفيق الحريري للتمريض

عنوان البحث: استكشاف محو الامية الصحية في المرضى الذين يعانون من الامراض المزمنة غير المعدية

فريق البحث: السيدة ماري اريفيان باكاليان, الباحث الرئيسي

باحث مشارك: هنادي سعد, د. سمر نور الدين

موافقة على المشاركة في البحث

وثيقة الموافقة

سيدي العزيز / سيدتي العزيزة

أنت مدعو للمشاركة في دراسة بحثية. الغرض من الدراسة هو تقييم المعرفة والاهتمام والرغبة في معرفة تشخيص مرضك ومخاطره. أيضا، للعثور على طرق كيفية محاولة شخص تحديد موقع معلومات حول عملية المرض والتحقق من صحتها.

لقد تم اختيارك كمرشح محتمل للمشاركة لأنك تتكلم العربية (لبناني، سوري، أو فلسطيني) من البالغين وعمرك يتراوح بين 40 إلى 80 عامًا كمرضى تمّ تشخيصه بمرض غير معدي (مرض تنفسي مزمن، داء السكري، السرطان، أو اضطرابات القلب والأوعية الدموية). يرجى قراءة المعلومات التالية بعناية ولا تتردد في طرح أي أسئلة قد تكون لديكم.

- وثيقة الموافقة المستنيرة هذه قابلة للتطبيق للاستخدام فقط في الدراسة الحالية.
- تمت الموافقة على طريقة استقطاب المشاركين في الدراسة من قبل لجنة الأخلاقيات في الجامعة الأمريكية في بيروت. وسيتم عرض المعلومات بشكل مجمع بحيث لا تحيز ربط المعلومات بالمخبر.
- اذا وافقت على المشاركة سوف تجرى المقابلة في غرفة خاصة.
- سنتلقى نسخة من نموذج الموافقة الذي توقعه.

أ. وصف المشروع

سيتم سؤالك أولاً عن خمسة أسئلة، وفي حالة الإجابة، سيطلب منك:

1. يرجى قراءة الصفحة الأولى والتوقيع عليها إذا قررت المشاركة في الدراسة.
2. أنت من بين 120 لبنانياً، عربياً، سوريين، فلسطينيين تتراوح أعمارهم بين 40-80 سنة، وتمّ تشخيصهم بمرض غير معدي الذين يتم تجنيدهم من 4 مراكز للرعاية الصحية الأولية في صيدا والمناطق المحيطة بها من خلال الممرضة في المركز.
3. كل ما نطلبه هو أن نجري مقابلة معك، ونسألك أسئلة حول كيفية تعاملك مع المعلومات المتعلقة بمرضك، من مقدمي الرعاية الصحية، والأسرة وغيرها من المصادر. سوف نسأل أيضاً بعض الأسئلة حول مشكلتك الصحية والوضع الاجتماعي. نتوقع أن تستغرق المقابلة 10 دقائق على الأكثر من وقتك.

ب. المشاركة الطوعية

المشاركة في هذه الدراسة طوعية بالكامل ؛ لا توجد عقوبات من أي نوع بسبب رفض المشاركة أو عدم الإجابة عن جميع الأسئلة في الاستبيان. عدم المشاركة في الاستبيان أو إجابة استبيان غير مكتمل لن يؤثر بأي حال من الأحوال على علاقتك بالمركز أو مع الجامعة الأميركية في بيروت.

ج. الخصوصية

مشاركتك في هذا الاستطلاع مجهولة تمامًا. ليس هناك طريقة تمكن أي شخص من معرفة ما إذا كنت شاركت أم لا. سيتم الإبلاغ عن البيانات بشكل مجمع فقط ، لذلك لن يتم استخدام أي من المعلومات التي ستقدمها بطريقة يمكن أن تحدد هويتك.

ج. السرية

أود أن أؤكد لك أن جميع المعلومات التي تقدمها ستستخدم لأغراض البحث وأن شكل نتائج الدراسة لن يسمح بتحديد أي مشارك في الدراسة.

لضمان سرية إجاباتك ، يرجى الامتناع عن كتابة اسمك أو أي معلومات تعريفية أخرى. سيتم الاحتفاظ بجميع الاستبيانات والبيانات في درج مغلق في غرفة خزانة مقفلة في كلية الحريري للتمريض في الجامعة الأميركية في بيروت. سيتم تحليل البيانات على جهاز كمبيوتر محمي بكلمة مرور في مكتب أمن في مدرسة الحريري للتمريض. يقتصر الوصول إلى البيانات على الباحث الرئيسي والباحثين الذين يعملون مباشرة على هذا المشروع. سيتم مراقبة السجلات ويمكن مراجعتها دون انتهاك السرية. سيتم تدمير جميع البيانات بشكل مسؤول بعد فترة الاحتفاظ المطلوبة (لفترة ثلاث سنوات).

هـ. المخاطر والفوائد

مشاركتك في هذه الدراسة لا تنطوي على أي خطر جسدي أو خطر عاطفي بالنسبة لك. فهي لا تتجاوز مخاطر الحياة اليومية. لديك الحق في سحب موافقتك أو التوقف عن المشاركة في أي وقت ولأي سبب. لن يتضمن قرار السحب الخاص بك أي عقوبة أو خسارة في المزايا التي يحق لك الحصول عليها. لا تؤثر المشاركة المتوقعة على علاقتك مع أي مركز للرعاية الصحية الأولية.

لن تتلقى أي فوائد مباشرة من المشاركة في هذا البحث ؛ لكن مشاركتك ستساعد الباحثين على فهم أفضل لمستوى معرفة للمرضى لتشخيص حالتهم الذين يعانون من الأمراض غير المعدية وما هي مخاطرها.

معلومات الاتصال

(1) إذا كان لديك أي أسئلة أو استفسارات حول البحث يمكنك الاتصال بالباحث الرئيسي ، السيدة ماري أريفيان باكاليان ،
الجامعة الأميركية في بيروت ،
رياض الصلح 1107 2020
صندوق بريد: 11 0236
بيروت، لبنان
هاتف: (961) 1-350000 ، تحويلة: 5972،
الفاكس: (961) 1-744476
البريد الإلكتروني: mb00@aub.edu.lb

(2) إذا كان لديك أي أسئلة أو مخاوف أو شكاوى حول حقوقك كمشارك في هذا البحث ، يمكنك الاتصال بالمكتب التالي في الجامعة الأميركية في بيروت:
مجلس المراجعة الاجتماعية والعلوم السلوكية ، الجامعة الأميركية في بيروت. رقم الهاتف: (961) 1350000 - extension 5454 ؛ البريد الإلكتروني: irb@aub.edu.lb

HEALTH LITERACY IN PATIENTS WITH NCDs

Appendix F

The true AAHLS scale

ALL ASPECTS OF HEALTH LITERACY SCALE (AAHLS)

I will be reading a number of questions to you and ask you to answer how often you do those activities: often, sometimes or rarely.

AAHLS Sept 2010:

FQ1	How often do you need someone to help you when you are given information to read by your doctor, nurse or pharmacist?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
FQ2	When you need help, can you easily get hold of someone to assist you?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	Not applicable
FQ3	Do you need help to fill in official documents?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Com Q1	When you talk to a doctor or nurse, do you give them all the information they need to help you?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Com Q2	When you talk to a doctor or nurse, do you ask the questions you need to ask?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Com Q3	When you talk to a doctor or nurse, do you make sure they explain anything that you do not understand?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Cr1	Are you someone who likes to find out lots of different information about your health?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Cr2	How often do you think carefully about whether health information makes sense in your particular situation?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Cr3	How often do you try to work out whether information about your health can be trusted?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Cr4	Are you the sort of person who might question your doctor or nurse's advice based on your own research?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Emp1	Do you think that there are plenty of ways to have a say in what the government does about health?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	

HEALTH LITERACY IN PATIENTS WITH NCDs

Emp2	Within the last 12 months have you taken action to do something about a health issue that affects your family or community?	<input type="checkbox"/> yes	<input type="checkbox"/> no
Emp3	What do you think matters most for everyone's health? (tick one answer only)	<input type="checkbox"/> a) information and encouragement to lead healthy lifestyles	<input type="checkbox"/> b) good housing, education, decent jobs and good local facilities

Appendix G

ALL ASPECTS OF HEALTH LITERACY SCALE (AAHLS)

Arabic form

يرجى وضع علامة على رد واحد فقط لكل سؤال بوضع علامة في المربع

أذا كنت تفضل ذلك؛ يستطيع احد اعضاء فريق العمل او فريق البحث قراءة الاسئلة لك

	نادرا	احيانا	غالبا	كم عدد المرات التي تحتاج فيها إلى شخص ما لمساعدتك عندما تعطي معلومات للقراءة من قبل الطبيب أو الممرضة أو الصيدلي؟
غير قابل للتطبيق	نادرا	احيانا	غالبا	عندما تحتاج للمساعدة ، هل يمكنك بسهولة الحصول على شخص ما لمساعدتك؟
	نادرا	احيانا	غالبا	هل تحتاج إلى المساعدة لملء اوراق رسمية؟
	نادرا	احيانا	غالبا	عندما تتكلم مع طبيب أو ممرضة ، هل تعطيهم كل المعلومات التي يحتاجونها لمساعدتك؟
	نادرا	احيانا	غالبا	عندما تتكلم مع طبيب أو ممرضة ، هل تسأل الأسئلة التي تحتاج ان تسالها؟
	نادرا	احيانا	غالبا	عندما تتكلم مع طبيب أو ممرضة ، هل تتأكد من أنهم قد شرحوا أي شيء لم تفهمه؟
	نادرا	احيانا	غالبا	هل أنت شخص يحب معرفة الكثير من المعلومات المختلفة عن صحتك؟
	نادرا	احيانا	غالبا	كم عدد المرات التي تفكر فيها بعناية حول ما إذا كانت المعلومات الصحية منطقية في حالتك الخاصة؟
	نادرا	احيانا	غالبا	كم عدد المرات التي تحاول فيها معرفة ما إذا كان يمكن الوثوق بمعلومات عن صحتك؟
	مش بالضرورة	يمكن احيانا	نعم حتما (طبعاً)	هل أنت من النوع الذي قد يستجوب طبيبك أو نصيحة الممرضة بناء على بحثك الخاص؟
	مش بالضرورة	يمكن احيانا	نعم حتما (طبعاً)	هل تعتقد أن هناك الكثير من الطرق ليكون لك قول في ما تفعله الحكومة حول الصحة؟

HEALTH LITERACY IN PATIENTS WITH NCDs

كلا	نعم	خلال الاثني عشر شهراً الاخيرة ، هل اتخذت اجراء لفعل شيء ما بشأن مشكلة صحية تؤثر على عائلتك أو مجتمعك؟	
السكن الجيد والتعليم والعمل اللائق والمرافق المحلية الجيدة	معلومات وتشجيع لقيادة أنماط الحياة الصحية	ما برأيك هو أكثر أهمية لصحة الجميع؟ (ضع علامة على إجابة واحدة فقط)	

Appendix H

Permission letter from Dr. Chinn
Dear Hanadi

You are very welcome to use the AAHLS in your project.

You can find more information about the scale and a rating form on my ResearchGate project page:

<https://www.researchgate.net/project/All-Aspects-of-Health-Literacy-Scale-AAHLS>



[All Aspects of Health Literacy Scale \(AAHLS\)](https://www.researchgate.net/project/All-Aspects-of-Health-Literacy-Scale-AAHLS)

www.researchgate.net

Follow project: All Aspects of Health Literacy Scale (AAHLS) by Deborah Chinn on ResearchGate, the professional network for scientists.

You'll see a list of researchers who have been in touch with me. I'm not sure whether the scale has been translated into Arabic, but you might get in touch with the other researchers to find out.

I'd very much appreciate it if you could either post something about your work on the ResearchGate page or else send me some information/findings to share.

all the best

Deborah

Dr Deborah Chinn BA(Hons) PhD, DipClinPsych, CPsychol

Lecturer

King's College London

Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care

HEALTH LITERACY IN PATIENTS WITH NCDs

James Clerk Maxwell Building 1.26

57 Waterloo Road

LONDON

SE1 8WA

Tel: 020 7848 3636

Mobile: 07804 614441

Appendix I

The Questionnaire

Please read carefully each question and respond with only one answer by placing a tick in the box of your choice.

can read out the questions to you.

1. What is your gender? Male Female
2. How old are you?
 40 – 50 years old 51 – 65 years old 66 – 80 years old
3. What is your marital status?
 Single Married Divorced or widowed
4. What is your nationality?
 Lebanese Palestinian Syrian Other
5. What is your highest educational level?
 Less than elementary or can read and write Holds a Brevet/middle school Holds a Baccalaureate diploma/high school Holds a university diploma
6. Since how many years have you been diagnosed as a non-communicable disease patient?
 Less than a year Two years back More than two years
7. What health problems do you have?

HEALTH LITERACY IN PATIENTS WITH NCDs

8. When was your previous visit to your doctor?

- One month – Four months
 Five months – Eight months
 Nine months – Twelve months
 More than a year

9. Are you employed?

If yes: What do you do?

If No: Are you retired Housewife Other

10. Do you have any relative who works in a health profession? Who?

Mother/father
 Son/daughter
 Sister/brother

11. What is your income?

Less than 750,000 LL
 800,000LL – 1000,000 LL
 Above 1000,000 LL

ALL ASPECTS OF HEALTH LITERACY SCALE (AAHLS)

I will be reading a number of questions to you and ask you to answer how often you do those activities: often, sometimes or rarely.

AAHLS Sept 2010:

FQ1	How often do you need someone to help you when you are given information to read by your doctor, nurse or pharmacist?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
FQ2	When you need help, can you easily get hold of someone to assist you?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	Not applicable
FQ3	Do you need help to fill in official documents?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Com Q1	When you talk to a doctor or nurse, do you give them all the information they need to help you?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Com Q2	When you talk to a doctor or nurse, do you ask the questions you need to ask?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Com Q3	When you talk to a doctor or nurse, do you make sure they explain anything that you do not understand?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	

HEALTH LITERACY IN PATIENTS WITH NCDs

Cr1	Are you someone who likes to find out lots of different information about your health?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Cr2	How often do you think carefully about whether health information makes sense in your particular situation?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Cr3	How often do you try to work out whether information about your health can be trusted?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Cr4	Are you the sort of person who might question your doctor or nurse's advice based on your own research?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	
Emp1	Do you think that there are plenty of ways to have a say in what the government does about health?	<input type="checkbox"/> often	<input type="checkbox"/> sometimes	<input type="checkbox"/> rarely	

Emp2	Within the last 12 months have you taken action to do something about a health issue that affects your family or community?	<input type="checkbox"/> yes	<input type="checkbox"/> no
Emp3	What do you think matters most for everyone's health? (tick one answer only)	<input type="checkbox"/> a) information and encouragement to lead healthy lifestyles	<input type="checkbox"/> b) good housing, education, decent jobs and good local facilities

Appendix J

الاستبيان

يرجى قراءة كل سؤال بعناية والرد بإجابة واحدة فقط بوضع علامة في المربع الذي تختاره.

إذا كنت تفضل ذلك ، يستطيع أحد أعضاء فريق البحث قراءة الأسئلة لك.

1. ما هو جنسك؟
 ذكر أنثى
2. كم عمرك؟
 40-50 سنة 51-65 سنة 66-80 سنة
3. ما هي حالتك الاجتماعية؟
 أعزب متزوج مطلق أو أرمل
4. ما هي جنسيتك؟
 لبناني فلسطيني سوري غير ذلك
5. ما هو مستواك التعليمي؟
 أقل من المرحلة الابتدائية حاصل على Brevet حاصل على البكالوريا حاصل على شهادة جامعية
6. منذ كم سنة تم تشخيصك كمريض الأمراض غير المعدية؟
 أقل من عام منذ عامان أكثر من عامين
7. ما هي المشاكل الصحية التي تعاني منها؟
8. متى كانت زيارتك السابقة لطبيبك؟
 شهر واحد - أربعة أشهر خمسة أشهر - ثمانية أشهر
 تسعة أشهر - اثنا عشر شهراً أكثر من عام
9. هل أنت موظف؟
إذا نعم: ماذا تعمل؟
إذا لا: هل انت متقاعد ربة منزل غير ذلك
10. هل لديك قريب يعمل في مهنة صحية؟ من؟
 أم/أب ابن/ ابنة أخ/أخت

□ أقل من 750000 ل ل □ 800000 ل ل - 1000000 □ أكثر من مليون ل ل

يرجى وضع علامة على رد واحد فقط لكل سؤال بوضع علامة في المربع

إذا كنت تفضل ذلك؛ يستطيع احد اعضاء فريق العمل او فريق البحث قراءة الاسئلة لك

		غالباً	احياناً	نادراً	كم عدد المرات التي تحتاج فيها إلى شخص ما لمساعدتك عندما تعطي معلومات للقراءة من قبل الطبيب أو الممرضة أو الصيدلي؟
غير قابل للتطبيق		غالباً	احياناً	نادراً	عندما تحتاج للمساعدة ، هل يمكنك بسهولة الحصول على شخص ما لمساعدتك؟
		غالباً	احياناً	نادراً	هل تحتاج إلى المساعدة لملاء اوراق رسمية؟
		غالباً	احياناً	نادراً	عندما تتكلم مع طبيب أو ممرضة ، هل تعطيهم كل المعلومات التي يحتاجونها لمساعدتك؟
		غالباً	احياناً	نادراً	عندما تتكلم مع طبيب أو ممرضة ، هل تسأل الأسئلة التي تحتاج ان تسالها؟
		غالباً	احياناً	نادراً	عندما تتكلم مع طبيب أو ممرضة ، هل تتأكد من أنهم قد شرحوا أي شيء لم تفهمه؟
		غالباً	احياناً	نادراً	هل أنت شخص يحب معرفة الكثير من المعلومات المختلفة عن صحتك؟
		غالباً	احياناً	نادراً	كم عدد المرات التي تفكر فيها بعناية حول ما إذا كانت المعلومات الصحية منطقية في حالتك الخاصة؟
		غالباً	احياناً	نادراً	كم عدد المرات التي تحاول فيها معرفة ما إذا كان يمكن الوثوق بمعلومات عن صحتك؟
		نعم حتماً (طبعاً)	يمكن احياناً	مش بالضرورة	هل أنت من النوع الذي قد يستجوب طبيبك أو نصيحة الممرضة بناء على بحثك الخاص؟
		نعم حتماً (طبعاً)	يمكن احياناً	مش بالضرورة	هل تعتقد أن هناك الكثير من الطرق ليكون لك قول في ما تفعله الحكومة حول الصحة؟
	نعم	كلا			خلال الاثني عشر شهراً الاخيرة ، هل اتخذت اجراء لفعل شيء ما بشأن مشكلة صحية تؤثر على عائلتك أو مجتمعتك؟

HEALTH LITERACY IN PATIENTS WITH NCDs

السكن الجيد والتعليم والعمل اللائق والمرافق المحلية الجيدة	معلومات وتشجيع لقيادة أنماط الحياة الصحية	ما برأيك هو أكثر أهمية لصحة الجميع؟ (ضع علامة على إجابة واحدة فقط)	
---	---	---	--

