HEALTH LITERACY:  
THE PERCEPTIONS AND EXPERIENCES OF PRIMARY HEALTHCARE NURSES  

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BACHELOR OF SCIENCE (HONOURS) IN COMMUNITY HEALTH NURSING.  

University of Malta  
Institute of Healthcare  
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DEDICATION

To myself for the patience
I have endured throughout
the three years
of my course
DECLARATION

I, the undersigned, hereby declare that this dissertation is the product of my own research, carried out under the academic supervision of Dr. Maria Cassar RN PhD. (Aber).

Ms. Ruth Abela

I.D. 127565 (M)
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I would like to thank sincerely my dissertation supervisor, Dr. Maria Cassar for her help, patience, guidance and dedication whilst tutoring me throughout the whole process.

Great appreciation also goes to my parents, for their unconditioned help and for providing support during the difficult moments. Their constant love can never be forgotten.

I would also like to thank my special boy Patrick, for being patient and spending a huge amount of time showing me how to work on my laptop.

Thanks to Nadia who managed to endure my nagging and make this dissertation possible and to Rose who was always there for me and gave me her support. Special thanks also go to my sister Marisa for being there when in need of encouragement, to Sandra my friend for her prayers and to Christine who was always there to listen.

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Lastly but surely not least, I thank Dave (the most complex man I have ever met in my life), for his never-ending encouragement, but most of all I thank him for always being there with a ‘helping drink.’
ABSTRACT

The purpose of this research study was to identify the nurses’ perceptions and experiences of health illiterate clients, their styles of teaching and learning adopted with these clients, together with recommendations that they thought would help enhance the education of such clients. A sample of eight (n=8) nurses working at the Medical Consultant Clinics within the 8 Health Centres around Malta were interviewed using semi-structured, face-to-face interviews which were tape-recorded. These were later transcribed and analyzed using qualitative thematic analysis. The concept of health literacy has never been studied on the Maltese Islands, nevertheless the study identified that nurses do have a certain awareness of difficult patients who seem unable to understand what is being told to them. In fact, findings from this study revealed that nurses have employed certain nursing interventions to enhance their patients’ understanding. The skills and abilities to employ such interventions were acquired only through experience throughout their nursing career. The nurses (n=8) were confident that they found no problems in giving information to their patients. In fact, one common theme that emerged from the data collected was that, it is the patients who do not understand the information given to them. All nurses stated that several times, most patients go back to the clinic to verify certain difficulties. Nurses were not aware of established health literacy assessment tools which would help them identify and adjust their teaching according to a patient’s specific educational and learning needs. Nurses agreed that it is absolutely crucial for patients to understand the information related to self-care. However, the data suggests that nurses may underestimate the close relationship between a patient’s health literacy and the extent to which the patient would engage in effective self-care after being provided with the related information. In determining the strengths and limitations of the nurses’ current practice in relation to health illiterate patients, the findings indicate the areas within the nurses’ role that may be addressed through further educational and research opportunities.
TABLE OF CONTENTS

Dedication ..................................................................................................................................... i
Declaration ................................................................................................................................... ii
Acknowledgements ..................................................................................................................... iii
Abstract ....................................................................................................................................... iv
Table of Contents .......................................................................................................................... v
List of Tables ................................................................................................................................ ix
1. Introduction .................................................................................................................................. 1
2. Literature Review .................................................................................................................. 4
   2.1 Introduction .......................................................................................................................... 4
   2.2 The meaning of Health Literacy .......................................................................................... 5
      2.2.1 The Origin of Health Literacy .................................................................................. 5
      2.2.2 The National Adult Literacy Survey – Health Illiteracy as a defined/recognised concept 6
      2.2.3 The Rating System of the NALS and its results ......................................................... 6
   2.3 The Relationship between Illiteracy and Health Illiteracy and the Reason why Health Illiterate Individuals are Noted to Fall within “At Risk” Category .................................................. 8
   2.4 Definitions of Health Literacy ........................................................................................... 11
   2.5 Health Literacy Assessment tools ..................................................................................... 12
      2.5.1 Assessing/ Screening health literacy ..................................................................... 15
   2.6 Other Factors associated with Health Illiteracy ............................................................ 16
      2.6.1 Consequences of Poor Health Literacy ................................................................ 18
   2.7 Important Factors to be Considered by Health Professionals ........................................ 20
   2.8 The Role of the Nurse in Relation to Health Illiterate Clients ........................................ 21
      2.8.1 Importance of Therapeutic Partnership ................................................................. 22
2.8.2 Factors that Can Hinder Practising Nurses from Completing a Health Literacy Assessment/Screening ................................................................. 24
2.8.3 Clues for Recognizing Health Illiterate Patients ........................................ 25
2.8.4 Suggested Strategies for Improving Health Literacy ................................ 25
2.9 Conclusion ........................................................................................................... 27

3 Methodology ............................................................................................................ 29
  3.1 Introduction ............................................................................................................. 29
  3.2 Purpose of the study .............................................................................................. 29
  3.3 Operational definitions ......................................................................................... 30
  3.4 Research design ..................................................................................................... 31
  3.5 Research setting .................................................................................................... 31
  3.6 Target Population and Sampling Technique ....................................................... 32
  3.7 Research tool ........................................................................................................ 33
  3.8 Pilot study ............................................................................................................. 34
  3.9 Validity and Reliability issues .............................................................................. 35
  3.10 Ethical Considerations ......................................................................................... 36
  3.11 Data Collection .................................................................................................... 37
  3.12 Data analysis ........................................................................................................ 38
  3.13 Conclusion ......................................................................................................... 39

4 Findings and Discussion ............................................................................................... 40
  4.1 Introduction .......................................................................................................... 40
  4.2 Data regarding the participants ........................................................................... 41
    4.2.1 Nursing qualifications that participants hold .................................................. 41
    4.2.2 Nurses’ place of practice ............................................................................... 41
  4.3 Nurses’ level of agreement/disagreement as to how easy they find it to communicate with patients at work ................................................................. 42
    4.3.1 Nurses’ perception as regards whether the information given by them is understood by their patient ................................................................. 46
  4.4 Nurses’ communication with their clients ................................................................ 49
  4.5 Nurses’ identification of at least 3 factors that they think are strong barriers to good communication between themselves and their patients ......................................................................... 50
    4.5.1 Illiteracy ..................................................................................................... 52
    4.5.2 Cognitive impairment ............................................................................... 54
4.5.3 Old age .............................................................. 56
4.5.4 Ignorance of their condition ........................................ 59
4.5.5 Social class .............................................................. 61
4.5.6 Bias ........................................................................ 63
4.5.7 Excitement .............................................................. 64
4.5.8 Denial ........................................................................ 65
4.5.9 Depression .............................................................. 66
4.6 Non-adherence to treatment regimes and advice ................. 68
4.6.1 Reluctance in Changing of Lifestyle ................................ 68
4.6.2 Financial Limitations ................................................... 69
4.7 Methods currently used by nurses to ensure that clients are receiving AND understanding the information provided to them .............................................. 72
4.7.1 Explanation .................................................................. 73
4.7.2 Repetition ..................................................................... 73
4.7.3 Hand Gesturing .............................................................. 74
4.7.4 Encourage the patients to call back .................................. 74
4.7.5 Other approaches ............................................................. 75
4.7.6 Take the initiative ............................................................ 77
4.8 Possible changes to facilitate the nurses' current practice ........ 79
4.8.1 Accompanied by relatives .............................................. 79
4.8.2 Preparation of tablets ....................................................... 80
4.8.3 Regular follow-up appointments ....................................... 82
4.8.4 Contact by phone ......................................................... 83
4.8.5 Less Appointment Forms .................................................. 84
4.8.6 Encouragement ............................................................... 86
4.8.7 I don't know ................................................................. 86
4.9 Frequency of Encountering Low Health Literate Clients ........ 87
4.10 Methods how the nurses address the needs of these 'Health Illiterate Clients' .......... 89
4.10.1 Educate them about their condition .............................. 89
4.10.2 Give one thing at a time ............................................... 90
4.10.3 Ask them to be accompanied ........................................ 91
4.10.4 Advise to apply for a hearing aid .................................... 92
4.10.5 Improving standards in communication ................................................................. 92

4.11 Suggestions or recommendations which, if implemented, the nurses’ think may enhance the care provided to the health illiterate clients ................................................................. 94

4.12 Nurses’ reasons for suggesting /recommending these steps ........................................... 97

4.13 Comments added by the nurses ..................................................................................... 99

4.14 Conclusion .................................................................................................................. 101

5 Conclusion and Recommendations ..................................................................................... 103

5.1 Conclusion .................................................................................................................. 103

5.2 Limitations of the study .............................................................................................. 105

5.3 Recommendations ....................................................................................................... 106

5.3.1 Recommendations for research ............................................................................... 106

5.3.2 Recommendations for education ............................................................................. 107

5.3.3 Recommendations for practice ............................................................................... 108

6 References ...................................................................................................................... 109

7 Appendices ..................................................................................................................... 121
List of Tables

Table 2.1. Definitions of Health Literacy — Page 11
Table 2.2. Comparison of the TOFHLA and REALM Assessment Tools — Page 14
Table 2.3. Health Literacy Levels and Expected Competencies — Page 15
Table 2.4. The Components of Nurse-Client Partnership — Page 23
Table 2.5. Suggested Strategies to Improve Health Literacy in the Health Care Settings — Page 26

Table 4.1. Nurses’ Level of Agreement/Disagreement as to How Easy They Find It to Communicate with Patients at Work — Page 43
Table 4.2. Nurses’ Level of Agreement/Disagreement as to Whether Patients Understand the Information They Give Them — Page 47
Table 4.3. Five Factors from the Table Presented Were Identified as Strong Barriers to Good Communication — Page 51
Table 4.4. Four Factors (Not Mentioned in the List Given by the Researcher) Were Indicated Under the Heading ‘Others’ as Strong Barriers to Good Communication — Page 62
Table 4.5. Frequency of Incidence — Page 72
Table 4.6. Frequency of Incidence — Page 88

Table 3. Comparison of Studies on Effects of Health Illiteracy. — Page 122
1. INTRODUCTION
1. INTRODUCTION

The concept of health literacy is relatively new in the health arena, and it has only been within the last decade that researchers identified the problems associated with health literacy, the role it plays in an individual's ability to understand health and self-care information, and its relationship to health care outcomes (Institute of Medicine, 2004).

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. (United States Department of Health and Human Services, 2000; Healthy People, 2010).

Results from a National Adult Literacy Survey (NALS) carried out by the United States (U.S.) Department of Education in 1992, suggested that individuals who were functionally illiterate, meaning not being able to read for example a label on a prescription bottle, and those with marginal literacy skills who were found to have difficulty with tasks involving words and numbers, were unable to function sufficiently in health care settings, rendering them 'health illiterate' and noted to fall within an 'at risk' category.

Although both health literacy and general literacy (which is the basic ability to read and write) are different, yet they are intrinsically linked, as most individuals with limited general literacy also have limited health literacy (Schwartzberg, VanGeest, & Wang, 2005). Health literacy does not only include the ability to read and write, but it also focuses on the capability to listen, follow directions, understand medical related forms, calculate using basic maths, and familiarise with professionals and health care settings.
Research evidence suggests that apart from educational levels, health literacy has a broader focus and it encompasses issues such as age, culture, individuality, and contextual situations (Jackson, Davis, Murphy, Bairnsfather, & George 1994; Weiss, Reed, & Kligman, 1995). Consequences of limited health literacy are poor healthcare outcomes, including lack of understanding and use of preventive services, poorer self-reported health, poorer compliance rates, increased hospitalizations, increased health care costs, and increased mortality.

Today, patients are being discharged sooner from hospital (Davidoff 1997; Schwartzberg, VanGeest, & Wang, 2005), with increased out-patient services. Such patients quickly find themselves on their own and are often required to assume new self-care responsibilities. Apart from having shorter clinic visits with no sufficient time to communicate with their doctor, researchers such as Davis et al., (2001) found that doctors often use medical terms that are inadequate and confusing to the patients.

It is at this very opportunistic moment that nurses, being often the first healthcare professionals a patient meets after the doctor’s encounter, may provide the majority of healthcare information and appropriate teaching and are in a key position to positively affect the lives of patients through education, producing potentially longstanding changes in patients' lives (Bastable, 2006).

However, several researchers (Boswell, Cannon, Aung, & Eldridge, 2004) still persist that health illiteracy is not fully understood nor currently considered by practising nurses. Clarifying the concept of health illiteracy is essential so that nurses develop an awareness of the phenomenon and its relationship to the outcomes of their communication and health educational efforts.

It is important to point out at this stage that no local research as yet has been carried out to check the illiteracy state of the Maltese population, and how this is affecting their health outcome. Thus, the concept of health illiteracy in Malta has never been discussed. As far as the
researcher is concerned this is the first small scale study that is being undertaken as regards this subject. Furthermore, no research has yet been carried out to establish whether nurses are actually aware of the existence of health illiterate clients in their place of practice. Building on the prominent commitment of all nurses to educate patients, the aim of this study was to explore the nurses’ perceptions and experiences of health illiterate clients, the current provision of care to these clients, and to explore nurses’ views and opinions as regards the need to change their current practice, in an attempt to address the needs of such clients.

The next chapter presents a review of the international literature regarding health literacy. Chapter three presents the methodology adopted to carry out the research study reported in this dissertation. The findings of the study are presented and discussed in the fourth chapter in the context of the located literature. Finally, chapter five presents a series of conclusions and recommendations drawn from the findings of the study.
2. LITERATURE REVIEW
2. LITERATURE REVIEW

2.1 INTRODUCTION

Issues arising around the concept of health literacy, the role it plays in an individual's ability to fully understand health and self-care information, together with its relationship to health outcomes, have been addressed in the recent literature developed in the last decade.

As health literacy is a new concept in health research, literature related to the effects of health illiteracy on the Maltese Islands appears to be limited.

However a number of research studies investigating the concept of health literacy in the United States of America were found. These studies are reviewed along this chapter to elicit the main findings of these studies. In parallel, the relevance of the located literature to the research study are sought and discussed along the dissertation.

The tables on pages 122-5 seeks to illustrate details of each of the studies referred to in this chapter in a comprehensive manner, together with a concise critique of each of the studies, in that the limitations are identified accordingly. No studies that focused precisely on nurses and the role of the nurse arising specifically around health literacy were located.
2.2 THE MEANING OF HEALTH LITERACY

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. (United States Department of Health and Human Services, 2000; Healthy People, 2010).

Putting it in a simple definition, health literacy has to do with how well individuals understand and are able to use health information to take care of their health. More than being able to read and write, health literacy includes the capability to listen, follow directions, understand medical related forms, calculate using basic maths, and familiarise with professionals and health care settings. It also includes making sense of medical words. Health literacy requires people to analyze health-related matters (Institute of Medicine, 2004).

2.2.1 THE ORIGIN OF HEALTH LITERACY

The term ‘Health literacy’ was first used in a 1974 paper published in the United States of America titled ‘Health Education as Social Policy’ (Sigmonds, 1974). At the time, health literacy was considered as a policy issue affecting the healthcare system, educational system and mass communication. This resulted in health literacy as being connected to health education and failures in health education were associated to poor health literacy (Ratzan, 2001).

It was then in 1995 with an article published in the Journal of the American Medical Association that Health literacy was introduced into the medical literature (Williams et al., 1995).
2.2.2 THE NATIONAL ADULT LITERACY SURVEY – HEALTH ILLITERACY AS A DEFINED/RECOGNISED CONCEPT

In 1992, a National Adult Literacy Survey (NALS) was carried out by the United States (U.S.) Department of Education. In this study, The National Centre for Education Statistics surveyed more than 26,000 randomly selected Americans and provided a detailed picture of their literacy skills to represent the country as a whole. The intent of the survey was not to measure literacy by reading level or last grade completed, but to assess how literacy skills affect the ability to function in everyday life situations.

2.2.3 THE RATING SYSTEM OF THE NALS AND ITS RESULTS

The survey was scored on five levels. Adults rated with a ‘level one’ literacy included people who were functionally illiterate which meant were those who had difficulty reading a story on the front page of a newspaper, whereas adults who rated with a ‘level five’ had high literacy and showed that they were able to perform more complex literacy tasks.

The results of the NALS found that 40-44 million Americans, or approximately one-quarter of the population, were functionally illiterate. Another 50 million U.S. citizens had marginal literacy skills. This indicated that nearly half of the adult population in America had inadequacies in reading or calculating skills (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993).
Although at the time no study had directly measured the health literacy of the U.S. population, however, it was possible to estimate the number of people who had low health literacy skills by using results from the 1992 National Adult Literacy Survey (NALS). By comparing results, it was concluded that adults who were functionally illiterate were those not being able to read a label on a prescription bottle, or read a card indicating the date of a follow-up appointment and those adults with marginal literacy skills and who were found unable to read a bus schedule, had difficulty with tasks involving words and numbers (National Workgroup on Literacy and Health, 1998). This rating system, suggested that individuals falling within these two categories meant that they were unable to carry out the basic reading tasks necessary to function sufficiently in health care settings, rendering them 'health illiterate' and placing them 'at risk' category.

It is important to point out, that since along the years no study had directly measured the health literacy of the U.S. population, the significance of the NALS (1992) survey, revealed the need of an assessment of adult health literacy, so that in 2003 a National Assessment of Adult Literacy was carried out in the United States. This appears to be the first large-scale national assessment which included a section designed specifically to measure health literacy which meant the ability to use literacy skills, and to read and understand written health concerned information encountered in everyday life (National Centre for Education Statistics, 2006).
2.3 THE RELATIONSHIP BETWEEN ILLITERACY AND HEALTH ILLITERACY AND THE REASON WHY HEALTH ILLITERATE INDIVIDUALS ARE NOTED TO FALL WITHIN “AT RISK” CATEGORY.

Although both health literacy and general literacy (which is the basic ability to read and write) are different, yet they are intrinsically linked, as most individuals with limited general literacy also have limited health literacy (Schwartzberg et al., 2005).

Because of the literacy demands upon patients in the increasingly complex health care system, individuals who are functionally illiterate or marginally literate are likely to have low health literacy skills (Kirsch et al., 1993).

The reason for this is that most healthcare directions involve words and numbers, for example, measuring medication, understanding nutrition labels and calculating blood sugar levels; all these require numeracy skills. Instructions and warning labels about how to properly take medications, how to correctly prepare for diagnostic tests, and directions for follow-up appointments can be overwhelming to many low-literate patients. Even understanding the terms on consent forms can be difficult for these individuals. In fact, this problem was discovered during a study carried out in 1998 by Davis, Arnold, Berkel and Holcombe, to determine whether patients understand consent forms before enrolling them in clinical trials. During this study (Table 3 (a) Appendix 1), the participants were tested for reading ability and then asked to first read either the standard South Western Oncology Group (SWOG) consent form (college senior reading level) or a simplified form (seventh-grade reading level). Patients stated that the simpler form was easier to read, less frightening, and significantly less likely to discourage them from participating in a clinical trial. Participants of this study preferred this form over the latter in almost twice the
As a result, the researchers suggested that a simplified, illustrated consent document having low literacy recommendations would be more easily understood by individuals with marginal-to-low reading skills.

People with limited health literacy often lack knowledge or are misinformed about the body’s function and causes of disease (U.S. Department of Health and Human Services, 2000). Without this knowledge, they may misunderstand the connection between lifestyle factors such as diet and exercise and various health outcomes. Therefore, illiteracy affects the quality of medical care, as patients are not able to perform necessary functions in the health care environment.

Another complex situation faced by these individuals, occurs in the primary health care setting, where, since they see different doctors for a different number of symptoms, it is noticeable that most of them have repeated difficulties in verbalising their problems in self care. Such communication is difficult for patients because of limited health literacy (Schwartzberg et al., 2005).

One other particular problem as suggested by the American Medical Association (1999) is that healthcare materials are usually written far above the average patient’s reading skills, so that low literacy individuals are at increased risk of adverse effects when they are in contact with the reading challenges of the current healthcare system.

It is important to note however, that although health illiteracy has been associated with illiteracy, Sullivan (2000) believes that even people with advanced literacy skills can have difficulty in obtaining, understanding and using health information. Highly literate, well-educated individuals also relate difficulty understanding information given to them by healthcare professionals, usually because the latter use vocabulary and discuss physiological concepts unfamiliar to those who lack a medical education. Research carried out in 2006 by Davis et al., (Table 3b Appendix 1) was
conducted to assess whether there was a difference in patient understanding and use of oral contraceptive pills (OCPs), and whether these two facts were associated with levels of literacy of the participants. The researchers found that patients of all literacy levels had the same difficulties with the use of OCPs and also faced same risks of misuse.

The problem of low literacy is not uniquely associated with America. Literacy assessment studies have since then been carried out throughout the years with similar findings of low literacy. The International Adult Literacy Survey Database (IALS) includes data pertaining to 23 countries or regions around the world including Europe, North and South America and the Pacific.

Since the NALS of 1992, several studies have looked into the scope of illiteracy from a health care perspective and a number of definitions have been put forward to explain the term Health Literacy. The debate of whether literacy affects a person’s health condition was raised when death rates from chronic diseases, rates of communicable diseases, and injuries were mostly found to be inversely related to education level (Neilson-Bohlman, Panzer, & Kindig, 2004).

The following section seeks to present the various definitions of Health Literacy as described over the years. Together with this, a description of the different tools that are used to measure health literacy skills will also be given, followed by an overview of the physical, psychological and social aspects related to the lack of such literacy.
2.4  **DEFINITIONS OF HEALTH LITERACY**

Many definitions for health literacy are found in the literature.

**Table 2.1. Definitions of Health Literacy**

<table>
<thead>
<tr>
<th>Source</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>The World Health Organization (WHO) (1998)</td>
<td>&quot;the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health&quot; (p. 210).</td>
</tr>
<tr>
<td>The American Medical Association (1999)</td>
<td>&quot;a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the healthcare environment&quot; (p. 553).</td>
</tr>
<tr>
<td>The Institute of Medicine (2004)</td>
<td>&quot;the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions&quot; (Committee on Health Literacy of the Institute of Medicine, 2004, p. 8).</td>
</tr>
<tr>
<td>Nutbeam (2006)</td>
<td>&quot;health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment.&quot; (p. 264).</td>
</tr>
</tbody>
</table>
Over the years, there has been a transition in the concept of health literacy. Both the WHO (1998) and the American Medical Association (1999) suggested that health literacy is a cluster of knowledge which makes an individual function better in the health care system. On the other hand, the later definitions by the Institute of Medicine (2004) and Nutbeam (2006) suggest that it is also the way in which a patient gathers the information needed to make appropriate health choices. The different definitions of health literacy propose that health literacy is not only the skills a patient acquires through knowledge but also the ability to process such information into making appropriate self care choices.

2.5 Health Literacy Assessment Tools

A number of assessment tools have been developed to assess the health literacy skills of patients (Institute of Medicine, 2004). These tools permit the healthcare staff to develop a better sense of the literacy level of the overall patient population, thus ensuring that patient education materials and other means of communication are aimed specifically to the patients' level of understanding.

The types of instruments that measure health literacy skills are: comprehension tests and word recognition tests (Davis et al., 1993). The two most commonly used tools to estimate health literacy are the Test of Functional Health Literacy in Adults (TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM). (Comparison of these two commonly used assessment tools is found in table 2.2).
The Test of Functional Health Literacy in Adults (TOFHLA) is a comprehension health literacy test measuring both numeracy and reading comprehension. This test is available in English and Spanish, and takes almost 22 minutes to administer (Weiss, 2003; Mika, Kelly, Price, Franquiz, & Villareal, 2005). A simplified, modified version of Test Of Functional Health Literacy in Adults (S-TOFHLA) takes approximately 7 minutes, and is more appropriate for screening purposes in health care settings (Hartsell, 2005). During both versions, the patients are provided with prescription drug labels or medical consent forms and other health care information and asked to respond to questions that judge their understanding of the materials (Weiss, 2003; Mika et al., 2005). The results are then rated as inadequate (unable to read and interpret health texts), marginal (has difficulty reading and interpreting health texts) and adequate (can read and interpret most health texts) (Parker, Baker, Williams, & Nurss, 1995).

There are several instruments measuring literacy skills that consist of word recognition tests. However, the most frequently used screening test, is the Rapid Estimate of Adult Literacy in Medicine (REALM). This is because it can be administered quickly by health care providers (Foltz & Sullivan, 1998; Murphy & Davis, 1997; Hartsell, 2005). This test consists of the patient reading 66 commonly used medical terms. Although the test can be administered within two to three minutes, yet its disadvantages are that it is only available in English and does not include comprehension or numeracy skills, as it is only a word recognition test (Foltz & Sullivan, 1998; Weiss, 2003; Hartsell, 2005).
### Table 2.2: Comparison of the TOFHLA and REALM Assessment Tools

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>TOFHLA</th>
<th>REALM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>Functional health literacy test</td>
<td>Medical word recognition test</td>
</tr>
<tr>
<td>Age</td>
<td>Adults only</td>
<td>Adults only</td>
</tr>
<tr>
<td>Administration time (min)</td>
<td>22 (7 for short version)</td>
<td>2-7</td>
</tr>
<tr>
<td>Scoring</td>
<td>Inadequate, marginal, or functional health literacy</td>
<td>Approximated grade level: 3rd and below, 4th-6th, 7th-8th, or 9th and above</td>
</tr>
<tr>
<td>Advantages</td>
<td>Measures functional health literacy, available in a shortened form and in Spanish</td>
<td>Quick, uses medical terminology</td>
</tr>
<tr>
<td>Limitations</td>
<td>Long version is time consuming, timed test can be frustrating</td>
<td>Assigns only grade-range equivalents. Available only in English.</td>
</tr>
</tbody>
</table>
2.5.1 Assessing/Screening Health Literacy

Researchers support the fact that health literacy screening is the best way for healthcare providers to plan and perform healthcare teaching (Doak, Doak & Root, 1996; National Work Group on Literacy and Health, 1998; Treacy & Mayer, 2000; Deveraux, 2004; Erlen, 2004). By comparing results from valid literacy screening instruments to years of school completed, healthcare providers can assess the literacy levels of patients seeking healthcare. (Table 2.3)

Table 2.3. Health Literacy Levels and Expected Competencies

<table>
<thead>
<tr>
<th>Health Literacy Levels</th>
<th>Task Competency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Below Basic</td>
<td>• Can identify a concrete activity to perform on simple, brief, instructions</td>
</tr>
<tr>
<td></td>
<td>• Can read instructions using words with few syllables and in simple, short, sentences</td>
</tr>
<tr>
<td></td>
<td>• Graphics are useful for emphasis and illustration</td>
</tr>
<tr>
<td>Basic</td>
<td>• Can read narrative using simple terms and declarative statements</td>
</tr>
<tr>
<td></td>
<td>• Can extract major points of information from narrative with middle</td>
</tr>
<tr>
<td>Level</td>
<td>Skills</td>
</tr>
<tr>
<td>--------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>School</td>
<td>- Graphics are useful for emphasis and illustration</td>
</tr>
<tr>
<td>Intermediate</td>
<td>- Can accurately read prescription label and take the medication according to directions.</td>
</tr>
<tr>
<td></td>
<td>- Can apply information to the use of a scale to locate answer</td>
</tr>
<tr>
<td></td>
<td>- Can interpret information presented in a narrative or graphic format</td>
</tr>
<tr>
<td>Proficient</td>
<td>- Able to compare and contrast different sources of information</td>
</tr>
<tr>
<td></td>
<td>- Understands difficult abstract concepts pertaining to medical information</td>
</tr>
<tr>
<td></td>
<td>- Able to calculate share of costs pertaining to health insurance plan of coverage</td>
</tr>
</tbody>
</table>

### 2.6 Other Factors Associated with Health Illiteracy

Throughout the years, research evidence suggested that apart from educational levels, issues such as age (the population with the largest burden of chronic disease and the greatest health related reading demands) also interferes with a person’s health literacy (Jackson, Davis, Murphy, Bairnsfather & George, 1994; Weiss, Reed & Kligman, 1995). In fact in a 1999 study of 3,260
Medicare patients enrolling in a managed care plan it was found that inadequate health literacy increased steadily with age, from 16% of those age 65-60 to 58% of those over 85 (Gazmararian et al., 1999) (Table 3c, Appendix 1).

Adults are living longer with increasingly complex health problems and often multiple chronic conditions (United Nations, 2002; Parker, Ahacic & Thorslund, 2005). It is vital that the patients themselves know the underlying disease process(s) and its influence on their health. The average adult patient takes multiple medications each day to manage a diversity of chronic diseases and often these medication regimes require complex instructions such as the time of day, specific diets, and whether or not to take with meals. Furthermore for some of these medications to be effective, individuals are asked to monitor blood levels, and the patient must have proper skills for this treatment.

Apart from age, individual features including learning disorders such as dyslexia and sensory handicap, are important factors that play a major role in low health literacy (Paasche-Orlow, Parker, Gazmararian, Neilson-Bohlman & Rudd, 2005). For example, patients with impaired hearing may not realize the amount of information they miss in the healthcare professional’s office (Osborne, 2006). According to King (2005), even the exchange of written notes is not sufficient for proper communication and when a hearing impaired patient nods in acknowledgement or agreement, it should not be assumed by the healthcare professional that all that was said was understood.

Additionally, health illiteracy can be associated with culture and ethnicity and other social factors such as financial problems (Foltz & Sullivan, 1996; Bennett et al., 1998; Artinian, Lange, Templin, Stallwood & Hermann, 2001; Beers et al., 2003).
Wersch and Van Uniken Venema, (1992); Berry (1990; 1994) suggest that more health problems are found in migrant groups. Such problems were associated to demographical and behavioural characteristics, environmental factors (housing, climate, and work) and other migration effects such as separation from the individuals' family, financial worries about the family in the country of origin, uncertainty about moving back or not, and acculturation stress. All these factors are often aggravated by socio-economic factors such as unemployment or being poorly paid in stressful jobs (Wallraf, 1988; Bjerregaard & Curtis, 2002).

2.6.1 **Consequences of Poor Health Literacy**

During the last decade, patients are being discharged sooner from hospital (Davidoff, 1997; Schwartzberg, VanGeest & Wang, 2005) with increased out-patient services, are quickly on their own and are often required to assume new self-care responsibilities. As health expands in modern societies, the role of the individual in health becomes more significant and diverse with new medical knowledge, drugs and treatments (as well as cost containment pressures).

Apart from having shorter clinic visits with no sufficient time to communicate with their doctor, researchers such as Davis et al., (2001) also found that another factor that predisposes individuals to health illiteracy is that doctors and healthcare providers often use medical terms that are inadequate and confusing to the patients.

Poor health literacy can lead to inefficiencies in the health care system. Individuals with insufficient levels of health literacy are less likely to understand oral and written information from health professionals and to comply with prescribed treatment and self-care regimes. They make
more medication or treatment errors and lack the skills needed to understand the healthcare system (Weiss, 1999), resulting in bad disease outcomes (Baker, Parker, Williams, & Clark, 1998). They also report poor health status and are less likely to use preventive care (Neilson-Bohlman, Panzer & Kindig, 2004) including potentially life-saving tests such as mammograms and/or pap smears and attend for their flu and pneumonia vaccines. Berkman et al., (2004) reported that these individuals also neglect taking their children for well child care visits.

Furthermore, in a study by Baker et al., (2002) (Table 3d Appendix 1) health illiterate people use more emergency services and are frequently hospitalized, whilst in a cohort study carried out by Baker et al., (2007) (Table 3e Appendix 1) low health literacy scores were also associated with higher mortality rates.

Lack of understanding is not just associated to medical terms. Several studies revealed that for patients with diabetes, hypertension or asthma, low health literacy is common and strongly correlated with poorer knowledge of one’s chronic condition(s). Williams, Baker, Parker and Nurss (1998) (Table 3f Appendix 1), found that only fewer than half of low literacy patients with diabetes knew the symptoms of hypo-glycaemia (a lowering in blood glucose) and others reported that they did not have high blood pressure when in reality, had a diagnosis of hypertension in their medical record and took anti-hypertension treatment. Another study by Williams, Baker, Honnig, Lee and Nowlan, (1998) (Table 3g Appendix 1) revealed that most of the low literacy patients with asthma could not follow proper use of an asthma inhaler. Whilst Schillinger et al., (2002) (Table 3h Appendix 1) found that patients with inadequate health literacy were less likely to achieve proper glycaemic control.
2.7 IMPORTANT FACTORS TO BE CONSIDERED BY HEALTH PROFESSIONALS

Today, patients are required to monitor their disease, adjust their treatments and medications and make use of the proper healthcare facilities (Parker, Baker, Williams & Nurss 1999). Because of the limited time with healthcare providers and the increase in outpatient services, patients now must be able to quickly understand and assess healthcare information and become an advocate for their own health.

As already stated, (Section 2.3 and 2.6), many factors can limit a patient’s health vocabulary (Davis, Williams, Branch & Green, 1999) and when faced by the doctors’ habitual use of medical terms, it often becomes a major source of miscommunication between them. Apart from this, Schwartzberg, Vangeest and Wang (2005) found that health illiterate patients find it difficult to participate in a conversation with healthcare professionals in a classified manner where the doctor or nurse in the clinic asks direct questions and the patient is expected to answer immediately. The patient may feel afraid or uncomfortable to answer direct questions or to ask about his or her health. Another very important factor for healthcare professionals to be aware of is that illiterate patients may often experience shame and embarrassment. Studies by Parikh, Parker, Nurss, Baker and Williams (1996) (Table 3i Appendix 1) showed that patients who find difficulty reading healthcare instructions, often fail to mention this to their healthcare provider because of the shame and embarrassment associated with poor reading skills. In the same studies, it was also revealed that 40% of patients with low functional literacy felt shame, 67.4% had never told their spouses about their illiteracy, 53.4% had never told their children and 19% had never told anyone. As a result of this, healthcare information provided to such patients is
often misunderstood, a factor that may contribute to the individuals' non-adherence with their plan of care, resulting in poor healthcare outcomes (Williams, Baker, Honig, Lee & Nowlan, 1998; Williams, Baker, Parker & Nurss, 1998; Gazmararian et al., 1999).

Nonetheless it is important that the patient is allowed to communicate with the health care professional in a discussion about their health. Berry, Seiders and Wilder (2003) suggest that by placing the patient in the centre of the healthcare system, it would empower the patient to actively take part in their health state with healthcare professionals. In fact, Schwartzberg et al. (2005), suggest asking the patient what they know, care about and find important in their life.

2.8 THE ROLE OF THE NURSE IN RELATION TO HEALTH ILLITERATE CLIENTS

After the doctor's encounter, nurses are often the first healthcare professionals who a patient meets and most of the patients' time is spent with nurses. One of the most important roles of nurses is that of patient advocate, reflecting their ability to protect the interests of patients who cannot represent themselves because of illness or inadequate health knowledge (Centre for Nursing Advocacy, 2004).

As health literacy is a patient's currency for understanding and using the healthcare system (Parker et al., 1999), patients who have inadequate health literacy often fail to navigate this system and this can directly impact their health status and quality of life. Nutbeam (2000); Gazmararian, Curran, Parker, Bernhardt and DeBuono (2005); declared that nurses are in a key position to positively affect the lives of patients through education, producing potentially
longstanding changes in patients’ lives (Bastable, 2006) and have an ethical responsibility to provide understandable healthcare information and enable the patient to make informed decision regarding their health care. In fact, nowadays patient education is considered central to achieving effective outcomes for patients and is often recognized in certain practice acts as a legal responsibility of nurses (Habel, 2003).

It is clear that since so many aspects of finding healthcare and health information, and staying healthy depend on understanding written information (National Centre for Education Statistics, 2006), it is essential that nurses understand health literacy. Boswell, Cannon, Aung and Eldridge (2004) stated that an individual’s health illiteracy is an important challenge that is not fully understood nor currently considered by practising nurses. It is fundamental that nurses should be aware of and able to accurately assess a patient’s health literacy status, thus providing safe and competent care (Murphy & Davis, 1997; Foltz & Sullivan, 2005; Hartsell, 2005).

2.8.1 Importance of Therapeutic Partnership

Nurses are capable of developing nurse-client partnership thus encouraging the patient to engage in participatory decision making and become knowledgeable enough to advocate for their healthcare. When participating in decision-making regarding their health, patients report high satisfaction with medical treatments and outcomes (Raeburn & Rootman, 1998; Osborne, 2005). There are five components to the nurse-client partnership: trust, respect, professional intimacy, empathy and power. Regardless of the context, these components should presumably always be present. (Table 2.4)
Trust

Trust is critical in the nurse-client partnership because the client is in a vulnerable position (Hupcey et al., 2001). Initially, trust in a relationship is fragile, so it is especially important that a nurse keeps promises to a client. If trust is breached, it becomes difficult to re-establish.

Respect

Respect is the recognition of the inherent dignity, worth and uniqueness of every individual, regardless of socio-economic status, personal attributes and the nature of the health problem (American Nurses Association, 2001; Milton, 2005)

Professional Intimacy

Professional intimacy is fundamental in the type of care and services that nurses provide. Apart from relating to physical activities such as bathing, professional intimacy involves psychological, physical and social elements. Access to the client’s personal information also contributes to professional intimacy (Kunyk & Olson, 2001)

Empathy

In nursing, empathy includes appropriate emotional distance from the client to ensure objectivity and an appropriate professional response (Kunyk & Olson, 2001).

Power

The nurse has influence in the healthcare system, specialized knowledge, access to privileged information, and the ability to advocate for the client and the client’s significant others (Newman 2005). The appropriate use of power, in a caring manner, enables the nurse to form a partnership with the client to meet the client’s needs.

<table>
<thead>
<tr>
<th>Table 2.4. The Components of Nurse-Client Partnership</th>
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<tr>
<td><strong>Trust</strong></td>
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<td><strong>Respect</strong></td>
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<td><strong>Professional Intimacy</strong></td>
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<td><strong>Empathy</strong></td>
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<td><strong>Power</strong></td>
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2.8.2 **Factors that Can Hinder Practising Nurses from Completing a Health Literacy Assessment/Screening**

Most patients do not consider themselves at being ‘at risk’ (Kirsch et al. 1993), in fact many of them may not believe that they have limited literacy skills and low health literacy. A patient’s education and reading level can influence a health literacy assessment.

Other factors include an individual’s deficits in vision, hearing and cognition. These impairments are often associated with the elderly population (Friedman et al., 1999). They include eye injuries, eye disorders, visual disturbances and conductive and sensorineural hearing loss (Porth, 2007). Cataracts are also a most common cause of visual loss in elderly patients. Cognitive capacity of patients is not always adequately evaluated by healthcare professionals. Several diseases and conditions such as Parkinson disease, brain injuries, cerebrovascular disease, cerebrovascular accident or stroke, brain tumours, seizures, dementia and mental retardation can all affect a patient’s cognitive functioning which directly effects their health literacy. In fact, failure to complete a cognitive assessment by healthcare practitioners can lead to a misjudgement of their low health literacy (Paasche-Orlow et al., 2005).
2.8.3 CLUES FOR RECOGNIZING HEALTH ILLITERATE PATIENTS

Williams, Davis, Parker and Weiss (2002), perceived that people with illiteracy or marginal literacy skills, often have had many years of practice at disguising their inadequacy. Nurses can recognize patients who may have low health literacy levels by certain behaviours. These include:

Non-adherence with health care treatment regimes, incomplete healthcare forms, missed clinic appointments, failure to verbalize basic information related to health status and treatment, making excuses such as forgetting one’s glasses or having a headache when asked to read. Some patients bring family members or friends to help with paperwork, recognize pills by looking at them rather than the prescription label and ask questions on subjects already covered in written handouts (Weiss, 2003; Osborne, 2005).

2.8.4 SUGGESTED STRATEGIES FOR IMPROVING HEALTH LITERACY

Latest research by Davis and Wolf (2004), Falvo (2004), Moore and Griffith (2005), Safeer and Keenan (2005), Mayer and Villaire (2007), DeWalt (2007), have presented several strategies in improving the health literacy of individuals. These strategies can be found in the table overleaf. (Table 2.5)
### TABLE 2.5. SUGGESTED STRATEGIES TO IMPROVE HEALTH LITERACY IN THE HEALTH CARE SETTINGS

| 1. Improve health literacy skills in the population | • Motivating patients to seek to improve basic educational health knowledge.  
• Raising awareness of health illiteracy in the health care profession. |
| 2. Improve written and multimedia communication | • Written material should be easily understood, simple and kept as short as possible  
• Use of non written material such as graphic illustrations, audiotapes, video tapes or computer assisted education |
| 3. Improve patient-provider communication in health care visits | • Assess the patient’s educational needs  
• Slowing down  
• Using plain, non medical language  
• Showing or drawing pictures  
• Limit amount of information in each visit  
• Repetition  
• Teach back techniques  
• Encouraging questions |
| 4. Alter systems of care | • Attitude of helpfulness  
• Scheduling of appointments  
• Office check in procedures  
• Referrals and ancillary tests |
2.9 CONCLUSION

This literature review sought to critically evaluate the literature arising around the concept of health literacy.

In conclusion, the literature located reinforces the widespread contention that one of the principal responsibilities of qualified nurses is to educate patients. The teaching responsibilities of nurses range across information giving, medications, procedures, wound care, health habits and knowledge of signs and symptoms and how individuals continue to take care of themselves once they are in their home.

The main highlights of the literature comprise the following points:

1. There is still great need to raise awareness among nurses that patients may have poor health literacy, and that the problem is often obscure (Parker, Davis & Williams, 1999).

2. Nurses who determine that their patients have health literacy problems will need to closely evaluate and possibly revise the educational approach used in their clinical setting (Weiss 2007; Schwartzberg, Cowett, VanGeest & Wolf, 2007).

3. Nurses should be aware of how sensitized and ashamed some patients are about not being able to read and communicate well in the health care setting, and this is the reason why nurses are expected to create a ‘shame-free environment’ in the clinic where patients with low literacy levels can seek help without feeling stigmatized, and in
so doing, will provide and promote the best possible care for our patients. (The Partnership for Clear Health Communications, 2009)

4. Nurses ought to always keep in mind that communication is essential for the effective delivery of health care, and in nursing, communication is the cornerstone of a positive nurse-patient relationship (Attree, 2001; Thorsteinsson, 2002).

5. There are various assessments and intervention tools available. Following appropriate validation, the potential adoption of such tools may be considered by nurses in Malta.

6. There are various factors apart from general illiteracy associated with health literacy, such as age, cognitive impairment, and social class.

7. Efforts done by nurses to address the needs of health illiterate clients need to be complemented by efforts from members of other professions.

The following chapters present each step of a research study which sought to explore these noted facets of Health Literacy within the context of the nursing profession in Malta.
3. METHODOLOGY
3 METHODOLOGY

3.1 INTRODUCTION

This chapter illustrates how the research study was planned, designed and conducted with an explanation of underlying rationale.

3.2 PURPOSE OF THE STUDY

The aim of the study was to explore nurses' perceptions and experiences regarding health illiterate clients.

The objectives of the study were:

1. To explore nurses' awareness regarding encounters with health illiterate clients.
2. To determine the nature of their experiences with such patients.
3. To explore how nurses currently seek to address the needs of health illiterate clients.
4. To explore nurses views and opinions as regards the need to change their current practice.
3.3 Operational Definitions

For the purpose of this study,

**Perception**: is defined as the ability to see clearly and intuitively into the nature of a complex person, and situation.

**Experience**: is defined as the approach and strategies adopted by nurses when they encountered health illiterate clients in their area of practice.

**Health Centres (HCs)** are the core of the Primary Health Care Services provided by the state. At present there are eight HCs situated in different localities in Malta. These include, Floriana HC, Gzira HC, Qormi HC, Paola HC, Cospicua HC, Mosta HC, Rabat HC and Birkirkara HC.

Besides the general practitioner and nursing services, every health centre provides various specialised health services. These include immunisation, speech therapy, dental services, antenatal and postnatal clinics, Well Baby Clinics, Diabetes clinics, Podology clinics and Medical Consultant Clinics (Ministry for Social Policy, n.d.).

The term “nurses” refers to qualified Staff Nurses and Enrolled Nurses.

The Mission Statement of the Primary Health Care in Malta is:

‘To ensure that all citizens have access to comprehensive primary health care services, offering a seamless continuity of care on a personalised basis, serving the service users attain the best state of health with special emphasis on Health Promotion and Disease Prevention rather than cure.’ (Ministry for Social Policy, n.d.).
3.4 Research Design

The study involved a descriptive, non-experimental design. Descriptive research is done to describe situations as they exist in the world (Burns & Grove, 2003). As the phenomenon investigated in this study is the nurses' perceptions and experiences regarding health illiterate clients, a structured interview consisting of both close-ended and open-ended questions (Bowling, 2002) was considered to be the most appropriate method to attain the objectives of the study.

A quantitative approach with close-ended questions is adopted to investigate a phenomenon by precise measurement and quantification. It gives no space to expression of individual opinion yet the questions facilitate the interviewee's response, since strict alternatives such as 'Yes', 'No' and 'I don't know' answers are generally used. On the other hand a qualitative research with open-ended questions adopts an in-depth analysis through the collection of narrative material (Polit & Beck, 2004) and lets the interviewee express his opinion fully. Both types of questions were needed in the interview, to facilitate the richness and spontaneity of the nurses' responses.

3.5 Research Setting

The study was conducted in the eight Medical Consultant Clinics found in each Health Centre in Malta. The Medical Consultant Clinic was set up in 1996 to improve the delivery of medical care within a Primary Care setting.
3.6 **TARGET POPULATION AND SAMPLING TECHNIQUE**

As already stated in the literature review, apart from several factors that can hinder patients from understanding what is being explained to them, researchers (Davis et al; 2001) found that doctors and other healthcare professionals often use medical terms that are inadequate and confusing to the patients. During the Medical Consultant Clinic held in the health centres, there is always the presence of the consultant and the nurse. After the consultant’s encounter, the patient often turns to the nurse for a second explanation.

Polit and Beck (2004) define the target population as being the entire population in which interests the researcher and enables him to generalise the results. For the purpose of this study, the entire target population of eight female nurses, each of which work, and are in charge of their respective Medical Consultant Clinic in the eight Health Centres around Malta and who have direct contact with both the consultant and the patients, made up the sample.

The Medical Consultant clinic was purposely chosen as patients who attend this clinic are usually between the ages of 20 and over, of different gender, suffering from a variety of medical conditions, have a different social status and come from different areas of Malta. This would secure that the nurses taking part in the sample meet a diverse population of clients. Had it been another clinic chosen for this study, such as the Diabetes clinic, the results of the study might have been biased as most of the patients who attend this clinic are mostly elderly, having type2 diabetes, are now out of a job and stand a chance of being the population who when they were young did not attend school due to the war era, making them illiterate. The ante-natal, post-natal and well-baby clinics are obviously catered for the young female generation so it would not have covered the full sense of the study. At the immunization clinic, the nurse who runs this clinic, is
not accompanied by the consultant, so the study would not have included the nurses’ perceptions of whether the patients understand what the doctor tells them, together with their experience of how they are dealing with these individuals. Apart from this, within all these mentioned clinics, there is no follow-up of the patients. As for the dental, speech therapy and podology clinics, these are not run by nurses. Hence, the researcher concluded that the most appropriate clinic to meet the scope of this study was the Medical Consultant Clinic.

3.7 Research Tool

Since there is no evidence regarding health literacy in Malta, after examining the different methods of data collection, it was decided that a semi-structured interview schedule would be the most appropriate for this study. (Appendix 5a;5b)

Although interviews have the disadvantage of being time-consuming, Polit and Beck (2004) state that interviews have an advantage over questionnaires as they have a higher response rate and can be more flexible. Structured face-to-face interviews can yield highly accurate data as interviewers can probe for responses and more complicated and detailed questions can be asked (Bowling, 2002). Yet interviews can be expensive and there is a potential for interviewer bias (Bowling, 2002) both when and how the questions are asked and when the answers are interpreted. Expensive, in the sense that travelling to the eight clinics around Malta where the appointments were held cost money in terms of transport/petrol cost and time. Each interview was of approximately thirty minutes duration with each nurse, excluding the time in waiting for the nurse to finish her clinic session, and the time spent on travelling. On evaluation of the advantages and disadvantages of questionnaires and interviews, the researcher concluded that
Chapter 3 Methodology

interviews best fitted the purpose of this research study. Alternative research studies such as focus groups were discarded mainly because the researcher was advised by the respective academic supervisor and advisors, that due to the fact that (a) the researcher was new to the world of data collection and (b) the target population was not too experienced with participating in research studies, such methods would have been significantly problematic.

Expenses also included recording and dictation equipment and transcription. As for minimising interviewer bias, in this study there was only one interviewer, and therefore nurses were assured (before starting the interview) that confidentiality would be maintained by limiting to one person (the interviewer), the number of people having access to information. A non-sequential coding system was adopted for a better confidentiality of the nurses (codes are used instead of the nurses' names. E.g. Respondent A). And data collected was only used for this study.

3.8 PILOT STUDY

A pilot study is done early in research to try out sampling strategies, analyze data collection techniques, to understand research questions and to gain experience of the research process (Mason, 2002). The recording equipment can also be tested to ensure that both voices are heard without any interference from background noise (Polit & Hungler 1999). A small-scale pilot study was conducted to ensure that the interviews are acceptable and clear to both the respondents and the interviewer. A nurse who used to work at the medical consultant clinic at Paola Health Centre and who is now retired was interviewed.

The pilot study showed that some minor alterations to the questions were needed to the structured interview. The wording of few questions was arranged for more clarity.
3.9 **Validity and Reliability Issues**

Validity is defined as the account to which a tool accurately represents the phenomena to which it refers (Silverman, 2005). Validity of a tool is done to make sure that the instrument is measuring the research question. The first step to test validity is face validity. Face validity is the degree to which the tool seems to measure what it is supposed to measure (Nieswiadomy, 1987). The dissertation panel at the Institute of Healthcare established face validity of the tool. The second step is content validity. This is the degree to which the tool represents completely the concept being measured (Nieswiadomy 1987). This was done by verifying that the questions asked were relevant to the topic after conducting the literature review.

Reliability is a measure of the precision of the instrument (Cormack 2003). Polit and Beck (2004) define reliability as the consistency with which the instrument measures the characteristic it is intended to measure. Testing for reliability of the tool should be done before commencement of the study. This was not carried out due to time constraints, but a pilot study was carried out to test the tool, the audio-taping equipment and to give the interviewer some practice. The researcher then discussed the outcome results for any flaws in the pilot study instrument with the research supervisor. As regards data, when this was all collected, the researcher met the interviewee a second time to check that all information given by the interviewee was properly understood by the researcher during the interview.
3.10 **ETHICAL CONSIDERATIONS**

Permission from the Ethics Board of the Institute of Health Care, University Research Ethics Committee of the University of Malta (Appendix 2), and from the Departmental Officer of Primary Health Care Department was sought and granted (Appendix 2). Fundamental ethical principles in research were thoroughly followed (Polit & Hungler, 1999). A covering letter was sent to the 8 participants, so that it was stressed to them before conducting the interview that they should suffer no physical and psychological harm and that the identity and nature of the responses were not going to be revealed and were only going to be used for this study. A pre-interview consent form was given to the participants for them to sign prior the interview. The ethical principles underlying informed consent are that “participants are as fully informed as possible about the study’s purpose and audience; they understand what their agreement to participate entails; they give their consent willingly; they understand that they may withdraw from the study at any time without prejudice” (Rossman & Rallis, 2003). It was also made clear that their answers would not affect their career in any way, all form of data collected would be erased after the study and the interview will only be carried out at the nurses’ convenience. The researcher clearly explained the nature of the study prior to each interview and asked for verbal and written consent (Appendix 4). The nurses were also given the investigator’s contact number in a covering letter (Appendix 3), in case they were unable to keep their appointment or had second thoughts about taking part in the study. No one was obliged to take part, and it was made clear that the participants were free to decline or withdraw from the interview at any time (though this never happened).
3.11 DATA COLLECTION

A set of eleven open and closed ended questions were prepared in advance but were clarified during the interview according to necessity. The tools were prepared in both English and Maltese language (Appendix 5a; 5b). This was done so that the nurses could express their opinions in the language they felt most confident. Accuracy of the Maltese tool was reviewed by an expert in Maltese linguistics.

The aim of the first six questions was to collect demographic data and identify how the nurses feel as regards their communication with their patients. The last five questions put more emphasis on the nurses’ perceptions regarding health illiterate clients and their experiences regarding the provision of care to these individuals.

The interviews were conducted over a period of fifteen days. Privacy is a very important ethical issue and this was maintained during the interviews by interviewing the nurse in her own clinic in private, when the consultants’ sessions were over. An explanation of the study and of the interview itself was done at the beginning of the interview. The presence of the recording equipment was acknowledged (Patton, 1990). Although recording is associated with several ethical disadvantages, using recording equipment is for the interpretation of the interviewee’s exact terms (Patton, 1990). A verbal and written consent were obtained prior the interview (as already mentioned).

All the nurses decided to be interviewed in Maltese since they felt more fluent in expressing their opinions in their native language. The interviewer read the questions out word by word, in the same sequence (Polit & Hungler, 1999). This decreased the chance of having Interviewer bias.
Chapter 3 Methodology

Each interview took around 30 minutes depending on the participant. During the actual interview, structured interview questions were adhered to but the nurses were also allowed to give their opinions and focus more on the actual problem. At the end of the interview, the participants were also given a chance to see if there was anything else they wanted to add. Interviews were then translated by a qualified teacher fluent in both languages. Any response which needed to be 'quoted' in the text of this research for the findings and discussion chapter (Chapter 4) was also translated from Maltese to English by the same person.

3.12 DATA ANALYSIS

Data analysis involves a process of reflective thought where the large volume of data acquired is reduced into a logical, comprehensible sequence (Burns & Grove, 2003). Codes comprising letters, were given to each participant, e.g. Respondent A, Respondent B (Res. A, Res. B). In presenting the data gathered through the closed questions in the interview schedule, boxes were used e.g. .... Content analysis of the data gathered from the open ended questions, began as soon as data was being collected. Using this process, the researcher was able to organise qualitative information according to emerging themes, categories and codes. According to Polit and Beck (2004), content analysis is the analysis of themes and patterns that emerge. The data from the open ended questions was assembled and carefully read through several times, and the significant themes were categorised according to specific themes using a coding frame (Appendix 6). The coding frame used in the analysis was developed by the researcher for the purposes of the research study, using the literature located, and the data itself.
3.13 Conclusion

This chapter outlined the method used to achieve the purpose of this study, that is, to explore nurses' perceptions regarding health illiterate clients. In order to gather information, structured face-to-face interviews were carried out to the eight female nurses working in their respective Medical Consultant Clinic in the eight Health Centres around Malta. Prior to the study, the interview schedule was piloted.

The ethical considerations involved in this study have been described; validity and reliability issues have also been outlined, together with the process of data analysis. The following chapter presents the data collected using the interview schedule. The use of tables, and quotations from the interview data seek to enhance the understanding of certain important aspects of nurses' perceptions and experiences.
4. FINDINGS AND DISCUSSION
4 FINDINGS AND DISCUSSION

4.1 INTRODUCTION

The purpose of this research study was to explore whether Primary Health Care nurses in Malta perceive health illiterate clients in their area of practice, how they currently address the needs of health illiterate clients, and how they think care towards these clients may be enhanced.

This chapter presents all the data that was collected during the thirty minute one-to-one interviews carried out with nurses (n=8) who work in their respective Medical Consultant Clinic. The data gathered from each question from the interview schedule (Appendix 5a; 5b) is presented and in turn discussed in the context of the literature. However it is very important to re-iterate at this point, that indeed literature focusing specifically on nursing and health literacy was not available. This limited significantly the extent to which the researcher could possibly ground and refer the findings of this research study to the literature located. The open-ended questions were analysed using content analysis, while the data gathered throughout the close-ended questions is presented in tables.
4.2 DATA REGARDING THE PARTICIPANTS

Eight female nurses who work at their respective Medical Consultant clinic around the eight health centres in Malta were interviewed. The nursing experience of the participants ranged between five and twenty-one years or over.

4.2.1 NURSING QUALIFICATIONS THAT PARTICIPANTS HOLD

The qualifications of the nurses included in this study varied between certificate and diploma in nursing studies.

4.2.2 NURSES’ PLACE OF PRACTICE

Each participant practices in their respective Medical Consultant Clinic at one of the 8 Health Centres around Malta.

Among the eight participants (n=8), seven had been practising as nurses between 16-21 years and over. Only one other participant had been practicing between 0-5 years. The researcher found this data to be quite beneficial to the study as it reflected that most of these participants have had quite an amount of experience in nursing, and it helped the researcher to analyze whether or not throughout their long standing career, these nurses had become aware of health illiterate clients although the concept of ‘Health Literacy’ has never been introduced in Malta. Prior to the interviewing, the researcher was hoping that all interviewees held a long number of years in
Chapter 4 Findings and Discussion

nursing as it was assumed that participants with less working years, would not have been competent enough to identify such clients. Yet according to one of the answers that was given by the nurse who had been practicing between 0-5 years, it proved to the interviewer that less working experience had not stopped this nurse from identifying that clients can have low health literacy (Box 4.1).

The answer given by this nurse is found below:

Box 4.1:

"I know that the patients have not understood what was said to them, because they remain staring at me, so I repeat" (Respondent C. (Res. C)

"Ninduna li l-pazjenti ma fehmunix, ghax jibqghu jiċċassaw lejja, allura nerġa' nirrepeti" (Res.C)

4.3 Nurses’ Level of Agreement/Disagreement as to How Easy They Find It to Communicate with Patients at Work

In the first part of the second question, the nurses had to answer to the statement which said, ‘I find it easy to communicate with patients at work’. A five-titled scale ranging from ‘Strongly disagree to strongly agree’ as to how easy they felt regarding their communication with patients on their place of work was presented to them. Out of the eight nurses, four agree that they find it easy to communicate with patients at work and four strongly agree. Table 4.1 shows the nurses’ level of agreement/disagreement as to how easy they find it to communicate with patients at work.
### TABLE 4.1  NURSES’ LEVEL OF AGREEMENT/DISAGREEMENT AS TO HOW EASY THEY FIND IT TO COMMUNICATE WITH PATIENTS AT WORK

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Don’t know</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Res. B</td>
<td>Res. A</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Res. C</td>
<td>Res. D</td>
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<td></td>
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<td></td>
<td>Res. E</td>
<td>Res. G</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Res. H</td>
<td>Res. F</td>
</tr>
</tbody>
</table>

Typical responses to this question were:

**Box 4.2**

“*No, I find no difficulty in communicating with the patients, it is they who do not understand*” (Res. B)

“*Le mhux jien ma nafx nikkomunika mal-pazjent, il-pazjent ma jifhimnix*” (Res. B)

**Box 4.3**

“*I feel capable of communicating with the patient*” (Res. D)

“*Inħossni kapaċi nikkomunika mal-pazjent*” (Res. D)
All eight nurses were confident that they find no difficulty in communicating with their patients. One common theme emerged from these responses; nurses feel that 'it is the patients who do not understand.'

Box 4.4

"I find it easy to communicate with the patient, but the patient does not always understand”
(Res. G)

"Insibha fačli nikkomunika mal pazjent, imma il-pazjent mhux dejjem jifhem” (Res. G)

A statement such as this gives reason for debating when one bears in mind that the Center for Advancement of Health (2003), declared that health care professionals such as doctors and nurses can also have poor health literacy skills, lacking the ability to clearly explain health issues to patients and the public. Baker (2005) and Rudd (2005), remind these professionals that at times, healthcare information and instructions that patients receive may be complicated, illegible, poorly planned, poorly written and delivered in a way that does not match the patients' literacy and language levels. In fact, language that is plain to one group of individuals may not be plain to others (Plain Language Action and Information Network 2009). According to the Institute of Medicine Committee on Health Literacy (2004), healthcare professionals often make mistaken assumptions about a person’s ability to read, ask questions and understand health information. It is also a mistaken idea when health professionals presume that lack of understanding is solely limited to the use of medical terms. In fact studies have shown that individuals also find it hard to understand basic health concepts such as making proper use of an asthma inhaler (Williams et al.,
1998) and they are also unaware of symptoms such as hypoglycaemia in diabetes (Williams et al., 1998).

Health communication researchers have known for a long time that patients remember about 50% of what they are told in a visit with a healthcare professional (Kessels, 2003), and most of what is remembered is very often remembered incorrectly. Inadequate communication affects the continuum of care, from prevention and screening to history taking and explaining diagnosis and treatment (Epstein & Street, 2007).

This is the reason why Gazmararian et al., (2005) and Nutbeam, (2000) state that nurses are ethically responsible for the patient education process and should carefully find out what they need to know. Nurses should also recognize the best moment for patients to learn (Potter & Perry, 2004) and use methods that would assure self-care continuity. Communication is essential for the effective delivery of health care, and in nursing, communication is the cornerstone of a positive nurse-patient relationship (Attree, 2001; Thorsteinsson, 2002).

Health literacy is a patient’s path for understanding and using the healthcare system (Parker, Baker, Williams & Nurss, 1999). When low health literacy is undetected, communication is not adjusted to meet the level of the patients (Safer & Keenan, 2005).

The responses to this question show that the nurses in the Medical Consultation clinic appear to be unaware that they too might be the problem of miscommunication with their patients. Quite often, as nursing professionals, it is easy to get caught up in teaching clients by using language that is complicated and difficult for a lay person to understand.

Nurses should be able to accurately assess a patient’s health literacy to ensure that they promote the patient’s understanding and navigation of the healthcare system (Parker et al., 1999). They
need to focus on health literacy in every patient assessment, including a patient's reading ability, mental status, level of understanding and ability to speak effectively (Cole, 2000). They should also be highly aware that low health literacy is a serious threat to patient safety, resulting in misunderstandings, miscommunication, mistakes, increased hospital admissions, longer hospitalizations, poor health outcomes and higher healthcare costs (Baker 2005; Rudd 2005; Weiss et al. 2005; Wolf et al. 2005; Schwartzberg, 2006). Nurses can help by, recognising problems of low health literacy, make changes in the material and the process of the teaching plan by making written and oral communication easy, and make sure that patients have received and understood the message in order to help the client achieve the identified objectives.

4.3.1 Nurses' perception as regards whether the information given by them is understood by their patient

The second part of this question demonstrates the nurses' perception regarding whether their patients understand the information given by them. The statement saying 'I think patients understand the information I give them', was given to the nurses. The same 5 titled scale ranging from 'Strongly disagree to strongly agree' was used again in this section. Out of the eight nurses, four disagree that patients understand the information they give them and the other four strongly disagree that patients understand the information they give them. Table 4.2 clearly shows what the nurses' perceptions are.
TABLE 4.2 NURSES’ LEVEL OF AGREEMENT/DISAGREEMENT AS TO WHETHER PATIENTS UNDERSTAND THE INFORMATION THEY GIVE THEM

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Don’t know</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Res. B</td>
<td>Res. A</td>
<td></td>
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<tr>
<td>Res. C</td>
<td>Res. D</td>
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<tr>
<td>Res. F</td>
<td>Res. E</td>
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</tr>
<tr>
<td>Res. H</td>
<td>Res. G</td>
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</tbody>
</table>

The responses of the nurses (n=8) to this question reveal that most oral communication is not believed to be understood by the patients. This is of great concern knowing that most health communication takes place orally in the healthcare setting (Anderson, Dodman, Kopelman & Fleming, 1979).

As already stated, low functional literacy has serious consequences for individual health. People in this group are less likely to understand written or verbal information from their health care providers, to follow medication directions or appointment schedules, or to succeed in finding a way to the health system to obtain needed care. A number of studies carried out amongst patients who are functionally illiterate have found that these individuals lack essential information about their specific conditions (Williams, Baker, Honig, & Lee, 1998) and are at risk for increased hospitalization (Baker, Parker, Williams, & Clark, 1998; Baker et al., 2002).
Chapter 4 Findings and Discussion

Apart from this, patients' literacy directly influences their access to vital information about their rights and their health care; in fact, according to the World Health Organisation (1998), achieving acceptable levels of health literacy is essential for maximizing the full potential for health worldwide and moving toward health and social equity. Lately, issues of inequities in health have received increased attention. One of the greatest challenges facing the health care system today is the need to ensure that adequate and accurate health information is available to everyone regardless of literacy level (McCray, 2005).

Despite the Healthy People 2010 goal of increasing health literacy (US Department of Health and Human Services, 2000), health literacy is not just "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" but it is also a critical means to reduce health inequities. Equity can be considered as being equal access to services for equal need, equal use of services for equal need and equal quality of care or services for all. Central to this is the recognition that not everyone has the same level of health or capacity to deal with their health problems, and it may therefore be important to deal with people differently in order to work towards equal outcomes.

Berman (1984); Daniels (1985); Bryant (1997); Braveman (1998); Kinman (1999); McIntyre and Gilson, (2002) agree that many discussions of health equity focus on the dissimilarities of health program inputs such as staff and services relative to need, all of which are avoidable and therefore unjust. To a point, inequity in health also refers to differences in health outcomes that are also avoidable and therefore unjust. The underlying social determinants which lead to poorer health outcomes among the disadvantaged need to be given special attention in order to reduce inequities in health status (Leon & Walt 2001; Marmot 2004) That is why the United States
Chapter 4 Findings and Discussion

Department of Health and Human Services in Healthy People 2010 (Objective 11-2), considers improving the concept of health literacy as a key component of effective health communication and a critical means to reduce health inequities. The data to this question shows that nurses need to perform some form of health literacy assessment on all patients before providing care and health information (Foltz & Sullivan, 2005; Hartsell, 2005).

At the beginning of the study, the questionnaire was assessed for its content validity. When this was carried out it had been decided that if ever an interviewee disagreed with the statements in questions 2b, the interviewer will proceed to questions 3 and 4. On the other hand, if ever an interviewee agreed or answered ‘Don’t Know’ with the statement in question 2b, the interviewer would proceed to question 5 (Refer to interview guide Appendix 5a; 5b). As four of the interviewees strongly disagreed and the other four disagreed to the statement in question 2b, with the latter, the interviewer proceeded to questions 3 and 4.

4.4 NURSES’ COMMUNICATION WITH THEIR CLIENTS

As regards the third question, this time the nurses were asked in a different manner why they think they do not communicate well with their clients. This question was constructed to check whether the participants had actually understood questions 2a and 2b. In this way the interviewer achieved a clear picture as to whether the nurses had a misconception regarding their communicating ability with their clients or whether it was in fact the clients who did not understand the nurses.

All eight interviewees believed that from their part they do not find it difficult to communicate with the patients. Most of them also referred to what was already said in question 2. They all strongly stated that it is the patient who does not understand them.
4.5 **Nurses' Identification of at Least 3 Factors that They Think Are Strong Barriers to Good Communication Between Themselves and Their Patients**

In this question, a list of 10 factors to poor communication was presented to the nurses. The factors mentioned were: Illiterate clients, Visual impairment, Old age, Hearing impairment, Social class, Cognitive impairment, Cultural differences, Language barriers, Ignorance of their condition and 'Others'.

Every nurse had to choose at least three factors which she thought were strong barriers to good communication between her and the patients who attend her clinic. One of the factors was titled 'others'. This was done so that the nurses were given the chance to really think what possible other factors apart from those presented in the question could serve as a barrier to communicating with their clients. This approach enabled the interviewer to compare and validate what was found in the literature review.

Out of the ten factors given to the respondents, five from the list presented were identified as strong barriers to good communication while four factors under the heading 'others' also emerged as strong barriers to good communication. Table 4.3 (overleaf) and table 4.4 (pg 62) show which factors were identified and in what order they were given priority.
### Table 4.3: Five factors from the table presented were identified as strong barriers to good communication

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Illiteracy</th>
<th>Cognitive Impairment</th>
<th>Old Age</th>
<th>Ignorance of their condition</th>
<th>Social Class</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td></td>
<td></td>
<td>Second</td>
<td></td>
<td></td>
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<tr>
<td>B</td>
<td>Second</td>
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<tr>
<td>C</td>
<td>Second</td>
<td>First</td>
<td>First</td>
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<tr>
<td>D</td>
<td>Third</td>
<td>Second</td>
<td>First</td>
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<td>E</td>
<td>First</td>
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<td>Second</td>
<td>Third</td>
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<td>F</td>
<td>Second</td>
<td>Third</td>
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<td>G</td>
<td>First</td>
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<td>Second</td>
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<td>Third</td>
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<td>H</td>
<td>Second</td>
<td>Third</td>
<td></td>
<td>First</td>
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</tr>
</tbody>
</table>
4.5.1 **ILLITERACY**

The data collected clearly shows that the most common barrier to communicating with patients is illiteracy. Quoted below are similar responses given by the participants (n=7) when asked this question.

Box 4.5

"Yes, we do get patients who are illiterate" (Res. C)

"Iva, ikollna pazjenti li huma illitterati" (Res. C)

Box 4.6

"Old and are illiterate" (Res. D) (Res. H) (Res. E)

"L-anzjani u jkunu illitterati" (Res. D) (Res. H) (Res. E)

Over the last decades, researchers have noted education to be a strong determinant of health, effecting both morbidity and mortality (Baker et al. 2007). Recent data have proved that inadequate adult literacy skills are strongly associated with less health knowledge, worse self-management skills, higher hospitalization rates, poorer physical and mental health, greater mortality risk, and higher health care costs (Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004).
Illiteracy is a serious problem, especially when it relates to health care. Deficiencies in basic reading, calculating, and comprehension skills considerably affect the lives of many people. Illiteracy affects the quality of medical care, as patients are not able to perform necessary functions in the health care environment such as reading an appointment slip or following the directions on a prescription label (Weiss, 1999).

Box 4.7

"Most of them don’t know how to read the information on the pill packages" (Res. H) (Res. F)

"Ħafna ma jkunux jafu jaqraw l-informazzjoni fuq il-pakketti tal-pilloli" (Res. H) (Res. F)

Illiteracy can have a grave effect on all areas of a person’s life (Baker et al. 1998; 2002; Schillinger et al., 2002) and if it is not identified and addressed, even opportunities such as those for disease prevention or treatment may be missed (Neilson-Bohlman, Panzer & Kindig, 2004) and the effects can be damaging to one’s health and well-being.

Although as can be seen in the answers given by nurses there exists a high prevalence of illiteracy, most nurses do not systematically ask patients about reading difficulties or screen patients’ reading ability (Davis, Long & Jackson, 1993) as in Malta there is still no rapid screening instruments such as those mentioned in the literature review.

Box 4.8

"Sometimes I think the patient is illiterate" (Res. B)

"Kultant nahseb il-pazjent ikun illitterat" (Res. B)
It is also of interest however, that in the answer, illiteracy was not marked as the first priority that acts as a barrier to good communication. There were other factors that were marked as first.

However, healthcare providers need to remember that people with illiteracy or marginal literacy skills, often have had many years of practice at disguising the problem (Williams et al., 2002), maybe this could be related to the fact that most adults with limited reading ability are deeply ashamed of it and are unwilling to reveal it to others such as compared to the study carried out by Parikh et al., (1996). Unfortunately, healthcare providers often hesitate to ask whether a patient has low literacy skills as this might be associated with failure to have learned to read (Quirk, 2000).

What may concern the nurse is to remember that one just ‘can’t tell by looking’ whether someone has sufficient skills to clearly understand health concepts and carry out health care instructions. Because of this, it is important that nurses deliver effective medical instructions by providing easy-to understand information to all patients.

4.5.2 Cognitive Impairment

Aging results in normal changes in cognition. The three most common changes are: the individual takes longer to digest information, is prone to get distracted easily, and is unable to understand and remember new information at the same time (Albert, 2002). About 10% of people older than 65 years have cognitive impairment, ranging from mild deficits to dementia (Evans, 1990). As the population of older people increases, the number of cognitively impaired older individuals is expected to rise (Rosa, Ana, Pedro, Ana & Elena, 1997). The participants (n=4)
also feel that cognitive impairment does play a role in keeping patients from understanding what is being told to them. Nurses quoted (Box 4.9):

Box 4.9

“Most patients seem unfocused. They really don’t know what is going on around them.” (Res. D)

“Ħafna pazjenti qishom mitlufin. Ma jafux x’inhu ghaddej madwarhom.” (Res. D)

Cognitive impairment is quite a major health problem in old age. It is a major cause of disability and can result in an inability to care for oneself during old age (Langa et al., 2001). Impaired cognition is frequently associated with poor medication adherence (Krueger, Berger & Felkey, 2005) as adults with cognitive decline or memory problems may have difficulty understanding how to take their medications, forget to take a dose, or take too much.

Box 4.10

“The patients remain staring at me especially the elderly, they just seem lost.” (Res. C)

“Il-pazjenti jibqghu jiċċassaw lejja, speċjalment l-anzjani, qishom mitlufin.” (Res. C)

This is the reason why nurses should remember that fast presentation of materials, and change in the usual setting of the clinic and any background distraction or disturbance, often reduce understanding and promotes forgetfulness in the older person.
Chapter 4 Findings and Discussion

However it is imperative for nurses to note that age is not the only cause of cognitive impairment. Other factors such as vision and hearing problems, stress, fatigue, depression and medicine can reduce cognition and health literacy, affecting the ability of the client to interact effectively with the healthcare provider.

Box 4.11

"They seem distracted". (Res. G)

"Qisu mohhom ma jkunx hawn". (Res. G)

Even young and middle-aged patients with chronic diseases may experience particular difficulties that need to be understood and addressed if the aims of a consultation are to be met. Most of the time, acceptance of any chronic disease involves both an adaptation of body image and a change in expectations of the future. In such circumstances, the patient may be going through a difficult time in which psychological and social problems can manifest themselves (Lee & Poole, 2005).

Nurses need to understand that moments like this can limit a patient’s ability to understand and recall health information when they are at the clinic. Failure to complete a cognitive assessment of such individuals can lead to a misjudgement of their low health literacy (Paasche-Orlow, et al., 2005).

4.5.3 Old age

An interesting point to note is that while analysing the data, it was found that whenever old age was mentioned, somehow both cognitive impairment and illiteracy were included. It seems that
the nurses combine all three factors together. It can be seen very clear from the responses that were given:

Box 4.12

“old age.. the elderly.. when they come on their own...they are cognitively impaired. In this clinic we get a lot of elderly patients.” (Res. C)

“I-eta.. l-anzjani... meta jiżu wahedhom ...l-anqas jkunu jafu fejn qeghdin. Hawnhekk jiżu ħafna anzjani.” (Res. C)

Box 4.13

“At times, I find it hard to explain to the elderly....maybe its because they have a low I.Q...”

(Res. E)

“Kultant insibha diffiċli infiehem lill-anzjani...forsi ġhax ikollhom l.Q. baxx....” (Res. E)

Box 4.14

“It is quite a problem to explain to the elderly, especially the ones who do not know how to read”

(Res.D) (Res. G)

“Hiża problema biex tfiehem lill-anzjani, speċjálment dawk li ma jafux jaqraw” (Res. D) (Res.G)
Functional health literacy is said to be markedly lower among older age groups, the population with the largest burden of chronic disease and the greatest health-related reading demands (Jackson, Davis, Murphy, Bairnsfather & George 1994; Weiss, Reed & Kligman 1995). In a study by Gazmararian et al., (1999), it was also revealed that reading skills deteriorates with age.

Reading is a complex cognitive process in itself, requiring a good vision, concentration, word identification, working memory, and information processing. Any deficiencies in these areas, may affect the reading comprehension, and unfortunately the chances are that these deficiency problems may increase with age. Other factors that can contribute to lack of health comprehension in the elderly include dementia or cognitive impairment, a higher incidence of chronic diseases that may impair cognitive function, a deterioration of physical and mental health, a higher chance of sensory impairment which effects visual acuity, and a lower frequency of reading habits. For the purpose of the readers, an explanation of this will be given in the following paragraph.

The prevalence of dementia increases considerably in those older than 65 years (Graham et al., 1997) although some can develop cognitive impairment without any relationship to dementia (Graham et al., 1997). Similarly, the increasing prevalence of chronic diseases in late middle-age (National Center for Health Statistics, 1999) such as hypertension, diabetes, and hypercholesterolemia may all lead to cerebrovascular disease and stroke which can affect reading ability. The same happens in the case of chronic obstructive pulmonary disease where because of reduced blood oxygen levels the prevalence of worse cognitive function is even higher (Etnier et al., 1999). Depression too may impair concentration (Devanand et al., 1996) and so would visual
acuity which causes a decreased ability to read printed words (Salthouse, Hancock, Meinz & Hambrick, 1996).

Box 4.15

“Most elderly are usually accompanied by their relatives. They just sit there and leave everything for the relative to understand, especially as regards appointments. But when the elderly come on their own... that’s a different story altogether....” (Res. G)

“Ħafna mill-anzjani jiġu ma tal-familja. Joqghodu bil-qegħda u jhallu kollox f’idejn tal-familja, speċjalment fejn jidħlu l-appuntamenti. imma meta l-anzjani jiġu waħedhom...dik storja oħra....” (Res. G)

One can say that the nurses (n=8) were perhaps correct in associating old age with cognitive impairment and illiteracy.

4.5.4 IGNORANCE OF THEIR CONDITION

Over the years, communication and information have increasingly been believed to be important in helping people to cope with their chronic illness (Coulter, 1998). A diagnosis of a chronic illness can create uncertainty and fear although these can be eased by information (Mushlin, Mooney, Grow & Phelps, 1994). Research has indicated that the majority of patients want to be
informed about their illness (Jenkins, Fallowfield & Saul, 2001), however they may vary in how much information they want.

Some of the nurses (n=3) feel that a barrier to communication between them and their patients is created due to the lack of knowledge that the patients have regarding their medical condition.

Comments from these nurses were:

Box 4.16

"Some patients don’t know the real dangers of their condition" (Res.E) (Res. F)

“Xi uhud mil pazjenti m’għandhomx ideja dwar il-periklu tal-kundizzjoni tagħhom.” (Res.E) (Res. F)

People with limited health literacy skills often also lack knowledge or have misconceptions about critical health topics, such as the body, its functioning, and the nature and cause of disease.

Box 4.17

“Yes, people just don’t care because they are ignorant of their condition, and I do believe that this creates a barrier to good communication.” (Res. H)

“Iva, hafna min-nies ma jaghtux kaz ta saħħithom, għax ma jafux dwar il kundizzjoni tagħhom, u nemmen li din iżżommu milli jikkomunika tajjeb magħna.” (Res. H)

Nurses need to know how patients may react to the initial symptoms and diagnosis of their condition and more importantly, they need to be able to recognise the efforts that patients make
to either obtain further information or to resist information that is offered to them. They also need to consider patients' level of pre-understanding and knowledge of their disease so they can understand patients' emotions and reactions in connection with the diagnosis and can support appropriate coping strategies (Koopman & Schweitzer, 1999). At this point nurses need to appreciate that certain health information that may be too complicated for health illiterate patients, can be more bewildering and could exacerbate fear and threaten to weaken patients' hopes.

### 4.5.5 SOCIAL CLASS

According to researchers such as Wallraff, 1988; Bjerregaard and Curtis, 2002, another group of individuals who are thought to have limited literacy skills include those who are unemployed or are poorly paid in stressful jobs. In fact, although the underlying relationships are not known, individuals with limited incomes/access to resources are also more likely than those with higher incomes/access to resources to have lower literacy skills (Kirsch et al., 1993).

Only one nurse expressed the opinion that social class might act as a barrier to good communication.

Box 4.18

"Maybe because of their social class" (Res. G)

"Forsi minhabba il-klassi soxjali taghhom" (Res. G)
Balsa and McGuire, (2001), affirm that poverty is related with many socio demographic variables which, in turn, are associated with limited health literacy. Limited access to health care, lack of financial resources, and cost of medication, have all been associated with decreased adherence rates (Balsa & McGuire, 2001), which in turn might unintentionally act as barriers to good communication between the patient and the healthcare professional.

In such circumstances, according to Krueger, Berger and Felkey, (2005), the role of the nurse is to understand these underlying causes of non-adherence and mis-communication and concentrate on helping these individuals to fully identify the importance of the treatment and their treatment instructions.

<table>
<thead>
<tr>
<th>Bias</th>
<th>Excitement</th>
<th>Denial</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Res. C First</td>
<td></td>
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</tbody>
</table>

Table 4.4 Four factors (not mentioned in the list given by the researcher) were indicated under the heading ‘Others’ as strong barriers to good communication
4.5.6 Bias

One nurse believes that being biased against certain advice or medication, unconsciously leads the patient to hold back from communicating with the healthcare provider. Her opinion was (Box 4.19):

Box 4.19

"Bias. Some patients tend to be biased towards certain medications and advice. One particular woman refused to take her anti-coagulant tablets. The reason for this was that some time before, her husband had died of cerebral haemorrhage, and he used to have the same type of tablets. So this woman believed that the same thing will happen to her too if she started having them." (Res. A)


Education is a factor that contributes to patient’s non-compliance with treatment (Potter & Perry, 2004). It has already been discussed in the text above that most of the health education information that is provided to patients in the healthcare setting, is usually presented too complicated for the average person to understand (Baker 2005; Rudd 2005).

If patients have difficulty understanding instructions given by a healthcare provider, they may not be able to understand their health condition, may have difficulty with treatment decision making,
and may not understand the importance of their medication adherence (Institute of Medicine, 2004).

4.5.7 **EXCITEMENT**

Other nurses (n=2) are of the opinion that because patients are excited when they go to their clinic, this stops them from understanding what is being told to them. Quotes included:

Box 4.20

"Sometimes the patient is so excited in front of the doctor, and does not know what is being said." (Res. B)

"Kultant il pazjent ikun tant ecitat quddiim it-tabib, li lanqas ikun qed jifhem x’qed nghidlu." (Res. B)

According to Schwartzberg, Vangeest and Wang (2005) health illiterate patients find it difficult to participate in a conversation with healthcare professionals in a classified manner where the physician or nurse in the clinic ask direct questions and the patient is expected to answer immediately. The patient may feel afraid or uncomfortable to answer direct questions or to ask about his or her health. Furthermore, health information provided in a stressful or unfamiliar situation is unlikely to be remembered (U.S. Department of Health and Human Services, 2008).
The other nurse said:

Box 4.21

"The patient is excited when he leaves the doctor's room, so I have to explain again, and when they are very excited, they still don't understand." (Res. C)

"Il-pazjent ikun eċitat meta johrog minn ħdejn it-tabib, allura jkolli nerġa noqghod nispjegalu, u meta jkunu eċitati ħafna, xorta ma jifhmx." (Res. C)

Because most healthcare teaching occurs in the consultants' clinic with limited time, nurses should learn to create an atmosphere that supports a positive learning experience and remember to teach patients when they are relaxed and ready to learn.

4.5.8 DENIAL

As already stated, most of the time, acceptance of any chronic disease involves both an adaptation of body image and a change in expectations of the future. In such circumstances, the patient may be going through a difficult time in which psychological and social problems can manifest themselves (Lee & Poole, 2005).

One particular nurse noticed that denial too can act as a barrier to good communication. Her explanation was (Box 4.22):
Chapter 4 Findings and Discussion

Box 4.22

"Sometimes, especially young males, find it difficult to accept having all the newly prescribed treatment. And when he is told that he is suffering of ‘this and that’...it’s like a form of denial. This denial keeps the patient from accepting what is being explained to them. You see, not all our patients are old, we get young patients that are hypertensive.” (Res. B)


Nurses need to understand that moments like this can limit a patient’s ability to understand and with the best plan in place, no learning will happen if the client is totally unmotivated. Remembering that illness, fatigue, depression and anxiety are all factors in motivation toward learning, and that these can be present in a health care setting, it is important for nurses to assess a patient’s motivation before commencing on a teaching plan.

4.5.9 Depression

During one’s life, the possibility of developing any mental disorder is nearly 50% (Kessler et al., 1994), so that at some point almost everybody has direct contact with an affected person. Recognition of mentally disordered persons is essential as it influences their attitude and
Chapter 4 Findings and Discussion

behaviour (Jorm, 2000). Moreover, mental health literacy is an important determinant of help-seeking behaviour.

As a matter of fact, one other nurse mentioned the fact that she finds it hard to communicate with mentally depressed patients. She said:

Box 4.23

“At times, when we get a mentally depressed patient, it is not always easy to communicate with him/her. Either because of the tablets that they are having....” (Res. D)

“Kultant meta jkollna lil xi hadd b’ ‘depression’, mhux dejjem inkunu nistghu nikkomunikaw mieghu jew maghha. Forsi minhabba l-medicini li jkunu qed jiehdu.....” (Res. D)

Less knowledge about mental illness and its symptoms and possible treatment approaches are negatively associated with health care use.

Healthcare professionals need to appreciate that the process of their communication with a depressed patient should take into account the patient’s slower rate of cognitive processing. It is also of extreme importance that one bears in mind that often many patients with chronic health conditions can also experience depression (Kando, Wells & Hayes, 2005). They may experience pain, sexual dysfunction, and other physical limitations. These frustrations can cause sadness and despair.
4.6 NON-ADHERENCE TO TREATMENT REGIMES AND ADVICE

In the first section of this question, the nurses were asked to answer with either a ‘no’ or ‘yes’ as to whether they had ever encountered clients who had not adhered to their treatment regimes or any advice given to them. All the nurses (n=8) answered yes to this question.

The second part of this question asked the nurses why they thought was the reason for their clients’ non-adherence to treatment or advice. A few factors already mentioned in response to the previous question, were again referred to by the nurses in response to this question. These included Bias (n=2), illiteracy (n=2), forgetfulness (n=2), excitement (n=2), cognitive impairment (n=4), ignorance of their condition (n=3), old age (n=1).

Another two interesting factors came up as regards patients’ non-adherence to treatment. These were: ‘reluctance to change their lifestyle’ and ‘financial problems.’

4.6.1 RELUCTANCE IN CHANGING OF LIFESTYLE

Nurses (n=2) mentioned that at times, there are clients who are reluctant to change their lifestyle. One of these nurses said (Box 4.24):
Box 4.24

“Some do not take their medication simply because they just don’t like taking tablets. Others refuse to take tablets because they won’t be able to drink alcohol.” (Res. F)

“Hemm min ma jihux it-'treatment' semplićiment għaliex ma jhobbx jiehu mediċini. Ohrajn jirrifjutaw li jieħdu mediċini għaliex ma jkunux jistgħu jixorbu alkohol”. (Res. F)

And the other nurse, sounded quite angry when she said:

Box 4.25

“They simply don’t want to make the change as regards diet or exercise” (Res. H)

“ Semplićiment ma jridux jagħmlu bidla fejn tidħol dieta u eżercizzju” (Res. H)

4.6.2 **FINANCIAL LIMITATIONS**

Another Nurse, (n=1) alluded the clients’ non adherence to treatment due to financial problems. Quite concerned about this problem, her comment was:

Box 4.26

“Maybe it’s because they do not have money to buy tablets...” (Res.D)

“ Forsi għax m’għandhomx flus biex jixtru l-medicina...” (Res. D)
Chapter 4 Findings and Discussion

Sometimes, nurses may feel frustrated when trying to communicate with patients who appear to be unmotivated and non-compliant in following self-care instructions. Bender, (2002) and World Health Organisation (WHO), (2003), have associated advice and medication non-adherence with five barriers which are very interesting to consider as regards the answers given to this question.

These barriers are: socioeconomic, disease, treatment, provider and patient related (Bender, 2002; World Health Organisation (WHO), 2003). Below is an explanation of these barriers:

Socioeconomic barriers include cultural and individuals’ beliefs about illness and treatment, inability to afford medications or regular healthcare visits and also lack of transportation (Wallace, Scott, Kinnert & Anderson, 2004; WHO, 2003). (Ironically though, it has been found that individuals with unfavourable socioeconomic circumstances are more likely to be smokers, have excessive alcohol consumption, sedentary lifestyle and unhealthy dietary habits).

The disease-related barrier comprises the nature of symptoms and the patients’ confusion about the accuracy of the diagnosis and the need for ongoing treatment.

Treatment related barriers include the complicated regimens that the individual is supposed to comprehend, different medication effects, and delayed onset of medication actions.

Provider related barriers refers to long waiting lists for follow-up appointments, short patient visits that limit teaching and also healthcare provider communication difficulties.

Patient related barriers include poor understanding of the need for treatment, lack of confidence in the healthcare professional or medication (Westin, Ahs, Persson & Westerling, 2004),
Chapter 4 Findings and Discussion

misunderstandings about side-effects, co-morbid problems, and lack of motivation to change behaviour or lifestyle.

Although all these factors must be addressed, to promote adherence Bender (2002) states that patient motivation may be the most important.

In such a situation, nurses because of their highly developed assessment skills, and frequent contact with clients, are in an ideal position to determine the ability levels of individuals (Cutilli, 2005; Monsivais & Reynolds, 2003). Nurses must go beyond their own assumptions, look beyond a client’s appearance and behaviour and seek out to conduct a full assessment of variables to uncover the reason for an individual’s non-adherence to treatment and advice.

On a 5 titled scale, ranging from ‘Always to Never’, the nurses were asked to mark how often they encountered problems of non-adherence with their clients. Answers to this question are shown in the table overleaf.


**Table 4.5** Frequency of Incidence

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Always</th>
<th>Often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
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4.7 **Methods currently used by nurses to ensure that clients are receiving and understanding the information provided to them**

The answers to this question clearly point out the various approaches that the nurses had to adapt both during and after the sessions to ensure that their clients are actually receiving and
understanding well the information provided to them. Four approaches that were mentioned by all the nurses (n=8) were: 'Explanation', 'Repetition', 'Hand gesturing', and 'encouraging the patients to call back' if they have any problems. The varied approaches adapted by the nurses are found in the quotes below.

4.7.1 EXPLANATION

All nurses (n=8) said that they explain several times to their patients. Responses were of the type mentioned here below:

Box 4.27

"I explain to them how to take their medication, for example, I show them what is written...1-1-1, and I tell them what it means...one in the morning, one at midday, and one in the evening."
(Res. A)

"Nispjegalhom kif ghandhom jiehdou il-medicini, per ezempju, nurhom x'hemm miktub...1-1-1, unghidilhom x'ifissru...ważda filghodu, wahda f'nofsinhar, wahda fil-għaxija." (Res. A)

4.7.2 REPETITION

This approach too was adopted by all nurses (n=8). An example that is representative of all the answers from participants, is found below:
Chapter 4 Findings and Discussion

Box 4.28

“I know that the patients have not understood what was said to them, because they remain staring at me, so I repeat”. (Res.C)

“Ninduna li l-pazjenti ma fehumix, għax jibqghu jiċċassaw lejja, allura nerġa’ nirrepeti” (Res.C)

4.7.3 Hand Gesturing

All the nurses (n=8) try to explain information that the patients might find difficult to understand by using hand gestures:

Box 4.29

“If they are illiterate I make gestures with my hand to try to explain to them even more clearly” (Res.E)

“Meta jkunu illiterati, naghmlilhom sinjali b’idejja biex nipprova nfiehemhom aħjar” (Res.E)

4.7.4 Encourage the Patients to Call Back

According to all the nurses (n=8), follow-up appointments are a method of ensuring that the patient has understood what was told to him/her during the session. An example of what the responses were to this approach is shown here:
Box 4.30

"I tell them to call whenever they have any difficulties. I also give them the telephone number and give them the days when we are available here to talk to them. The patients come back several times to talk about various difficulties" (Res. D)

"Nghidilhom biex icemplu kull meta ikollhom xî diffikultà. Intihom ukoll in-numru tat-telefon u nghidilhom il-ğranet addatatli li aţna nkunu nistgħu noqgħdu nkellmuhom. Il-pazjenti kemm-il darba jerġħu jiġu biex jistaqsu dwar diversi diffikultajiet" (Res.D)

4.7.5 Other approaches

One nurse (n=1) said that she tries to ‘change the wording’ that was said during the session using simple terms. It is important to remember that researchers such as Davis et al., (2001), found that doctors and healthcare providers often use medical terms that are inadequate and confusing to the patients. Another nurse (n=1) felt that ‘assuring the patient’ is of great concern especially knowing that the patients are usually very excited after their encounter with the consultant. Only two nurses (n=2) said that they use the ‘teach back’ technique. When using this method, the healthcare professional explains a concept or behaviour to a person, then asks the person to explain it back in his or her own words. Several researchers find that this method helps patients to clarify what they really have understood from all the information that was given to them.

These nurses’ suggestions are shown below:
When evaluating the answers to this question, it is perhaps evident that among the four suggested strategies adopted by Davis and Wolf (2004), Falvo (2004), Moore and Griffith (2005), Safeer and Keenan (2005), Mayer and Villaire (2007), DeWalt (2007) (mentioned in the literature review), the nurses already implement one; that which involves improving patient-provider communication by repeating, changing the wording, using the ‘teach back’ technique, and assuring the patient.

However one discouraging factor that came out from these answers is that some nurses admitted that they find it less complicated when taking the initiative to do certain things for these health illiterate patients rather than trying to explain to them what they should do. This goes totally
against the latest definition of Health Literacy given by Nutbeam (2006), which says that by improving people’s access to health information, health literacy is critical to empowerment.

4.7.6 **TAKE THE INITIATIVE**

By looking at the two answers shown below, it seems that some nurses have become discouraged in finding ways as to ensure that their patients have understood the information given to them. The opinions expressed by these nurses were:

Box 4.32

“*Sometimes, I myself go down and get the tablets for them because it is less complicated*” (Res.D)

“*Ġie li ninżel jien, u ngibilhom il-mediċini, ghax inqas ikkumlifikata*” (Res.D)

“*Quite often I go to the reception myself to do the appointments, because the patients get mixed up*” (Res. E)

“*Ħafna drabi mmur jien ir-reception u nagħmlilhom l-appuntamenti, ghax il-pazjenti jithawdu*” (Res. E)

Partridge, (2005) emphasises that patients with long term conditions should always be helped to learn how to manage their own condition. However, as the term health literacy has only recently appeared in the healthcare literature and has not yet been introduced on the Maltese Islands, there seems to be a lack of knowledge of understanding health literacy and without this knowledge there is no opportunity for the nurses to implement certain other approaches in
practice. From the data gathered it seems that the interviewees have employed certain nursing interventions to enhance their patients’ understanding only by experience throughout their nursing career.

This is why it might be quite interesting to note in the answers given, that not one nurse stated the importance of at least assessing the patient’s educational level. In fact a common theme that emerged from all the nurses (n=8) is that although they try to teach and educate the patients, several times although these patients almost always state that they understood their healthcare teaching yet these same patients frequently returned to their clinic to ask again about their difficulties. This could signify that had the issue of health literacy been introduced in Malta, nurses would be made more aware of this problem and they would be in a favourable position to use several other methods to educate their clients such as employing assessment techniques for health literacy and make use of easy written, visual and auditory materials (Houts, Doak, Doak & Loscalzo, 2006).
4.8 POSSIBLE CHANGES TO FACILITATE THE NURSES’ CURRENT PRACTICE

One question in the interview schedule, asked the nurses whether they could think of anything that could be implemented or changed to facilitate their current practice.

Three nurses suggested that the patients ought to be advised to be accompanied by relatives when they come for their session. Others (n=4) commented on the way the tablets are packed. Again, nurses (n=6) expressed the wish of giving regular follow-up appointments. Other nurses (n=6) seemed very concerned about the healthcare materials given to patients. A number of nurses (n=6) find that contacting the patients by telephone will be of utmost help, yet they expressed their disappointment regarding the lack of an external telephone line in their clinic which stops them from doing so. One other nurse said that she tries to do her best to encourage patients to live a healthy lifestyle.

Below are the various opinions as expressed by these nurses. Various authors have investigated that by using the same methods mentioned above by the nurses (n=8), they could facilitate current practices as regards the patients’ understanding. Hence the data is encouraging.

4.8.1 ACCOMPANIED BY RELATIVES

It was suggested by nurses (n=3) that having a relative or friend accompanying the patient, would help the patient feel more confident that what they miss from what is being said to them, might be explained to them again by their partner when they leave the consultant’s clinic. Research by Weiss, Reed and Kligman, (1995), shows that health illiterate patients often ask the assistance of
family or friends after their health visits to interpret what their clinicians told them so that a very important strategy is to ask patients whether they would like a family member or friend to be with them during their clinic visit.

The nurses' suggestions were like of the type below:

Box 4.33

“Patients should be encouraged to bring some relative with them” (Res. F)

“Il-pazjenti ghandhom ikunu nkoraggati biex igibu lil xi qraba maghom” (Res. F)

4.8.2 Preparation of Tablets

Quite a number of nurses are worried as how the patients’ medications are prepared. It seems that a common problem among their patients is the understanding of their medication names and regimes and that most patients recognise or refer to the tablets they are taking by the colour or shape of the tablets. As regards preparation of tablets, according to the Institute of Medicine (2006), unfortunate events in the administration of drugs, are the most common of medical errors. These occurrences arise for a variety of reasons which include prescriber error, dispensing error and drug interactions, but they can also be the result of communication problems (Institute of Medicine, 2006). Low health literacy is significantly associated with a poorer understanding of medication names, indications, and instructions and adherence to treatment regimes (Baker et al., 2007; Hernandez, 2008).
Nurses’ suggestions were similar to the one below:

Box 4.34

“Tablets should be prepared specifically for the individual patient in bottles and not in ready packed paper bags. The bottles should be written purposely according to the dose the patient is to have” (Res. E)

“Il-mediċini għandhom ikunu preparati apposta għall-pazjenti individwali fi fliexken u mhux f’borsizzippakkjit bil-lest. Il-fliexken għandhom ikunu miktuba għal ta’ l-apposta bid-doża li suppost jieħu l-pazjent” (Res. E)

Given the prevalence of chronic diseases, the challenge of managing multiple medications, and the incidence of adverse drug events particularly among the elderly, (Gurwitz et al., 2003) there is a need to communicate more safely and effectively with patients about medications. Attention should be given to several common mistakes that can confuse the patient, for example a very common problem occurs when a brand is substituted due to pharmacy formulary restrictions, and a prescription for the new brand is written again by the consultant. This is the reason why any changes to the dose or frequency, as well as addition or deletion of medications, should be documented and explained carefully to the patient. According to Piette, Schillinger, Potter and Heisler (2003) effective communication regarding medications can help avoid medication-related errors and has been shown to promote medication adherence in chronic diseases.
Chapter 4 Findings and Discussion

Although nurses have a very important role in educating the patients, certain components of education can be shared among a healthcare team that comprises the consultant, nurse and pharmacist. Given their formal training in obtaining medication histories and counselling on their use, pharmacists may be the ideal people to help out in providing the proper information as regards medication to the patients (Schwartzberg, Cowett, VanGeest & Wolf, 2007).

4.8.3 Regular follow-up appointments

The suggestion of regular follow-up appointments came up again as an answer to this question. This could probably signify that most nurses are not very confident that their patients understand the information they are given and are probably afraid to risk their patients’ self management at their homes. Below is a version of the answers given by the nurses at the Medical Consultant Clinic:

Box 4.35

“Regular follow-up appointments help a lot” (Res. D)

“Appuntamenti regolari migliorano l’adeguatezza” (Res. D)

However, one should bear in mind that often patients with low literacy develop ways to hide their inadequacy and that according to Williams et al., (2002), nurses can recognize patients who may have low health literacy levels by certain behaviours: one of these is that these patients tend to miss their appointments. This might mean that the nurses are wrong in assuming that follow-up
appointments would help low health literacy patients, especially the ones that are illiterate. Literacy problems can prevent a patient's ability to attend appointments because they may not be able to read their appointment booklet or get confused when trying to follow directions to the consultant's office (Baker et al., 1996). Patients with inadequate health literacy face many obstacles when accessing and using the health care system (National Centre for Education Statistics, 2006).

One interesting approach though, as suggested by experts is to call patients several days after delivering important information to further emphasize understanding (Schwartzberg, 2000), and if any concerns are brought forth, the patient receives a call from a nurse educator.

4.8.4 CONTACT BY PHONE

In fact, bearing in mind that experts recommend this approach, it was quite encouraging that during the interviews, almost all nurses suggested contacting their patients at home to check on them and the majority of them actually emphasised that they need a direct telephone line in their clinic so they will be able to contact their clients. Courson, (2005) found that help lines staffed by nurses provide assistance to low health literate patients by telephone.

Such phone calls can be helpful for reinforcing particularly important information. Below are typical versions to this suggestion as given by the nurses (Box 4.36):
Box 4.36

“Sometimes when I receive their blood results, I find that either they are newly diagnosed diabetics, or that their cholesterol levels are high, so I contact them by phone and tell them to take care of their diet.” (Res. D)

“Ġie li meta nirċievi r-riżultati tad-demm, insib li xi ħadd ibati bid-diabete, jew ir-riżultat tal-kolesterol ġie għoli, allura nċemplilhom u nghidilhom jieħdu ħsieb id-dieta” (Res.D)

“I need an external telephone line in my clinic, so I will be able to contact patients and talk privately and they too would find it easier to contact me on a direct telephone line.” (Res.E)

“Ghandi bżonn linja tat-telefon għal barra fil-klinik tieghi, ħalli nkun nista’ nċempel lil-pazjent u nitkellem privat magħhom, u huma ukoll isibuha faċi li jikkontattjawni fuq linja diretta”. (Res E)

4.8.5 LESS APPOINTMENT FORMS

Nurses also felt that ‘less appointment forms’ would help facilitate their practice. A most common habit during a health care encounter is that the consultant often mentions several different ideas, prescribes medications, and suggests self-care behaviours. Apart from several factors that can hinder patients from understanding (as already mentioned), another problem that patients encounter when they attend the health clinics, is the amount of instructions and educational materials that they are presented with on their first appointment. These include
several other appointment forms for various other health departments, description of tests and medication instructions. According to Schwartzberg, Vangeest and Wang (2005), these forms are written at a college level so that it makes it harder for the lay person to read and understand them.

Most nurses agreed that the patients are given too many healthcare materials such as instruction and diet forms, blood investigation and X-ray forms and appointment forms, when they come to their clinic.

Comments regarding this problem were similar to the type below:

Box 4.37

“When they come the first time, the patients do not understand one thing that is told to them (Interviewee is laughing). When the patient comes we give them so many papers and ‘rubbish’...a card for this and a form for that... I think its best that the patient gets only one card for everything, I mean sometimes, even I get confused, let alone them, you know, they are lay people not medically oriented like us.” (Res. F)

“Meta jiġu l-ewwel darba, il-pazjenti ma jifhmux waħda milli nghidulhom (il-partecipanta qieġħa tidhaq). Meta jiġu l-pazjenti, intuhom tant karti u ‘imbarazz’... ‘card’ għal dik u formola għall-oħra... Naħseb l-ahjar li l-pazjent ntuh ‘card’ waħda għal kollox, irrid nghid kultant anke lili jħawdu aħseb u ara lil pazjent li mhuwiex ‘medically oriented’ bhalna.” (Res. F)

Nurses understand privacy issues (Morra, 2000) and can assist patients who may have hesitated to ask questions or clear any difficulties in front of the consultant, by slowing down during
interactions with patients and any family members, limiting the amount of information, use words and examples familiar to the patient, use pictures or models to explain important concepts and provide explanation for follow-up instructions, such as preparation for tests or medications (Partnership for Clear Health Communications 2004; Bastable, 2006).

4.8.6 ENCOURAGEMENT

According to Krueger, Felkey and Berger, (2003), a good relationship between the patient and health care provider, that includes encouragement and reinforcement from the provider, has a positive impact on adherence. One nurse feels that encouraging the patient, helps to empower the patient in taking care of his/her health. Her opinion was:

Box 4.38

“I also encourage them to diet and exercise and to try to change their lifestyle” (Res. C)

“Nipprova naghmlilhom kuraġġ biex jibdew jagħmlu dieta u eżercizzju” (Res. C)

4.8.7 I DON’T KNOW

Yet one nurse at that particular moment could not come up with any ideas and seemed to be at a loss when asked suggesting ways to facilitate their practice with their hard-to-reach clients. Her answer was (Box 4.39):
Chapter 4 Findings and Discussion

Box 4.39

"I really don't know what we can do" (Res.E)

"Veru ma nafx x'nistghu naghmlu" (Res. E)

At this point the interviewer read out a definition providing the meaning of the term “Health Literacy” and a typed copy of the definition was also given to the interviewee (Appendix 5a; 5b).

This next question sought to enquire how often do the nurses (n=8) encounter ‘Low Health Literate Clients’ at their clinic. The same scale used in question 4.7 was used in this question

4.9 Frequency of Encountering Low Health Literate Clients

On a 5 titled scale, ranging from ‘Always to Never’, the nurses were asked to mark how often they encountered ‘Low Health Literate Clients’. As seen from the answers, one cannot disregard the fact that the nurses do actually encounter these type of clients. Answers to this question are shown in the table overleaf (Table 4.6).
### Table 4.6 Frequency of Incidence

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Always</th>
<th>Often</th>
<th>Sometimes</th>
<th>Rarely</th>
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</table>
4.10 METHODS HOW THE NURSES ADDRESS THE NEEDS OF THESE 'HEALTH ILLITERATE CLIENTS'

In the quotes given below, one can see the different approaches that the nurses (n=8) use to address the needs of these clients. The nurses mentioned methods of communication and teaching strategies used with hard-to-reach patients, although most gave only one or two strategies, and did not elaborate. The approaches are not much different to the ones already explained in question 4.8 regarding the current methods used by nurses to ensure that clients are receiving AND understanding the information provided to them.

4.10.1 EDUCATE THEM ABOUT THEIR CONDITION

According to Bastable, (2006), nurses are in a key position to positively affect the lives of patients through education, so that answers such as the one below seem to prove that nurses feel the need to improve the patient comprehension:
"Usually I try to explain and give knowledge about their condition. The nurse should be responsible to educate the patients about their condition and teach them how to lead a healthy life" (Res.A)

"Ħafna drabi, nispjegalhom u nghallhom dwar il-kundizzjoni ta' saħħithom. In-nurse għandha tkun responsabbli biex teduka lil-pazjent dwar il-kundizzjoni tagħhom u tghallhom kif jgħixu ħajja aħjar" (Res. A)

4.10.2 Give one thing at a time

The issue of improving oral communication by limiting the number of topics communicated at one time seems to be of great concern to the nurses. This can be seen in the suggestion given below:

"When faced with a lot of things such as appointment forms and investigation forms, they get more confused so we give them ‘one thing at a time’ (Res. A) (Res.F)

"Meta jkollhom ħafna formoli tad-demm jew ta’ l-appuntamenti, aktar jithawdu, allura nispjegawihom ħaġa b’ħaġa, wahda wara l-oħra.” (Res. A) (Res.F)
4.10.3 Ask them to be accompanied

Most nurses feel that health illiterate patients can benefit when they have a relative/friend with them, so that if the patient does not understand what is being explained during the consultant’s session or forgets what was said during the session, there is always the presence of someone else who can later remind or explain to the patient. Suggestions of this kind were (Box 4.42):

Box 4.42

“When we see that they cannot assimilate things, we ask them whether it is possible that they get someone to accompany them on their next appointment” (Res. A)

“Meta naraw li ma jistgħux jassimilaw l-affarijiet, insaqsuhom jekk hux possibi li darb’oħra jgibu lil xi hadd magħhom” (Res. A)

“Both the consultant and I, insist that someone comes with them especially the elderly, because these, if they don’t have a family, they just mess about and mess about with their treatment and its useless trying to explain”. (Res. B) (Res. G)

“Kemm il-konsulent kif ukoll jien, ninsistu li jgibu lil xi hadd magħhom, speċjalment l-anzjani, għax dawn jekk ma jkollhomx familja, jibqghżu iħawdu u jħawdu bil-medicini u għalxejn tispjegalhom”. (Res.B) (Res.G)
4.10.4 ADVISE TO APPLY FOR A HEARING AID

As already stated in the literature review, health illiteracy is not only associated with general illiteracy. Several other factors such as sensory handicap, can also affect health literacy. After reading the definition of the term ‘health illiterate clients’ among the eight nurses, only one nurse referred to occasions when they have physically disabled patients at their clinic. The nurse referred to hearing impaired patients. Her method of addressing the needs of such clients was (Box 4.43):

Box 4.43

“As regards the hearing impaired, most of the time I get hoarse trying to explain, and sometimes when I tell them to apply for a hearing aid, they say that they already have one but they do not wear it because it bothers them” (Res. B)

“Ghal min ghandu nuqqas ta’ smiegh, hafna drabi ninhanaq nipprova nispjegalhom, u kultant meta nghidilhom japplikaw ghal ‘hearing aid’, jghiduli li digà ghandhom u ma jilbsuhiex ghax iddejjaqhom.” (Res. B)

4.10.5 IMPROVING STANDARDS IN COMMUNICATION

Again in this question, aspects of communication seemed to imply that issues concerning communication and education are of paramount importance in day-to-day experiences of nurses dealing with health illiterate clients. These included, ‘encouraging patients to call in case of
difficulties’, ‘follow-up system’, ‘repetition’ and ‘simplifying the wording’. Quotes presented below, given by nurses verify this (Box 4.44):

Box 4.44

“ I try to assure them and encourage them to call if they have any difficulties. “(Res. C)

“ Nipprova nserhilhom moħhom u nghidilhom iċemplu jekk ikollhom xi diffikulta” (Res.C)

“Follow-up system is very good. The patients are all the time coming to look for me to talk about their difficulties” (Res. D) (Res. H)

“Il-‘follow-up’ system tajba ħafna. Il-pazjenti ħafna drabi jiġu jfitxxuni biex jitkelimu dwar xi diffikultajiet. (Res. D) (Res. H)

“I repeat. Several times the patients come again to ask me what the doctor said. I think they feel more comfortable with us” (Res.G) (Res. H)

“Nirrepeti. Ħafna drabi il-pazjenti jiġu lura biex jistaqsuni nirrepeti dak li jkun qalilhom it-tabib. Nahseb ħossuhom aktar komdi magħna” (Res. G) (Res. H)

“I try to explain slowly in simple words what they need to know.” (Res. H)

“Nipprova nfiemhom bil mod u nuża kliem sempliċi.” (Res. H)
4.11 SUGGESTIONS OR RECOMMENDATIONS WHICH, IF IMPLEMENTED, THE NURSES’ THINK MAY ENHANCE THE CARE PROVIDED TO THE HEALTH ILLITERATE CLIENTS

As regards methods to enhance the care for health illiterate clients, it appeared difficult for interviewed nurses to create a plan for hard-to-reach patients, how to assess their learning needs and what are appropriate teaching strategies. Again the issues of ‘educating the patients’ about their conditions, ‘encouraging the patients to be accompanied with some relative’ and ‘calling the patients at home’ were suggested.

Box 4.45

“If we had the opportunity to call them at home in between follow-ups and check whether they have any difficulties... (Res. B) (Res.D)

“Kieku kellna l-opportunita nċemplulhom id-dar bejn appuntament u iehor u nistaqsuhom jekk għandhomx xi diffikulta.... (Res. B) (Res. D)

Box 4.46

“It will be a good idea if there was some kind of home help service, where the patients who come to the MCC and who find it hard to understand their treatment regimes are visited regularly by the home help nurse who can assist them in their difficulties” (Res. H)

Meta jkollok klient u tinduna li dan ma fehemx metta ġie l-MCC, tajjeb li jkun hemm servizz ta ‘nurse’ li kultant żmien issegwi lil-klient fil komunita u tara li dan qieghed isegwi dak li ġie ordnat lilu’ (Res. H)
Nurses (n=6) also focused on the need of ‘improving healthcare materials’, and ‘using less appointment forms’. At this point it is interesting to note that in certain circumstances, although pictures do not serve as a replacement for written or verbal communication, as understanding is best when pictures are combined with written or verbal explanations researchers (Houts et al., 2006) have long known that visual images are remembered better than letters and words and that they improve patients’ understanding of what they need to do.

Box 4.47

"It will be good if there is a system that we can make their appointments from our own clinic”
(Res. G)

"Tajjeb kieku nistghu ngħamlulhom l-appointmenti kollha mill- klinik” (Res.G)

Box 4.48

"They dont understand all the different appointment forms we give them on one session. Forms ought to be written in simple words with pictures which indicate to the patients what they are supposed to do. We should provide booklets with pictures” (Res. C)

"Ma jifhmux dawk l-'appointment forms' kollha li ntuhom f' "session" waħda. Il-'forms' għandhom ikunu miktubin bi kliem sempliċi, bi-istampi li juru lii-pazjent x'għandu jgħamel. lmissna ngħamlu kotba zgħar bi-istampi” (Res. C)

However, it seemed that because they find it hard to identify hard-to-reach patients, especially low-literate patients, nurses could not think of specific information and education needs of these
patients. In fact most nurses (n=6) felt that responsibility for improving health literacy should include other healthcare professionals.

Box 4.49

“As regards tablets, I don’t see how we can help the patients. It has to be the pharmacists’ duty to explain to them about the tablets” (Res. B)

“Rigward il-medicini, ma nistax nahseb kif nistghu nghinu lil pazjent. Irid jiği mill ispizjar li joqhod ifhemhom” (Res. B)

Box 4.50

“I really don’t know what to say especially with the elderly (interviewee is laughing) if they don’t know how to read, I mean there is no other way how to explain to them. I mean the pharmacist writes down on the box how they are to take their medication such as 1-1-1, but as regards other things, for those who do not know how to read there is no way out....(Res. B)

“Veru ma nafx x’naqbad nghid, specjalment dwar l-anzjani (Il-partecipanta qeghda tidhaq) jekk ma jafux jaqraw, irrid nghid m’hemmx mod iehor kif tispjeghalhom. L-ispizjar jiktbilhom fuq il-kaxxa 1-1-1, imma dwar affarijiet oħrajn, ma naħsibx li hemm xi mod iehor... (Res. B)

Most of the above answers (to questions 10 and 11a,) of the interview schedule, have a similarity to the answers given to the prior questions. This is interesting as the issue of Health Illiterate patients was not yet mentioned before these last two questions. This approach was taken to check the nurses’ perception of this phenomenon and whether any particular methods to
enhance the patients’ understanding were being already implemented. All nurses (n=8) seem aware that there exists some kind of barrier between them and their patients. As with most other points in this chapter, the researcher was not able to ground and refer the findings of this study to the literature, because literature focusing specifically on nurses’ Health Literacy is not available /existent.

4.12 Nurses’ reasons for suggesting /recommending these steps

It is evident from the answers below that all the eight nurses are very concerned as regards the health status of their patients. For the purpose of the reader, all the nurses’ statements were left exactly as they were told during the interview (Box 4.51). These answers which are very heartening seem to prove that it is true that nurses actually are in a key position to positively affect the lives of patients through education and are capable of producing potentially longstanding changes in patients’ lives (Nutbeam 2000; Gazmararian et al., 2005; Bastable 2006).
### Chapter 4 Findings and Discussion

**Box 4.51**

"The patient needs to be looked at holistically. We have to imagine ourselves in their place and empathise with them. When they come to our clinic, for sure they would need a lot of understanding" (Res. A)

“Irridu nharsu lejn il-pazjent mill-att holistiku. Inpoġgu lilna nsusna min fokhom u n’empatizzaw magħhom. Meta jiġu fil-klinika tagħna, żgur ikollhom bżonn min jiżhom“. (Res. A)

“For the good of the patient” (Res. B) (Res. E)

“Għall ahjar tal-pazjent” (Res. B) (Res. E)

“To make things easier for these patients” (Res. C)

“Tghamel l-affarijiet aktar faċlji ghal dawn in-nies” (Res. C)

“My mind is at rest that the patient is informed 100% about what is going on” (Res. D)

“Mohħi mistrieh li l-pazjent jaf 100% x’inhu jiġri” (Res. D)
“Well in the long run, it is the patient who is going to gain. Treatment is taken better by the patient. The patient is in less danger and will have less problems. Also in this way there will be more order of things and maybe we will be able to decrease the follow up appointments of the same patients and give more chance to newly diagnosed patients to attend our sessions.” (Res. F)


“This helps them not to miss their hospital appointments” (Res. G)

“B’hekk ikollhom anqas ċans li jiltro l-appuntamenti ta l-isptar.” (Res.G)

### 4.13 Comments added by the nurses

In order to strengthen the gist of these interviews, in this last question, each participant was given a chance to add any comments they wished. Different responses as added by the nurses (n=8) are given below:

Nurses agree that it is absolutely crucial for patients to understand the self-care information. They are not sure that health illiterate patients or clients really understand what they need to (Box 4.52).
Chapter 4 Findings and Discussion

Box 4.52

“The consultant gives very good service here. Several times, although we know that the pharmacist has already told them how to take their tablets, we still tell them to come back and we explain to them again, the time and the doses how they should have their tablets.” (Res. C)


They emphasized the need for more repetition, more follow-up and more proof to make sure that the information is indeed understood by patients.

Box 4.52

“My real wish is that we get an external telephone line in our clinic.” (Res.D)

“lx-xewqa tieghi hi li jkollna linja għal barra fil-klinik taghna”. (Res.D)

“I think the community nurse can help a lot” (Res. H)

“Naħseb li l-‘community nurse’ tghin ġafna” (Res.H)

Some also seemed frustrated as regards their inability to make their patients understand (Box 4.54).
**Chapter 4 Findings and Discussion**

**Box 4.54**

**"Patients are given half an hour for their session. Sometimes certain patients never understand, even if you explain and explain". (Res. E)**

**"Il-pazjenti għandhom nofs-siegħa kull 'session'. Kultant ċertu pazjenti qatt ma jifħmu, lanqas jekk tispjegalhom u tispjegalhom". (Res. E)**

**4.14 Conclusion**

This chapter sought to present and discuss the data gathered through the interviews carried out amongst eight nurses working within the primary care arena in Malta.

Although health illiteracy was never mentioned in the first 8 questions, it was very clear from the data gathered, that the nurses (n=8) do encounter health illiterate patients in their place of practice. In their responses, nurses focused mostly on the fact that health information is not always understood by the patients, and they demonstrated their understanding of health literacy (after a definition of this was given), only within the context of general illiteracy and old age. The data suggests that throughout their career, nurses have adopted their own ways as how to get through to these patients. No other concerns towards other factors that can cause health illiteracy were mentioned by the nurses. It is also clear from the data that the nurses lack an understanding of the essential relationship that exists between a patient’s health literacy and the patient’s participation in their own healthcare. In fact there were limited examples that indicated that nurses were encouraging their patients to engage in participatory decision-making as a result of receiving information. Therefore empowerment of patients as given in the latest definitions of
Chapter 4 Findings and Discussion

Health Literacy did not emerge from the data of this research study. This was not very surprising to the researcher, as it seems that health literacy within the nursing population has never been explored before on the Maltese Islands. However, several interesting suggestions as regards enhancing their current practice with low health literate patients were mentioned.

Against the backdrop of the located literature, one may cautiously conclude that often experiences and perceptions of nurses in Malta, indeed echo those of nurses in other contexts. However, in the light of the small scale of this study and the particular factors of the context of health literacy in Malta, such associations need to be done with caution.

It is hoped that the findings of the study have shed light on a number of recommendations that may help nurses understand and enhance their practice with health illiterate clients, which in the long run will benefit all.
5. CONCLUSION AND RECOMMENDATIONS
5 CONCLUSION AND RECOMMENDATIONS

5.1 CONCLUSION

The Healthy People 2010 goal of increasing health literacy (US Department of Health and Human Services, 2000) identifies health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." Moreover, health literacy is also a critical means to reduce health inequities (US Department of Health and Human Services, 2000). Central to this is the recognition that not everyone has the same level of health or capacity to deal with their health problems, and it may therefore be important to deal with people differently in order to work towards equal outcomes.

Today, patients need to quickly understand healthcare information because of the limited period of time of their encounters with healthcare providers, and the increase in outpatient services. Also, patients now must be able to effectively evaluate healthcare information from various sources and become advocates for their own health. Patients’ health literacy skills directly effects their healthcare status and quality of life.

One of the most important roles of nurses is that of patient advocating, reflecting their ability to protect the interests of patients who cannot represent themselves because of illness or inadequate health knowledge (Center for Nursing Advocacy, 2004). However, Boswell, Cannon, Aung and Eldridge, (2004) stated that an individual’s health illiteracy is an important challenge that is not fully understood nor currently considered by practising nurses. As quite often, after
Chapter 5 Conclusion and Recommendations

the physician’s encounter, nurses are the first healthcare professional a patient meets and most of the patients’ time is spent with them, it is fundamental that nurses are able to accurately assess a patient’s health literacy status, thus providing safe and competent care (Murphy & Davis, 1997; Foltz & Sullivan, 2005; Hartsell, 2005).

As the concept of health illiteracy has not yet been introduced in Malta, the aim of this research study was to explore nurses’ perceptions regarding health illiterate clients at Health Centres in Malta. Additionally, this study also aimed to explore nurses’ experience with health illiterate clients, how nurses currently provide care to these clients and the nurses’ views and opinions as regards the need to change their current practice towards these clients.

The study revealed that in fact, most patients do consider the nurse as their advocate in the healthcare system as all the nurses said that several times the patients go back to them to clarify difficulties. It appeared difficult however for the nurses to ‘make out’ who health illiterate patients are, how to evaluate their learning needs and what exactly are their appropriate teaching strategies. Since they find it hard to identify these patients, especially poorly literate patients, it seemed difficult for some nurses to reflect on the specific information and education needs of these patients. Since many also appeared worried about patient understanding and are unsure about how to validate their teaching, it seems that this may be an important issue on the nurses’ part as this might indicate that the nurses need some kind of patient education process. It is interesting to note that all the nurses mentioned that it is the patients who do not understand and none of these nurses (n=8) expressed the need for improving their own understanding of the reality of health illiterate patients and how to communicate and teach.
them. In a more efficient manner, such a finding indicates that communication training towards health illiterate clients is needed among nurses and other healthcare professionals.

5.2 LIMITATIONS OF THE STUDY

According to the researcher's opinion, the significantly limited time and resources available to pursue with the research study was the utmost limitation of the study, moreover this was the researcher's first attempt at carrying out a research study.

Time constraints made it also impossible to check for 'respondents' validation'. Ideally, a study would be performed on a longer-term basis where the researcher could go back to participants to verify the findings/results. Having now been introduced to the concept of 'health illiteracy', for the first time, the nurses would have been in a better position to express their opinions. Nevertheless, the questions generated considerable data, which helped the researcher meet the aims and objectives of the study.

The subject of health literacy has never been approached on the Maltese Islands, so the researcher had no local literature available. As a result, the research was carried out by aid of various websites using the internet. Another disadvantage faced by the researcher was that no statistical studies showing the illiteracy picture of the Maltese population as a whole especially within the elderly population has ever been carried out and this hindered the researcher from calculating the risks as to what the chances are that elderly, illiterate clients attend the clinic.

The coding frame was not piloted due to unfavourable circumstances of doing so.
5.3 **RECOMMENDATIONS**

The information gathered helped to shed light on approaches that if implemented, will aid in providing optimum care to health illiterate clients. The following recommendations regarding research, education and practice are suggested to improve such care.

### 5.3.1 **RECOMMENDATIONS FOR RESEARCH**

The results of this small-scale study show that more research is needed on nurses’ perceptions regarding provision of care to health illiterate clients. A replication study on a larger scale including all nurses working in all the clinics at the eight health centres around Malta would be more appropriate, and would give a general look at these nurses’ awareness of and experience with health illiterate clients. The researcher could not come to the conclusion that most clients do not understand their health information, yet from the nurses responses, stating that several patients go back to them to clarify healthcare uncertainties, it was assessed that there actually are health illiterate clients in Malta.

It would also be interesting to widen the focus onto other healthcare professionals such as general practitioners, pharmacists and reception staff, verifying whether they too meet hard-to-reach clients during their practice and whether they are aware of health illiteracy.

Had there been space for further research, a more accurate result to this study would have been that of studying the patients’ discharge outcome, bearing in mind that most clients are not necessarily followed-up, so that there has been no evidence as to how the client is managing his/her health at home.
5.3.2 RECOMMENDATIONS FOR EDUCATION

As regards the Maltese population, a literacy assessment study would provide a better picture of the illiteracy state in Malta.

The need for awareness regarding the concept of health illiteracy among all the healthcare professionals is clearly an asset.

There should be ongoing training opportunities to help professionals keep in touch with methods of providing information to health illiterate patients. These include especially, consultants, doctors, nurses, pharmacists and reception staff where information regarding, illness, preparation for diagnostic tests, the use of medical equipment such as inhalers, medication management and appointment schedules were found to be the most confusing issues for health illiterate clients. It is also significant that these professionals remember that patients have a right to participatory decision-making and empowerment.

The healthcare team should also be educated on their approach towards such clients, recognising the importance of creating a shame-free environment in which patients feel comfortable asking questions about what they do not understand.
5.3.3 RECOMMENDATIONS FOR PRACTICE

Introduction of some kind of health literacy tools adjusted for the Maltese population would help identify the literacy state of the client, so that when providing education both the nurse and other healthcare professionals would be able to identify and adjust their teaching according to the patients' educational needs.

Nurses also expressed the need for a direct telephone line in their clinics. The possibility of this direct line needs to be explored and consequently started if thought to be beneficial for the people involved. The medical consultant clinics' nurses will have constant access to check on their health illiterate clients, and the clients themselves will find it easier to call the nurse directly in case of difficulties. It is important to keep in mind that the patients may not always be feeling well to go to the clinic to look for the nurse.

A system for direct contact with community nurses should be introduced. The nurses at the Medical Consultant Clinics can inform the community nurses working around the clinics' catchment area to perform follow-up house visits to patients who seemed to have had some kind of difficulty in understanding concepts that were explained to them during their clinic visit such as medication regimes or hospital appointments.

Healthcare information materials such as diet sheets, medication regimes, diagnostic test preparations and appointment forms should be presented in short, clear, and plain language and should also include pictures whenever possible. Several appointment booklets regarding different clinics would also be beneficial if they were colour coded.
6.REFERENCES
6 References


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Jenkins, V., Fallowfield, L., Saul, J. (2001) Information needs of patients with cancer; results from a large study in UK cancer centres. *Br J Cancer* 84, 48–51


Chapter 6 References


Chapter 7 Appendix

7 APPENDICES
**TABLE 3. COMPARISON OF STUDIES ON EFFECTS OF HEALTH ILLITERACY.**

<table>
<thead>
<tr>
<th>Name</th>
<th>Aim</th>
<th>Method</th>
<th>Number of Participants</th>
<th>General Findings</th>
<th>Limitations</th>
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<tbody>
<tr>
<td>Study a) Davis, T., Halcombe, R.F., Berkel, H.S., Pramanik, S. &amp; Divers, S.G. (1998) Informed Consent for Clinical Trials: a Comparative Study of Standard Versus Simplified Forms</td>
<td>This study was conducted to test the researchers' hypothesis that a simplified consent form would be less intimidating and more easily understood by individuals with low marginal literacy skills.</td>
<td>During July 1996, 183 adult patients were tested for reading ability and then asked to read either the standard Southwestern Oncology Group (SWOG) consent form (16th grade level) or a simplified form (7th grade level) developed at Louisiana State University Medical Center—Shreveport (LSU). Participants were then interviewed to assess their attitudes toward and comprehension of the form read. Then they were given the alternate consent form and asked which one they preferred and they were asked to state the reasons why.</td>
<td>183 patients</td>
<td>Overall, participants preferred the LSU form over the SWOG form (P = .0033). Nearly all participants thought that the LSU form was easier to read the SWOG form (P&lt;.0001). However, the degree to which the participants understood the forms was essentially the same for the LSU form and the SWOG Form.</td>
<td>Participants were not assessed for comprehension of the material included in the consent forms but rather on their preference of either one of the forms. Also, the researchers didn't look into the validity of the contents of either of the consent forms; even though the participants preferred the shorter, simplified consent form, the researchers did not assess whether this form covered all the content of the other longer version.</td>
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<td>Study b) Davies, T.C., Fredrickson, D.D., Potter, L., Brosliette, R., Bocchini, A., Williams, M.V., &amp; Parker, R. (2006) Patient Understanding and Use of Oral Contraceptive Pills in a Southern Public Health Family Planning Clinic.</td>
<td>The purpose of this study was to assess the understanding of: 1) contraception, 2) OCP use and what to do about missed pills; 3) OCP side effects and risks and 4) self-reported OCP adherence among OCP users in a public health family planning setting. The secondary purpose was to evaluate the hypothesis that the literacy level of these patients was associated with OCP understanding and use.</td>
<td>400 OCP users from a southern public health family planning clinic were orally tested for literacy, demographics, contraceptive knowledge, OCP use, side effects, and adherence.</td>
<td>400 OCP users. Patients were predominately African American (86%); 78% had completed high school and 42% read below a 9th grade level.</td>
<td>376 participants (94%) understood what to do when they missed one pill, yet few knew the correct action to take after missing two or three pills (19% and 3% respectively); 33% reported missing one or more pills in the past 2 weeks. Literacy was not associated with OCP use, knowledge, or adherence. Patients of all literacy levels had limited understanding of OCP side effects and what to do about multiple missed pills. This puts them at risk for misuse.</td>
<td>Data for this study was collected by self reporting method of the study participants. There was no way to guarantee that the participants were giving all the information to the researchers at the time of the study.</td>
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*Appendix 1*
### Table 3. Comparison of studies on effects of health illiteracy (cont.)

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<tr>
<th>Study</th>
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<th>Method</th>
<th>Number of Participants</th>
<th>General Findings</th>
<th>Limitations</th>
</tr>
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<tbody>
<tr>
<td>c) Gazmararian, J.A., Baker, D.W., Williams, M.V., Parker, R.M., Scott, T.L., Green, D.C., Fehrenbach, S.N., Ren, J. &amp; Koplan, J.P. (1999) Health Literacy Among Medicare Enrollees in a Managed Care Organization</td>
<td>To determine the prevalence of low functional health literacy among community-dwelling Medicare enrollees in a national managed care organization.</td>
<td>Cross sectional survey consisting of questions to determine demographics, self-rated health, physical functioning, chronic conditions, health care use, mental health, cognitive impairment, social support, and health behaviors. A short version of TOFHLA was then distributed at the end of the interview to assess functional health literacy.</td>
<td>3260 patients aged 65 or over enrolled in a Medicare (insurance) programme</td>
<td>23.5% of English-speaking and 34.2% of Spanish-speaking respondents had inadequate health literacy and another 10.4% and 19.7%, respectively, had marginal health literacy. Characteristics associated with higher rates of inadequate health literacy included black race, older age, fewer years of school completed, and having a work history. The relationship between age and health literacy showed a strong trend, with the prevalence of inadequate health literacy steadily increasing from 15.6% of individuals aged 65 to 69 years to 58.0% of those aged 85 years or older.</td>
<td>Most patients who dropped out of the study were of 85 years or over and no data was collected to compare with the study results. This could have altered the generalizability of the findings.</td>
</tr>
<tr>
<td>d) Baker, D.W., Gazmararian, J.A., Williams, M.V., Scott, T., Parker, R.M., Green, D., Ren, J. &amp; Peel, J. (2002) Functional Health Literacy and Risk of Hospital Admission Among Managed Care Employees</td>
<td>The aim of the study was to check if functional health literacy was an independent risk for increased hospitalizations.</td>
<td>3620 Medicare managed care enrollees were the cohort used for this study. The participants undertook a TOFHLA test and through this were categorized into different groups. Frequency of hospital admissions of these groups was recorded and later compared for analysis purposes.</td>
<td>3620 patients were recruited for this study. Patients with adequate health literacy were less likely to be hospitalized than patients with marginal or inadequate health literacy (hospitalisation rates being 26.7%, 33.9% and 34.9% respectively). Those with inadequate or marginal health literacy were also subject to more frequent admissions than their other study counterpart.</td>
<td>Only half of the eligible patients participated to this study. The authors also noted that the ones that did not participate were of higher socioeconomic status, thus their results could have been biased. However, on comparison, the rates of admission for those who participated to the study and those who didn’t was deemed comparable. Also, the study didn’t look at reasons for hospital admission, therefore this study couldn’t look at admissions from complications of chronic conditions against admissions for elective procedures.</td>
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<tr>
<td>Study c) Baker, D.W., Wolf, M.S., Feinglass, J., Thompson, J.A., Sazmarian, G.A., Huang, J. (2007) Health Literacy and Mortality Among Elderly Persons</td>
<td>The aim of this study was to determine whether low health literacy levels independently predict overall and cause-specific mortality.</td>
<td>The survey assessed race/ethnicity, education, annual income, health behaviors, body mass index, chronic medical conditions, depression, self-rated physical and mental health (measured by the 12-item Short-Form Health Survey), impairments in instrumental activities of daily living, and use of health care services and prescription medications. Health literacy was evaluated by measuring each enrollee's reading fluency using a shortened version of the Test of Functional Health Literacy in Adults (S-TOFHLA).</td>
<td>3344 patients completed a 1 hour interview survey.</td>
<td>For participants with adequate health literacy (n = 2094; 64.2%), the crude mortality rate was 18.9% compared with 28.7% in those with marginal health literacy (n = 366; 11.2%) and 39.4% in those with inadequate health literacy (n = 800; 24.5%; P &lt; .001).</td>
<td>The short version of TOFHLA was used and this was not deemed as the best measure available for assessing the level of health literacy of the study participants. Out of all the eligible patients only half participated in the study. The authors report that the half that did not participate to the study were of higher socioeconomic background.</td>
<td></td>
</tr>
<tr>
<td>Study f) Williams, M., Baker, D., Parker, R. &amp; Nurss, D. (1998) Relationship of Functional Health Literacy to Patients' Knowledge of Their Chronic Disease: A Study of Patients With Hypertension and Diabetes</td>
<td>To examine among patients with hypertension or diabetes the relationship between their functional health literacy level and their knowledge of their chronic disease and treatment.</td>
<td>A cross-sectional survey of patients with hypertension and diabetes presenting to the general medicine clinics at 2 urban public hospitals. Literacy was measured by the Test of Functional Health Literacy in Adults. Knowledge of their illness was assessed in patients with diabetes or hypertension using 21 hypertension and 10 diabetes questions based on key elements in educational materials</td>
<td>A total of 402 patients with hypertension and 114 patients with diabetes were enrolled.</td>
<td>Fewer than half of low literacy patients with diabetes knew the symptoms of hypoglycemia and had no idea of what hypertension was.</td>
<td>Sample size may have prevented a statistical difference between the patient's literacy level and blood pressure and blood glucose levels.</td>
<td></td>
</tr>
</tbody>
</table>
Table 3. Comparison of studies on effects of health illiteracy (cont.)

<table>
<thead>
<tr>
<th>Name</th>
<th>Aim</th>
<th>Method</th>
<th>Number of Participants</th>
<th>General Findings</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study g) Williams, M.V., Baker, D.W., Honnig, E.G., Lee, T.M., Nowlan, A. (1998)</td>
<td>To determine the relationship of literacy to asthma knowledge and the ability to use a metered dose inhaler.</td>
<td>Cross sectional survey using REALM, asthma knowledge question oral test and demonstration of metered dose inhaler (MDI) technique (6 item assessment).</td>
<td>Convenient sample of 273 patients presenting to the emergency department for an asthma exacerbation and 210 patients presenting to a specialist asthma clinic for routine care.</td>
<td>Inadequate literacy was common and strongly correlated with poorer knowledge of asthma and improper MDI use</td>
<td>Participant of this study were predominantly African Americans and mostly young adults rather than elderly people. Also the number of participants in each schooling criteria was not comparable and a statistical difference could have been obtained.</td>
</tr>
<tr>
<td>Study h) Schillinger, D., Grumbach, K., Piette, J., Wang, F., Osmond, D., Daher, C., Palacios, J.D., Daher, C., Palacios, J., (2002)</td>
<td>To examine the association between health literacy and diabetes outcomes among patients with type 2 diabetes</td>
<td>Cross sectional observational study. Patients enrolled compiled a questionnaire and answers were analyzed through the TOFHLA test.</td>
<td>408 English and Spanish speaking patient; all having type 2 diabetes</td>
<td>Patients with inadequate health literacy were less likely than patients with adequate health literacy to achieve proper glycaemic control.</td>
<td>This study focuses only on what the patient relates of his condition at the time of questionnaire, and does not assess initial knowledge of the patient, knowledge of signs and symptoms or relation of data to other chronic conditions.</td>
</tr>
<tr>
<td>Study i) Parikh, N.S., Parker, R.M., Nurss, J.R., Baker, D.W., Williams, M.V. (1996) Shame and health literacy: the unspoken connection</td>
<td>The purpose of this study was to determine the relationship between shame and low functional literacy in the health care setting.</td>
<td>Cross sectional survey using TOFHLA and questions regarding difficulty and shame</td>
<td>Purposeful sample of 202 patients attending the Emergency Department and walk in clinics at a public hospital in Atlanta, Georgia.</td>
<td>TOFHLA scores revealed 42.6% of patients had inadequate or marginal functional health literacy, but only 67.4% of these admitted they had trouble reading or understanding what they read. 39.7% of patients with low functional literacy admitted shame.</td>
<td>This study focuses only on what the patient relates of his condition at the time of questionnaire, and does not assess initial knowledge of the patient, knowledge of signs and symptoms or relation of data to other chronic conditions.</td>
</tr>
</tbody>
</table>

Appendix 1

**Participant of this study were predominantly African Americans and mostly young adults rather than elderly people. Also the number of participants in each schooling criteria was not comparable and a statistical difference could have been obtained.**
Ms Ruth Abela – BSc Student  
C/O Paola Health Centre

Re: Your request to carry out a research within the PHD entitled 'Literacy and health outcomes in Primary Health Care settings. Nurses' Views regarding caring for health illiterate clients'

Dear Ms Abela,

I am pleased to inform you that your request to carry out the research within the department has been fully approved. May I inform you that as we have to abide to the Data Protection Law, we cannot provide you with a list of data subjects' contact details unless the data subjects and the researcher are both public officers. The data subjects also have to sign a consent form that also includes a data protection statement prior to participating (see E below). Any modifications of this approach would have to be first discussed with the data protection officer. Where statistics are involved, only data in terms of age, sex etc can be forwarded to you but not names of individuals.

May I bring to your attention that the researcher is obliged to apply necessary safeguards as a condition for carrying out this research, namely -

A. The personal data (of data subjects) accessed or given are only to be used for that specific purpose to conduct the research and for no other purpose;
B. At the end of the research, all personal data should be destroyed;
C. All references to personal data should be omitted in the report unless consent is specifically obtained from the person being identified in the research report;
D. Participation in the research being conducted should be at the discretion of the individual, and they can refuse any participation whatsoever if they so wish;
E. If data subjects (patients/staff) are going to be interviewed, video recorded or given a non-anonymous questionnaire to fill, a consent form should be signed by the participating data subject and a privacy policy statement read to them; Faces should be hidden or digitally modified as to conceal identity;
F. Any other measure deemed fit by the respective Head, depending on the research to be carried out.

The director also appreciates very much if he is provided with a copy of the research findings when it is concluded.

Yours truly,

[Signature]

Dr Mario Vella, DPO  
f/ Dr D Vella Baldacchino, Data Controller, Primary Health Department
To be completed by Faculty Research Ethics Committee

We have examined the above proposal and advise

Acceptance / Refusal / Conditional acceptance

For the following reason/s:

Signature Date 05/10/08

To be completed by University Research Ethics Committee

We have examined the above proposal and grant

Acceptance / Refusal / Conditional acceptance

For the following reason/s:

Signature Date 21/4/08
Health Literacy: The Perceptions and Experiences of Primary Healthcare Nurses

Dear Colleague,

I would like to invite you to participate in a research study conducted by myself as part of BSc. (Hons.) in Community Health Nursing programme which I currently pursue. The research study is being done with the consent of the University of Malta, Institute of Health Care, Ethics Committee and the Primary Health Care Department.

The purpose of the research study is to explore how Primary Health Care nurses currently address the needs of health illiterate clients, and how the care delivered towards them may be enhanced.

Participation in this research study involves taking part in an interview which should not last more than 30 minutes. I will be asking you the questions myself, at any time and place you chose.

The interviews will be tape recorded. Please be assured that all the data will be kept in strict confidentiality during the process of the research study and will be destroyed on completion of the study. All transcribed data will be coded. Your name will not appear anywhere. Participation in the research study will not influence your work or job position in any way.

Signed consent from yourself is requested before the interview. Hence if you agree to participate kindly fill in the form attached overleaf.

I will be happy to answer any questions you may have about this research study. You may contact me by email at dragon_rutabe@hotmail.co.uk or at Paola Health Centre. Please note that you can withdraw your consent to participate at any time.

Thank you in advance for the time you will dedicate and for your cooperation in this research study. I sincerely appreciate your participation. It is hoped that your contribution will help in developing practices that address the needs of health illiterate clients in the Primary Health Care sector more efficiently and effectively.

With kind regards,

Ruth Abela

Staff Nurse

Paola Health Centre
Appendix 4

Pre-interview Consent Form:

Ruth Abela
No. 1 flat 2
Giovanni Balaguer Street,
Balzan
Bzn1044
Tel: 21 472089
Mob: 79496323
Email: dragon_rutabe@hotmail.co.uk

Study Title: Health Literacy: The Perceptions and Experiences of Primary Healthcare Nurses

To Ms ..........

I confirm that I understand the information given to me regarding the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason and without penalty, and that I may withdraw my data once it has been provided if I wish to do so.

I understand that the data I provide will be stored securely throughout the project and destroyed afterwards, and that confidentiality will be maintained at all times.

4) I agree to take part in the above study.

Name of Participant                Date               Signature

Name of researcher                Date               Signature
Appendix 4

Formula ta’ Kunsens

Ruth Abela,
No. 1 flat 2
Giovanni Balaguer Street,
Balzan
Bzn1044
Tel: 21 472089
Mob: 79496323
Email: dragon_rutabe@hotmail.co.uk

Titlu ta’ I-istudju: Health Literacy: The Perceptions and Experiences of Primary Healthcare Nurses

Lis-sinjura ............

Jien nikkonferma li qed nifhem l-informazzjoni provduta lili dwar dan l-istudju u ghandi l-opportunita’ li nirrispondi xi domandi.

Jien nifhem li il-partecipazzjoni tieghi hi voluntarja u li jiena liberu/a li nieqaf fi kwalunkwe hin, minghajr ma naghti r-ragunijiet tieghi u li nista’ niehu lura l-informazzjoni li tajt meta u x’hin nixtieq.

Jien nifhem li l-informazzjoni li tajt ha tkun mistura/protetta matul il kors tal-progett, li tigi imhassra mat-tmiem tal-progett u li jibqa’ kollox kunfidenzjali.

4) Jien naqbelli niehu sehem fdan il-progett.

Isem tal-Partecipant Data Firma

Isem tar-Ricerkatrici Data Firma

130
Statement of Interest

I have read the information letter and have been given the opportunity to ask questions. I give my consent to participate in this study.

Participant's Name:

________________________________________

Participant's Signature:

________________________________________

Job Title:

________________________________________

Date:

________________________________________
Health Literacy: The Perceptions and Experiences of Primary Healthcare Nurses

The aim of the study was to explore nurses' perceptions and experiences regarding health illiterate clients.

The objectives of the study were:

1. To explore nurses' awareness regarding encounters with health illiterate clients.
2. To determine the nature of their experiences with such patients.
3. To explore how nurses currently seek to address the needs of health illiterate clients.
4. To explore nurses views and opinions as regards the need to change their current practice.
Nurses’ Perceptions and Experiences of Health Illiterate Clients

Please answer all questions

1a. How long have you been practicing as a nurse (in years)?

- 0-5
- 6-10
- 11-15
- 16-20
- 21 and over

1b. What qualifications do you hold?

- Certificate
- Diploma
- Degree
- Masters
- PHD
- Other

1c. Where do you currently practise?

2. On the scale below please note your agreement/disagreement with the following statements. At this point the interviewee is shown a copy of the scale below.

a) I find it easy to communicate with patients at work

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Don’t know</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

b) I think patients understand the information I give them

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Don’t know</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 5a

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If interviewee disagrees with the statements in questions 2b, proceed to question 3 and 4 below.

If interviewee agrees or answers "Don't Know" with the statement in question 2b kindly proceed to question 5.

3. Kindly explain why you think you DO NOT communicate well with clients.

4. Kindly identify at least 3 factors which you think are strong barriers to good communication between yourself and your patients.

- Illiterate clients
- Visual impairment
- Old age
- Hearing impairment
- Social class
- Cognitive impairment
5. Have you ever encountered clients who do not adhere to their Rx regimes and advice received?

Yes □

No □

If Yes, what would you say was the reason for this?

6. How often do you encounter such problems with clients?

At this point the interviewee is shown a copy of the scale below

<table>
<thead>
<tr>
<th>Always</th>
<th>Often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
</table>

□
7. Kindly describe methods/approaches you currently use to ensure that clients are receiving **AND**
understanding the information you provide.

---

---

---

8. What do you think may be done/changed to facilitate your current practice?

---

---

---

At this point the interviewer reads out a definition providing the meaning of the term “Health Illiterate
Clients”. A typed copy of the definition is also given to the interviewee.

Health Literacy is defined as “the degree to which individuals have the capacity to obtain, process, and
understand basic health information and services needed to make appropriate health decisions. These skills
include reading, listening, problem-solving and decision making. Health illiteracy can be caused by lack of
education, visual, hearing or cognitive impairment, language or cultural differences, or a combination of these
barriers.
9. Given the definition I just read to you, how often would you say that you encounter Health Illiterate Clients. The interviewee is here referred to the scale used in question 6.

<table>
<thead>
<tr>
<th>Always</th>
<th>Often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
</table>

10. How do you address the needs of the clients I described to you?


11a. Do you have any suggestions or recommendations which, if implemented, you think may enhance the care provided to the health illiterate clients?


Appendix 5a

11b. Kindly explain why you are suggesting/recommending this:


Finally, is there anything you may want to add


THANK YOU very much for participating in this interview!
1a Kemm ilek tipprattika bħala nurse (fis-snin)?

| 0-5 | 6-10 | 11-15 | 16-20 | 21 u izjed |

1b X’tip ta kwalifikasi ghandek?

Certificate       Diploma       Degree       Masters       PHD       Ohrajn

1c Fliema klinika tipprattika bħalissa?

2. Fuq l-iskala ta hawn taht, jekk jghobok immarka dak li taqbel miegħu jew le.

2a Jien insibha faċli biex nikkomunikaw mal klient fuq ix-xoghol tiegħi

Ma naqbilx totalment     ma naqbilx     Ma nafx     Naqbel     Naqbel ħafna

2b Jien naħseb li l-klienti jifhmu l-informazzjoni li intihom

Ma naqbilx totalmant     ma naqbilx     Ma nafx     Naqbel     Naqbel ħafna

3 Jekk jghobok spjegali x’tahseb li ġegħlekk issibha diffiċli biex tikkomunikaw mal- klient
4 Semmi tlett fatturi li taħseb li jżommuk lura milli tikkunika sew mal- klient:

Klienti illiterati
Persuni neqsin mid-dawl

Nuqqas ta tagħlim dwar il-kundizzjoni tagħhom
Persuni neqsin mis-smigħ

L-eta
Persuni neqsin mid-dawl

Il-klassi soċjali tagħhom

‘Cognitive Impairment’

Kulturi differenti

Il-lingwa

Fatturi oħra

5a Qatt iltqajt ma klienti li ma jieħdux il kura li jkun ordnalhom it-tabib, jew ma semghux min xi parir li jkun tagħhom?

Iva Le

5b Jekk iva, għalfejn taħseb li ġara hekk?

6 Kemm il darba iltqajt ma klienti f’din is sitwazzjoni? Immarka fuq l-iskala t’isfel

Dejjem hafna drabi Kultant Rari Qatt

7 Iddiskrivi metodi li inti bħala ‘nurse’, tuża biex taċċerta ruħek li l-klient jifhem dak li tkun qiegħed tghidlu
8 X’tahseb li jista jsir jew jiġi mibdul sabiex lilek jiffaċilizzalek din il problema?

Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. These skills include reading, listening, problem-solving and decision making. Health illiteracy can be caused by lack of education, visual, hearing or cognitive impairment, language or cultural differences, or a combination of these barriers. (United States Department of Health and Human Services, 2000; Healthy People 2010)

9. Wara li qrajna din id-definizzjoni, kemm il darba taḥseb li fuq ix-xogħol tiegħek tiltaqa ma dawn it-tip ta klienti?
Dejjem hafna drabi Kultant Rari Qatt

10. Kif tindirizza il-bżonnijiet tal-klienti li għadni kif semmejtlek?

11a. Għandek xi suġġerimenti li taħseb jistgħu jiġu implimentati sabiex jghinu lil dawn it-tip ta pazzjenti?

11b. Jekk jghoġbok spjegali għaliex qed tissuġġerixxi li tagħmel hekk

12. Fli- aħħarnett, għandek xi kummenti li tixtieq iżżid?
The coding frame.

3. Kindly explain why you think you do not communicate well with clients

<table>
<thead>
<tr>
<th>Illiterate</th>
<th>Biased</th>
<th>Excitement</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient may be illiterate</td>
<td>There are some who are biased against certain tablets.</td>
<td>Sometimes the patient is excited in front of the doctor and does not know what is being told to him / hers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Denial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sometimes especially males find it difficult to accept having all that treatment, especially if the patient is young and when you tell him that he is suffering of this and that.....like a form of denial</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Old age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Another thing is the elderly. Their cognitive impairment. In this clinic we get more elderly patients.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cognitive impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient does not know where he is</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ignorance of their condition</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>They are ignorant of their condition</td>
<td>Sometimes we also get depressed patients and it's hard for them to understand</td>
</tr>
</tbody>
</table>
5 a. Have you ever encountered clients who do not adhere to their treatment regimes and advice received?  

b. If yes what would you say is the reason for this?

<table>
<thead>
<tr>
<th>Bias</th>
<th>Illiteracy</th>
<th>Forgetfulness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sometimes they say “I was afraid to take the new tablets.”</td>
<td>Maybe it’s because they are illiterate and cannot read.</td>
<td>They want to ask a lot of questions but they forget.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Excitement</th>
<th>Cognitive Impairment</th>
<th>Lack of Finances</th>
</tr>
</thead>
<tbody>
<tr>
<td>They are usually very excited in front of the doctor.</td>
<td>They are not focused when you are talking to them.</td>
<td>Maybe it’s because they do not have money to buy tablets.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ignorance of their condition</th>
<th>Reluctance to change lifestyle</th>
<th>Old Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>They are ignorant of their condition.</td>
<td>Some do not take their medication simply because they just don’t like taking tablets. Others refuse to take tablets because they won’t be able to have alcohol.</td>
<td>Old age – they forget, or are illiterate.</td>
</tr>
</tbody>
</table>
7. Kindly describe methods/approaches you currently use to ensure that clients are receiving and understanding the information you provide

<table>
<thead>
<tr>
<th>Explanation</th>
<th>Hand Gestures</th>
<th>Teach back technique</th>
</tr>
</thead>
<tbody>
<tr>
<td>I explain to them how to take their medication, for example, I show them 1-1-1 and I tell them what it means.. one in the morning, one at midday, one in the evening</td>
<td>If they are illiterate I make gestures with my hand to try to explain to them even more clearly</td>
<td>I ask the patient to repeat what he understood</td>
</tr>
<tr>
<td>Repetition</td>
<td>Assurance</td>
<td>I take the initiative</td>
</tr>
<tr>
<td>I know that the patients haven't understood what was said to them, because they remain staring at me, so I repeat.</td>
<td>I assure them</td>
<td>Sometimes, I myself go down and get the tablets for them because it is less complicated</td>
</tr>
<tr>
<td>Encourage to call me</td>
<td>Give a close follow-up appointment</td>
<td>Change wording</td>
</tr>
<tr>
<td>I also give them the telephone number and give them the days when we are available here to talk to them</td>
<td>I keep on following the patient, infact we give him a close follow-up appointment to check the patient’s compliancy to treatment</td>
<td>I change the wording and try to use simple terms</td>
</tr>
<tr>
<td>Accompanied by relative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I tell them to get some relative with them</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8. What do you think may be done/changed to facilitate your current practice?

<table>
<thead>
<tr>
<th>Accompanied by relatives</th>
<th>Preparation of tablets</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients should be encouraged to bring some relative with them</td>
<td>Tablets should be prepared specifically for the individual patient in bottles and not in ready packed paper bags. The bottles should be written purposely according to the dose the patient is to have</td>
<td>I really don’t know what to say especially with the elderly (interviewee is laughing)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Encouragement</th>
<th>Contact by phone</th>
<th>Follow-up appointments</th>
</tr>
</thead>
<tbody>
<tr>
<td>I also encourage them to diet and exercise and to try to change their lifestyle</td>
<td>Sometimes when I receive their blood results, I find that either they are newly diagnosed diabetics, or that their cholesterol levels are high, so I contact them by phone and tell them to take care of their diet</td>
<td>Follow-up appointments help a lot</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>External telephone line</th>
<th>Less appointment forms</th>
<th>Words on appointment forms ought to be simplified</th>
</tr>
</thead>
<tbody>
<tr>
<td>I need an external telephone line in my clinic, so I will be able to contact patients and talk privately and they too would find it easier to contact me on a direct telephone line.</td>
<td>They don’t understand all the different appointment forms we give them</td>
<td>Forms written in simple words with pictures which indicate to the patients what they are supposed to do</td>
</tr>
</tbody>
</table>
10. How do you address the needs of the clients I described to you?

<table>
<thead>
<tr>
<th>Give knowledge about their condition</th>
<th>Give ‘one thing at a time’</th>
<th>Ask them to be accompanied</th>
</tr>
</thead>
<tbody>
<tr>
<td>I explain and give knowledge about their condition</td>
<td>When faced with a lot of things such as appointment forms and investigation forms, they get more confused so we give them ‘one thing at a time’</td>
<td>When we see that they cannot assimilate things, we ask them whether it is possible that they get someone to accompany them on their next appointment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Advise to apply for a hearing aid</th>
<th>Assurance</th>
<th>Encourage them to call me</th>
</tr>
</thead>
<tbody>
<tr>
<td>As regards the hearing impaired, most of the time I get hoarse trying to explain, and sometimes when I tell them to apply for a hearing aid, they say that they already have one but they do not wear it because it bothers them</td>
<td>I assure them</td>
<td>I also give them the telephone number and give them the days when we are available here to talk to them</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Follow-up system</th>
<th>Repetition</th>
<th>Use simple words</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follow-up system is very good. The patients are all the time coming to look for me to talk about their difficulties</td>
<td>I repeat. Several times the patients come again to ask me what the doctor said. I think they feel more comfortable with us</td>
<td>I try to explain slowly in simple words what they need to know</td>
</tr>
</tbody>
</table>
11. **Do you have any suggestions or recommendations which, if implemented, you think may enhance the care provided to the health illiterate clients?**

<table>
<thead>
<tr>
<th>Educate the patients about their condition</th>
<th>Call patients at home</th>
<th>Booklets with pictures</th>
</tr>
</thead>
<tbody>
<tr>
<td>The nurse should be responsible to educate the patients about their condition and teach them how to lead a healthy life</td>
<td>If we had the opportunity to call them at home in between follow-ups and check whether they have any difficulties...</td>
<td>We should provide booklets with pictures</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Explanation from the pharmacist</th>
<th>Accompanied by someone</th>
<th>Less forms</th>
</tr>
</thead>
<tbody>
<tr>
<td>As regards tablets, I don’t see how we can help the patients. It has to be the pharmacists’ duty to explain to them about the tablets</td>
<td>Patients need to be accompanied by someone</td>
<td>We should give less appointment forms to patients</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Individualised pill bottles</th>
<th>Don’t know</th>
<th>Home help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pills should be prepared in individualised pill bottles</td>
<td>I don’t know</td>
<td>It will be a good idea if there is some kind of home help service, where the patients who find it hard to understand their treatment regimes are visited regularly by the home help nurse who can assist them in their difficulties</td>
</tr>
</tbody>
</table>
Appendix 6

Examples of Data Coded to Question no. 3

<table>
<thead>
<tr>
<th>Illiterate</th>
<th>Biased</th>
<th>Excitement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Res. A</td>
<td>Res. A</td>
<td>Res.B</td>
</tr>
<tr>
<td>Res. B</td>
<td></td>
<td>Res.C</td>
</tr>
<tr>
<td>Res. D</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Res. E</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Res. F</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Res. G</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Res. H</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Denial</th>
<th>Old age</th>
<th>Cognitive impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Res. B</td>
<td>Res. C</td>
<td>Res. C</td>
</tr>
<tr>
<td></td>
<td>Res. D</td>
<td>Res. D</td>
</tr>
<tr>
<td></td>
<td>Res. E</td>
<td>Res. F</td>
</tr>
<tr>
<td></td>
<td>Res. G</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ignorance of their condition</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Res. E</td>
<td>Res. D</td>
</tr>
<tr>
<td>Res. F</td>
<td></td>
</tr>
</tbody>
</table>