EDUCATIONAL NEEDS OF NEWLY DIAGNOSED CANCER PATIENTS IN LEARNING ABOUT CANCER : A QUALITATIVE STUDY IN THE MALAYSIAN URBAN SETTING

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EDUCATIONAL NEEDS OF NEWLY DIAGNOSED CANCER PATIENTS IN LEARNING ABOUT CANCER: A QUALITATIVE STUDY IN THE MALAYSIAN URBAN SETTING

ABSTRACT

Patients with chronic diseases such as cancer are able to have better outcomes if they understand about all aspects of the disease, develop the correct attitude to manage themselves and their disease better; and engage in preventive practices that can help them prevent worsening of disease or recurrence. Patient education is an intervention that has proven to be effective in different settings for this. However in the Malaysian cancer setting, the educational needs of patients are poorly understood. The aim of this study was to explore and understand the educational needs of newly diagnosed cancer patients in learning about cancer in the Malaysian urban setting. Qualitative, in-depth interviews were carried out via Zoom with 23 cancer patients who were newly diagnosed over the past 6 months and had sought services at the National Cancer Society of Malaysia. The patients reported having specific educational needs at the point of diagnosis, during their treatment journey; and in terms of emotional and psychosocial management. Delivery of patient education included challenges from both the patients themselves as well as system-level delivery. Patients reported that their cancer-related educational needs were partially fulfilled but had suggestions on how to better provide effective patient education. Newly diagnosed cancer patients have educational needs that are being partially fulfilled. Further research and improvement can aid in designing and delivering better educational solutions which can benefit patients.

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ABSTRAK

Pesakit yang menghidap penyakit kronik seperti kanser dapat sembuh dengan lebih baik jika memahami segala aspek penyakit, mempunyai sikap yang betul untuk menguruskan penyakit secara kendiri dan terlibat dalam amalan preventif yang dapat mengurangkan kebarangkalian penyakit bertambah teruk. Pendidikan pesakit adalah sebuah penyelesaian yang efektif, Namun, di Malaysia keperluan pendidikan pesakit kurang difahami. Kajian ini bertujuan memahami keperluan pendidikan pesakit kanser yang baru didiagnos di kawasan bandar di Malaysia. Temuduga mendalam kualitatif dijalankan melalui Zoom bersama 23 pesakit kanser yang baru didiagnos dalam jangka masa 6 bulan dan telah menggunakan perkhidmatan di Persatuan Kanser Kebangsaan Malaysia. Pesakit melaporkan mempunyai keperluan pendidikan khusus ketika didiagnos, semasa perjalanan perawatan dan dari segi pengurusan emosi dan psikososial. Penyampaian pendidikan pesakit menampakkan pelbagai cabaran dari segi kendiri pesakit dan juga di peringkat system. Pesakit melaporkan bahawa keperluan pendidikan mereka dari segi kanser tidak dapat dipenuhi sepenuhnya tetapi menawarkan cadangan untuk meningkatkan kadar efektif pendidikan pesakit. Pesakit kanser yang baru didiagnos ada keperluan pendidikan yang tidak dapat dipenuhi pada masa ini. Kajian dan penambahbaikan diperlukan dalam mereka dan menyampaikan intervensi pendidikan yang dapat membantu pesakit.

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HANDS THAT SERVE ARE HOLIER THAN LIPS THAT PRAY

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CHAPTER 1: INTRODUCTION

1.1 Study Background

Chronic non-communicable diseases are diseases in which patients often have to live or suffer with the diseases for an extended period of time; in many instances for the entirety of their lives (Lindner, H.et al, 2003). Coping with the disease is and its symptoms requires behavioural changes in the patient which can enable them to have better quality of lives and in many cases, better disease outcomes (Harvey, P. W. et al, 2008). However, behavioural change is not something which is easy for most of these patients to undertake, especially since it is influenced by multiple factors, one of which is the patient's own learning in terms of the disease and how to manage it.

In order to become capable of managing their own disease, patients need to first understand well about the disease, its signs and symptoms and possible complications. For this purpose they really need to be well-versed in terms of knowledge, characterised as being in the cognitive domain. In addition, patients need to also have the correct attitude to be able to manage their disease in terms of staying motivated, self-aware and also self-efficacious in terms of disease and lifestyle management. This requires learning which is tailored in the affective domain. Finally, patients also need to be well-oriented in terms of carrying out proper preventive practices as well as adhering to medication, or being able to give themselves injections. All these processes requires some amount of learning in the psychomotor domain (Krau, S. D., 2011).

Patients with cancer, as one of the chronic non-communicable diseases, need to especially be engaged in learning across the three domains as they need to have a good understanding of the disease, be able to have the correct attitude and also be engaged in providing correct practices across the different stages of their treatment journey (Ritsema, T. S. et al, 2014). Their ability to complete treatment and go into remission which involves long-term management of the disease requires patients to be well-equipped with the knowledge, attitude and the correct behaviour in the long-term. This also will help them in the long-term prevention of recurrence of their cancer or risk in terms of the onset of new-cancers.

1.2 Study Rationale

Education for patients, however has not been a field which has been comprehensively studied within the chronic disease sphere. This is especially more true in the cancer context. Patient educational programmes do exist, and are carried out in multiple settings. However, there are rarely structured or systematic and have a myriad of other challenges including in whether they are delivered effectively to patients.

This lack of understanding of whether education is being provided adequately to patients may be one of the causes behind the large rates of drop-out from treatment amongst cancer patients in particular, as well as the reluctance in many patients to even begin treatment. In such settings, there is a need to understand whether patients when they are newly diagnosed with cancer are facing any form of educational problems (Vallis, M.et al, 2019).

The first step to designing educational programmes to cater to and remove the educational problems is to understand if there are educational problems existing among patients. This in turn, may enable patients to learn better about their condition which will subsequently translate into better behavioural elements from patients subsequently improving their disease outcomes.

1.3 Problem Statement

There are some significant research and system gaps that necessitate the undertaking of this study as a foundation stone to preclude or even to initiate research and innovation to be carried out into this particular area of cancer control. A major challenge in cancer control, like in most other chronic diseases, is the precondition that in order to obtain good long-term control and good outcomes, patients need to be able take responsibility for management of their disease alongside healthcare professionals; i.e. carry out some form of self-management (Davy C., et al, 2015). This requires patients to be understand well their disease, carry out good habits which help them prevent recurrence and relapse; and stay motivated to carry out all these good practices continuously over the long run (Harvey, P.W. et al, 2008). Evidence has shown clearly that a strong factor influencing the success of patients being active in the management of their own disease is largely driven by how much patient education has been provided and received by patients (McGowan, P., 2011). Patient education has been espoused in is used in various settings in the management of cancer patients throughout the world. (Faury, S., 2017; Howell, D., 2017). In these settings patient education is used to help patients understand about symptoms, cope with their condition, undertake self-management and even help them manage mental health situations (Faury, S., 2017; Howell, D., 2017). In Southeast Asian and Malaysian settings, it has been identified as part of each country's priorities that one of the areas on the ground that need to be focused on is the impetus to provide effective patient education (Bhoo-Pathy, N et al, 2017). In Malaysia, some form of patient education is being provided in various levels when dealing with cancer patients, both in the public and private sector. However, it remains unknown whether patients are aware of their education needs when it comes to cancer; whether these educational needs are being met or provided in a structured manner; or preferences of patients' in terms of the techniques to provide such interventions.

1.4 Research Objectives

The objectives of this study were:

i) to explore the educational needs of newly diagnosed cancer patients in learning about cancer

ii) to describe the perceptions of newly diagnosed cancer patients on current fulfilment of their educational needs in learning about cancer.

1.5 Research Questions

What were the educational needs of newly diagnosed cancer patients in learning about cancer?

What were the perceptions of newly diagnosed cancer patients on current fulfilment of their educational needs in learning about cancer?

1.6 Significance of study

In the specific context of management of cancer patients in Malaysia, this study will be one of the first that explores and attempts to understand the learning needs of patients. The data and insights obtained from this study will then be extremely valuable in providing a baseline in helping healthcare professionals, researchers and policymakers design, develop and deliver structured and effective interventions in the area of patient education. The short-term gain of such interventions will be to provide the patients with the knowledge and make them more confident in managing their own disease. In the long-run this will actually play a significant part in improving clinical outcomes including in overall survival. As one of the first such studies carried out in Malaysia in this setting, the data will prove to be invaluable for this purpose.

1.7 Operational definitions

The operational definitions for some of the more commonly used terms within this study are as defined below.

1.7.1 Respondent

Respondents in this study refers to newly diagnosed cancer patients living in Kuala Lumpur and diagnosed within the past 6 months.

1.7.2 Healthcare Professional (HCP)

Healthcare professional in this study refers to professionals working within the healthcare industry namely doctors, nurses, medical assistants, radiographers, and other allied health staff.

1.7.3 Peer

Peer in this study refers to individuals living with cancer who have completed treatment

1.7.4 Peer-support

Peer-support in this study refers to programme where individuals living with cancer who have completed treatment work to support newly diagnosed patients via counselling, sharing of experiences and even assisting in removing of barriers

1.7.5 Patients

Patients in this study refers to individuals who have been diagnosed with cancer

1.7.6 Patient Education

Patient education in this study refers to the rocess of teaching and learning about a condition or disease to a person suffering from the disease. It includes teaching them about the disease itself, how to care for themselves, how to prevent further worsening of the disease, treatment options including benefits and risks; and also how to take care of their mental health.

1.7.7 Treatment journey

Treatment journey in this study refers to a cancer patient's entire treatment process from the point of screening, diagnosis, various modalities of treatment, period of completion of treatment and subsequently; cure, relapse or recurrence or remission

1.7.8 Survivor

Survivor in this study refers to any cancer patient from the point of diagnosis, although in some literature this is used to refer to patients who have completed their treatment **1.8 Scope of study**

The study will encompass obtaining the opinions of cancer patients who have been recently diagnosed within the past 6 months. Through qualitative interviews being conducted with patients over the period of 3 months within the radius of Kuala Lumpur, the study will seek to understand what are the educational needs of these patients and focus on obtaining their input pertaining to this. This study will then use the insights obtained from those patients to understand whether these needs are common across different geographical setting as well as to try and correlate these findings with established theoretical frameworks and assumptions while seeking to explain the reasons for them.

1.9 Limitation of study

This study is not quantitative in nature. Thus, it will not be able to prove causation or correlation in terms between two factors. In addition, the study is only being carried out within one setting of a healthcare institution of a non-governmental nature in the capital city of Kuala Lumpur. The data and insights obtained from the study, thus cannot be used to reflect the opinions of all cancer patients in Malaysia in terms of educational needs; for example, and be utilised for programme planning or policymaking.

1.10 Chapter summary

This chapter first provided the background for the study before embarking to explain in depth, the study rationale and providing the problem statement for the study. The study went on to state its objective, research question and outline the scope of the study. The chapter also elaborates on the significance of the study while also providing in detail the significance of the study in the Malaysian cancer scene and its limitations.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter will elaborate in detail the background information related to the areas of interest in this proposal. This chapter will summarise the information related to the landscape around the area in which this study is based. Discussed within this section will be the concepts underpinning this educational area, the related challenges and what are the gaps within the research area that needs to be addressed which then make up the foundation stones for this research and why it is being carried out.

2.2 Patient Education

Patient education is the process of educating patients about their health, wellness, treatment plans, potential outcomes and other information which is critical for the patient to be able to manage their condition. The process requires the patient to learn to modify/change their behaviour and produce the changes in knowledge, attitude and skills needed to maintain or improve health (American Academy of Family Physicians, 2000).

Patient education aims to instil the patient with a sense of autonomy in being able to manage their own condition as well as to equip them with the knowledge necessary to make their own decisions in terms of managing their health. Patient education underpins the management of all chronic disease and is critical to ensure that patient has good outcomes. Good patient education carried out well will help to ensure that the patient is able to have high degree of health literacy (the capacity of a patient to obtain, communicate, process and understand basic health information and services which can enable them to make appropriate health decisions). Increased health literacy is the end goal for patient education (American Academy of Family Physicians, 2000).

Among the benefits of patient education for both patient and treating health professional are as described in the table below:

Table 2.1 Benefits Of Patient Education To Patients And Treating Health Professionals

Benefit to patient	Benefit to treating health professional
Improved understanding of condition, diagnosis or disease	Increased patient compliance to treatment or management plan
Improved understanding of methods and means to manage different aspects of medical condition	Improvement of patient outcomes as patients more likely to respond well to treatment plan
Improved self-advocacy in terms of acting independently from the managing healthcare team as well as in interdependence with them	Improvement in terms of cooperation as patients feel that they are involved more thoroughly in the process.
Increased motivation to comply with the treatment/management plan	Improvement in terms of informed consent as patients feel better and more thoroughly informed
	Reduced utilisation of resources, as there is expected reduction in use of additional resources including visits and follow-ups,
	Increased patient satisfaction as

	patients are happier with the management team Improved risk management as patients have realistic expectations and more unlikely to initiate malpractice measures.

2.3 Therapeutic Patient Education

Therapeutic Patient Education is a more complete aspect of education where health care professionals train patients in the skills of self-managing or adapting treatment to their particular chronic disease and in enabling them to learn coping processes and skills (World Health Organization, 1998). Therapeutic patient education can contribute to reducing the long-term cost of care as well as to provide better outcomes for patients.

Healthcare professionals trained in educating patients, caregivers and other individuals involved in the patient’s care can provide therapeutic patient education which can be used to enable patients to manage their own treatment, health conditions and prevent avoidable complications while maintaining or improving quality of life (World Health Organization, 1998). Therapeutic patient education is intended to produce a therapeutic effect additional to that of all other treatment interventions including surgical, pharmacological, physical therapy and even radiotherapy (World Health Organization, 1998).

Criteria of Therapeutic Patient Education programmes include:

i) takes into account the patient's adaptation processes (coping issues, health beliefs, sociocultural perceptions)

ii) take into account the subjective and objective needs of the patient, irrespective of whether this is expressed or not.

iii) it is an integral part of the care process

iv)it concerns the patient's daily life and psychosocial environment

v) it engages the patient's caregiver and family

vi) it is a continuous process which is adapted to the course of the disease, the patient, and the patient's daily life and the patient's treatment journey.

vii) it is structured, organised and provided systematically.

viii) it is provided to the patient through a variety of media.

ix) it is multiprofessional, interprofessional and intersectoral

x) it includes an evaluation of the learning process and its long-term effectiveness

xi) it is provided by healthcare professionals trained in patient education

2.4 Comprehension in patient education

Patient education is often carried out without any clear idea on whether patients understand this material or not (Davis, T.C., 1990). Variations in the patients' education levels, literacy skills and language barriers are often ignored by provision of a one size fits all material. In fact, patients who have poor literacy are likely to conceal their literacy, even when asked directly about it. Such misunderstandings often interfere with all aspects of patient education including in care provision such as diagnosis or treatment (Davis, T.C., 1990).

Comprehension is one of the most critical literacy skills in healthcare. Contextual understanding of words in the medical setting is a complex process requiring the use of logic, language, and experience. However, comprehension is almost never tested directly in patient settings. In short, while we are often concerned about whether patients are being given educational materials or not, no one is really concerned on whether they are able to understand the materials at all. We are not evaluating whether patient is able to comprehend what is being provided to them. Readability and understanding of materials is something which should underpin the process of educating a patient (Davis, T.C., 1990).

Studies have found (Polishchuk, D.L et al, 2012; Horner, S. D. et al, 2000)that in multiple settings, there is a huge discrepancy between the reading comprehension of the average patient and the ability levels required to read available patient education materials . As long as patients are unable to comprehend their disease and their own role in managing it, there is going to be a huge gap in enabling patients to understand, accept, follow instructions and play and active role in their own care. Unfortunately at this time, we are not really carrying out active measures to evaluate whether or not patients are able to understand health information, and unless we are able to integrate this into the care provision process, we are bound to fail at providing effective care (Davis, T.C., 1990).

2.5 Evaluating Patient Education Programmes

Patient education programmes are currently mostly being assessed in terms of impact to the patient's health status (Lane, D. S., & Evans, D., 1979). These measures include:

i) Physiologic measures of control such as blood sugar levels or hypoglycemia episodes;

ii) Compliance to treatment regimens such as testing on whether patient is able to administer insulin (insulin administration techniques) properly or diet practices;

iii) Knowledge in terms of understanding of basic pathophysiology of disease, basics of how medicine works and the effects of medication on symptoms.

iv) Use of health services in terms of number of hospital visits, decreased use of emergency room, and use of costing data in terms of expenditures

v) Adaptability in terms of absence of major role disruptions, absence of depression or anxiety episodes, evidence of efforts to cope with problems of living with the disease

These various indicators are largely useable to evaluate the impact of education programmes on these aspects of the patient's life (Lane, D. S., & Evans, D., 1979). Patient education programmes are supposed to be able to change the clinical signs and symptoms of the disease towards a less pathological state. Changes in compliance indicators reflect the success of educational programmes in changing the actions of the patients in terms of disease management in terms of adherence.

Knowledge of the disease is measurable by conventional questionnaires for assessing whether the patient has subject knowledge in the cognitive domain over the subject matter or not (as reflected by knowledge test scores). However, studies continue to prove that this may not be directly related to disease control i.e. a patient with high amounts of knowledge still manifests poor behaviour in terms of disease control. Patient education programmes are also well able to demonstrate their effectiveness in terms of whether there is a decrease in the appropriate health services. This, in turn, may result in a decrease of overall costs.

Patient education programmes are also able to improve how the patient adapts to his/her disease. This may also be translatable as an improvement in the patient's quality of life, generally as how a patient changes him or herself so that their attitudes and behavior is able to cope and adjust to the new living conditions they are now required to be in due to being a patient (Lane, D. S., & Evans, D., 1979) .

2.6 Factors Influencing Patient Learning

Three major groups of factors are related to influence patient education. These are i) patient factors; disease factors and system factors. All have separate but interlinked roles in determining whether or not a patient is easily able to learn (Farahani, M. A. et al, 2013).

Patient factors which influence learning are underpinned by the socio-emotional characteristics of patient in terms of the extent in which they affect the patient's own perspective towards his/her own health and the subsequent capacity and desire to change life habits (Koo, M., Krass, I., & Aslani, P., 2006). Age of the patient has an impact in the patient's ability to learn and receive information. An elderly patient, for example, may have slower learning capacity due to the physiological slowdown of his/her body or even the onset of dementia which may also impair learning. In addition, the emotional effect of disease may affect those of different ages differently, with younger people likely more prone to have emotional disturbances which may affect learning capacity in terms of the knowing about the disease.

Gender is also a factor affecting learning. Women, for example, are more likely to receive, retain and act on education compared to men. They are more willing to participate and learn. Men, however, are more likely to refuse to accept disease, minimise its impact and participate in educational interventions. Ethnicity, socio-economic factors are also very involved in playing a part in whether a patient learns. Cultural factors such as attitudes towards health also have an impact on the ability to learn and make changes from educational interventions. This is because this inherently is connected to the patient's own beliefs.

Educational levels are also closely connected to this as people with better education are themselves easier to bring onboard educational interventions in terms of participation. The patient's social environment, relationships with family, job and friends all have an impact on their capacity to respond to teaching and be able to learn. Larger household size, for example, is related to poorer control and thus poorer response to educational interventions. Even something as simple as being able to attend an educational intervention is tied closely to whether there is family member who can attend together with them. Generally, patients who are active, independent and able to be better oriented towards self-control and self-mastery will be able to respond better to teaching programme. Emotional factors may influence a patient in spurring them to do or not do any form of activity as well as also playing a role in the psychoemotional makeup of a patient which may affect their disease (Koo, M., Krass, I., & Aslani, P., 2006).

Differences in how a disease affects a patient often makes it difficult to categorise a patient and hold them up to an easy standard in whether they can learn or not. However, there are various disease factors which seem to show similar signalling abilities in terms of how they affect patients' learning. This includes illness severity, age of onset, length of illness and mode of therapy. Severe patients often are too ill to be involved in any form of educational activity while patients who are older are also often also not cooperative with educational approaches.

Patients who have had disease from a young age are usually more likely to be more cooperative; however they are also sometimes more bleak in their outlook, more pessimistic and may find it difficult to learn. Mode of therapy may be another form of challenge for patients who often have to have their treatments interfere with any life activities which may include learning. Radiotherapy, for example, may have a stronger impact in terms of side-effects for patients who may then find it difficult to participate in patient education programmes (Farahani, M. A. et al, 2013).

The impact of system factors on patients are quite complex and not as easy to make out. The patient's location in the system, for example is one of these. Hospitalised patients may be easier to teach as they are in one place and can be accessed regularly. However, when they are hospitalised, patients may be more demotivated or even more ill which may decrease, again their capacity for learning. Relationship of the teaching programmes with other health services may also be a factor. Patients are more likely to participate in programmes tied in with their appointments, for example, compared to being in some that are not and more in a stand-alone format. As these may require more visits, patients may be reluctant to attend.

The educator's own teaching style and even who the educator is may also have a role to play in terms of determining the learning and whether it happens in a patient. Amount of exposure to educational programmes may also play a role, especially since many patients are exposed in different times to differing lengths of educational exposure. All these play a role in education and whether it happens in the context of the patient.

CHAPTER 3: THEORETICAL AND CONCEPTUAL FRAMEWORKS

3.1 Theoretical Framework

The theoretical framework for this study is based on the following process. First, peer-reviewed evidence is used to highlight the arising educational problems within this particular educational landscape. Subsequently, selected learning theories are used to explore and explain these problems using the various theoretical viewpoints. One of the seminal works which details the issues pertaining to cancer-related patient education is a review by Chelf, J.H et al (2001). This review compiles 10 years of evidence in the educational area and summarises areas in which patient education needs to be further developed specifically in terms of cancer. These are:

i) Preferred learning methods – patients with cancer want as much information as possible, especially about their condition. They can use written materials as a source of knowledge, but are more comfortable when learning via interactions from their healthcare professionals (with doctors being the primary choice, but nurses a close second). Different patients also have different preferences about what they want to learn about; as well as when they want to learn about it. This then becomes an issue on whether information can then be tailored in terms of delivery for each individual patient.

ii) Learning Materials – patients feel that other than this face-to—face 'learning' sessions, they also need to have a supplemental take home material, with many expressing a preference for printed material. These materials will not be the primary method of learning for these patients, but rather will function as an adjunct which they can go back to refresh and recall information from the face to face sessions.

iii)**Literacy and Readability** – many patients felt that both the explanation by healthcare professionals as well as printed material, in the instances when it was available, was written at a level too high for them to understand. At the same time, there are also studies in which highly literate populations report that the material was too simple and ‘childish’ for them. As such, among strategies being considered is the development of materials at multiple levels for patients, or moving to audiovisual approaches since spoken vocabulary levels are usually much higher than written vocabulary; with the effect that the gap between highly literate groups and groups with lower literacy may differ.

iv) **Use of Multiple Media as Learning Materials-** the interactivity offered by multiple media materials such as Internet websites, telephone interventions and videos seem to be preferred by patients. These multiple media can provide greater depth of content and repeated accessibility which can provide greater independence for patients in meeting their learning needs. Also, different patients have different preferences and thus the variety of different media as learning materials will definitely appeal to different types of patients and even to the same patients at different times.

v) **Learning needs-** Most of the patients were looking to learn and understand about the treatment process, including the outcomes from different treatment modalities. Interestingly, from the provider perspective, there was a different outlook where healthcare professionals were of the opinion (and supported by evidence) that knowledge about symptoms were more important for patients as they helped patients cope better. In truth, the heterogeneity across the spectrum of learning needs is also a challenge as the type of ‘students’ i.e. patients who want/need to learn are also highly variable.

3.2 Theorised Educational Problems

An analysis of these abovementioned categories revealed that there may be certain educational problems which cancer patients may face. These extrapolated problems form the basis of the suggested theoretical framework on which this study is based, and will subsequently be validated via the actual data collection process. These educational problems are as elaborated on below:

i) difficulty for patients in incorporating the information provided to them as they have a difficulty in assimilating the knowledge being learnt into established anchoring ideas.

ii) large intrinsic cognitive load i.e. the large amount of scientific content provided to them which they are required to learn and understand

iii) knowledge decay i.e. difficulty in retaining the knowledge provided to them over a long period of time, making them confused about their treatment strategies and other aspects of their treatment journey. This is also compounded by their disease, the mental health issues related to the disease and the difficulty they have in mental cognition and comprehension.

iv) lack of metacognitive knowledge where these patients have a lack of self-awareness, being unaware of their own self-strengths and self-weaknesses.

v) the information related to cancer and the treatment journey is outside the learner's zone of proximal development (ZPD) and thus something that they cannot learn unaided.

vi) the complexity of information and skills that makeup the learning content a patient needs to learn in the entire process of their treatment journey is something that requires them to have a structure of support points i.e. scaffold - in order to gradually empower them to progress along their learning journey in relation to the disease.

3.3 Theoretical Foundations

The educational problems theorised above are underpinned by certain theoretical foundations according to certain educational theories as elaborated in detail below. The six theories used for understanding and conceptualising this discussion are:

i) Ausubel's Assimilation Theory (Ausubel, D., 1985)

ii) Cognitive Load Theory (Sweller, J., 2011)

iii) Attkinson and Shiffrin's Information processing Theory (Atkinson, R. C., & Shiffrin, R. M., 1968)

iv) Pintrich's Metacognitive Knowledge Theory (Pintrich, P. R., 2002)

v) Vygotsky's Zone of Proximal Development (ZPD) theory (Chaiklin, S., 2003), and

vi) Bruner, Wood & Ross' Theories on the Concept of Scaffolding. (Olson, D. R., 2014).

According to Ausubel's Assimilation Theory (Ausubel, D., 1985), an individual's own existing cognitive structure is the main underlying factor that influences learning and retention of new meaningful material. Each individual's cognitive structure is organised hierarchically and thematically. More general ideas are located higher in the cognitive structure and more specific ideas are lower down in the structure. New information can only find its way into the cognitive structure through a specific channel called anchoring ideas. These are specific ideas within the cognitive structure that offer entry points for new information to 'anchor' or 'lock' on to the existing cognitive structure. This can be through methods such as subsumption where new ideas are eased in through existing general ideas or superordinate learning where new concepts/information are learnt from already established ideas. Combinatorial learning where both these methods are combined is also another strategy to introduce new learning where new information is not specifically anchored to one concept but rather is contextual to a broad informational background, interacting to the existing cognitive structure and being assimilated to form a more highly differentiated cognitive structure and being retained in the process.

The Cognitive Load Theory (Sweller, J., 2011) discusses the types of cognitive loads connected to the total amount of 'load' in a learner's working memory. These are the intrinsic cognitive, extraneous cognitive and the germane cognitive loads respectively. The intrinsic cognitive load represents the ability of an individual to innately process subject matter material to be learnt. This intrinsic cognitive load increases when a huge amount of processing is needed to process the subject matter. Extraneous cognitive load is the additional processing needed to deal with issues unrelated to the learning task itself while germane cognitive load is the deep processing needed to comprehend the stored information by organising, integrating, and connecting this information to information existing prior to this learning episode in the learner's long-term memory. Each individual is unique in terms of their intrinsic cognitive load, thus it remains critical to be able to reduce extraneous cognitive loads when and wherever possible during the learning process while consciously trying to attempt maximisation of the germane cognitive load.

The Information Processing Theory (Atkinson, R. C., & Shiffrin, R. M., 1968) breaks down human memory into 3 sections: sensory memory, short-term memory and long-term memory. Information that a learner receives through their senses is usually held within their sensory memory (audiovisual inputs are one part of this). Short-term memory retains learned information for about only 30 seconds and even that in small, structured 'bits' such as a series of numbers. One of the challenges of learning is to move learned information into long-term memory and retain that information. The Information Processing Theory as well as Ebbinghaus in his memory curve (Newman, E. J., & Loftus, E. F., 2012) have elaborated on how learnt information is lost or 'decays' after an initial period when it is learnt, also termed in lay-speak as how quickly one forgets. Retaining learn information over time requires repeated studying (rehearsal) where information is re-encoded and recall (repeated retrieval of the information) from long-term memory. Strategies which have been developed for this rehearse-recall process include spacing, where learning sessions are spread out over a period of time; self-referencing where the learner is enabled to think about the information and how it relates to them personally; and finally elaborative rehearsal where learners are able to provide their own meaning to information gleaned subsequently connecting it to information stored in their own long-term memory. This comes about via repeated re-engagement with the material in multiple ways, providing multiple opportunities for recalling the material again and again while at the same time building new connections to the material.

In Pintrich's Metacognitive Knowledge Theory, (Pintrich, P. R., 2002), an individual's own cognitive processes are cognizant in enabling them to learn. Regulation of their own processes such as study skills, memorising skills and ability to monitor their own learning encompass this area of metacognitive knowledge. There are three main types of metacognitive knowledge: i) content knowledge- which is the learner's ability to evaluate their own knowledge level of a certain subject; ii) task knowledge- which is the learner's ability to evaluate the level of a task's difficulty in various aspects such as enormity and depth; and iii) strategic knowledge- which is the learner's own ability to use multiple strategies for learning information. These components need to be used by the learner in order to maximise their own ability to learn or to upregulate their own cognition.

Vygotsky introduced the concept of Zone of Proximal Development which can be interpreted as the distance between the existing knowledge levels/capabilities of a learner, and what knowledge/capabilities that they are able to learn with or without help. (Chaiklin, S., 2003). Vygotsky put forward the thought that learners would not be able to advance very far on their own if they were to do so themselves. He also put forth the concept of More Knowledgeable Others (MKO), individuals (or teachers) who have a better grasp of the material than the learner, and when they guided or supported the learner, the learner would be able to acquire the knowledge/capability which they could have not if they had to do it by themselves. In this way, the learner's ZPD continues to be expanded.

Bruner built on Vygotsky's unfinished work to put forward the concept of instructional scaffolding, a support structure for performing an action (Olson, D. R., 2014). A scaffold refers to the guidance/support from an instructor/competent peer to enable the learner to move along and expand their ZPD in terms of making learning gains. It builds on the learner's level of knowledge and progresses from there. The support provided by the instructor/teach may include resources, task compelling, templates, guides, coaching or even task modelling. As learners progress they develop autonomous learning strategies (metacognitive knowledge) and the scaffolding can gradually be removed at which stage the learner is independent.

3.4 Application of Theoretical Foundations to Theorised Educational Problems

In the following section, the above-mentioned educational theories are applied to the theorised educational problems of the cancer patient population in order to determine whether or not these problems were explainable by these theories. These then gives a strong theoretical grounding to the study to be undertaken.

Theorised Problem 1: Difficulty in Incorporating Information Imparted to Them

Cancer patients, especially those starting their cancer journey at diagnosis, often have little or no experience related to the subject. With the few exceptions, many do not even have a health science background. In this situation, Ausubel's Assimilation Theory (1985) clearly highlights the difficulties these patients have in learning about this new information i.e. about cancer This is because they really then do not have any form of cognitive structure to assimilate information. Their existing cognitive structure may not have any thematic structures with anchoring ideas allowing for this new information to enter into their cognitive structure. This will make it difficult for them to learn about this entirely new area of learning, which unfortunately they do have to understand as they embark on this treatment journey. As such, this theorised educational problem is grounded in terms of educational theory.

Theorised Problem 2: Cognitive Load

The Cognitive Load theory (Sweller, J., 2011) clearly elaborates on how learners falter with large intrinsic cognitive loads. This may be especially true of cancer patients who are in a sense, being ‘forced’ to learn as they have to find out as much as they need to about the disease because they are now faced with it. In addition, the only teaching-learning process usually takes place in the gap after news has been broken to the patient about their diagnosis or in the space during consultations. The amount of information shared to the patient most likely forms a high amount of intrinsic cognitive load while the delivery of this information which is usually verbally but maybe rushed due to situation in which it is being delivered (in rushed conditions in between clinics) may well form a challenge in terms of high extraneous cognitive load. The likelihood of patients facing such an educational problem which is the high intrinsic load in terms of the inherent difficulty of the material being presented as well as the extraneous cognitive load in terms of delivery fits into the logic of the educational theory.

Theorised Problem 3: Knowledge Decay

Information Processing Theory (Atkinson, R. C., & Shiffrin, R. M., 1968) divides memory into short-term, long-term and sensory memory, with the objective of learning to retain information in the long-term memory so that it can be recalled. The process of decay is a naturally occurring one and in such cases for usual learners can be prevented via certain strategies. For cancer patients, no such structured system is available (such as assessments, quizzes or other rehearsal and retrieval techniques) so information given at one time when stored in the long-term memory, will decay. In that aspect, knowledge decay seems to be a likely educational problem that patients will face.

Theorised Problem 4: Lack of Metacognitive Knowledge

Pintrich's Metacognitive Knowledge Theory (Pintrich, P. R., 2002) requires the learner to be able to understand and develop their own metacognitive knowledge in order to be able to improve learning. Since there is a lack of a formal learning environment, there may be overt challenges for cancer patients to be able to assess and determine their own content knowledge, for example; or even be able to evaluate their task knowledge about an area like giving themselves injections which they have never been able or needed to know before. Also, their own ability to be able to use different strategies to learn information may be impaired due to their own shock and mental distress related to the diagnosis. All this possibly impairs the patient's own metacognitions and causes a learning problem for them in terms of the receipt of cancer-related information.

Theorised Problem 5: Away from Zone of Proximal Development

Cancer is not something you deal with in your daily life. It is thus really unlikely that you would have the capacity to be able to deal with such a task easily or learn how to deal with such absorbing such information easily. Contextualising this within the ideas of Vygotsky’s Zone of Proximal Development (ZPD) theory (Chaiklin, S., 2003), the patient is like a learner who is in the zone where the learner cannot do tasks by him or herself, in the cancer care concept, of course. This is because the tasks of cancer care are beyond the patient or learner working by themselves to learn. Applying this educational theory to this example passes the logic test.

Theorised Problem 6: Lack of scaffolding

The last educational problem is somewhat connected to Vygotsky in the sense that it extends the logic line along the ideas of Bruner, Wood & Ross’ Theories on the Concept of Scaffolding. (Olson, D. R., 2014). Cancer patients will be able to learn cancer information/tasks/skills if they are provided with the ‘scaffold’ where peers or experts such as healthcare professionals function to guide and support them along this journey. Unfortunately again, the lack of a formal and structured learning environment for patients in this aspect causes this to be a stumbling block i.e. an educational problem that represents another hurdle for patients in their treatment journey.

The framework in Figure 1 provides a graphical representation of the theoretical framework underpinning the study.

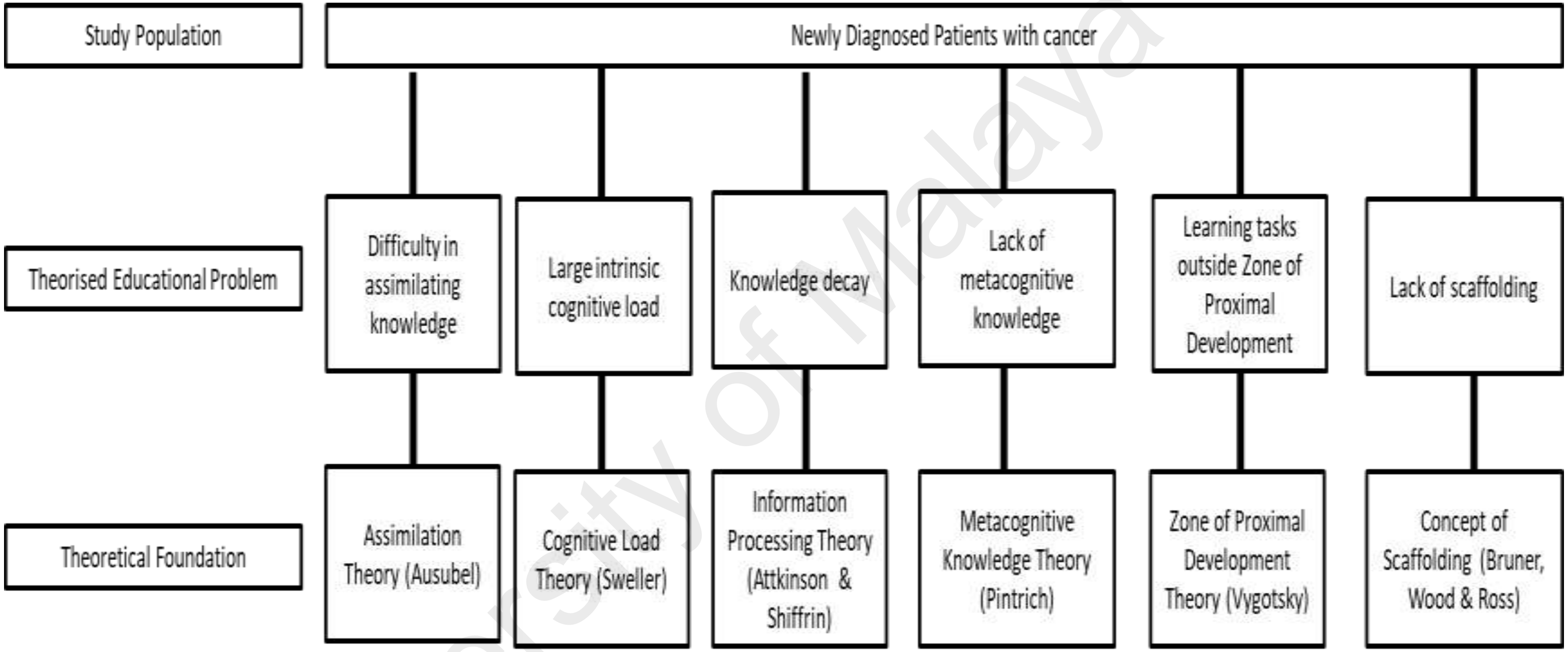


Figure 1: Theoretical Framework of the Study

3.5 Conceptual Framework

From peer-reviewed literature, it has been determined that there are various different factors which can influence an individual's learning (Brady, E. M., 1984). These factors are then also reflective of the possible factors that may have a role to play on whether an individual faces educational problems.

As in most behavioural elements, socio-demographics have a role to play as drivers of educational problems learners may face (Darkenwald, G. G., & Hayes, E. R., 1988). Gender and ethnicity have been theorised to be a driver of these processes although the evidence on this does seem to be mixed. Age has definitely been labelled as an important factor influencing learning. In general there has been an inverse correlation between age and learning in adults, though this may not be as linear a relationship as previously predicted. Occupation and education are two other factors which are somewhat intertwined; with both having an effect on the learner's capacity and ability to learn. Again, the evidence seems to be quite straightforward for the most part, with higher levels of education and higher-occupational categories having less problems with learning than their counterparts with lower levels of education.

In terms of behavioural characteristics, it is quite clear that the element of motivation plays a strong part in influencing an individual's learning. Arguably, motivation may even overcome the inherent effects of socio-demographics. Thus the cause of motivation and the type of motivation that the learner may have will play a big part in determining the type and amount of learning that may take place (Courtney, S., 2018). Learners with intrinsic motivation will have the highest interest and ability to learn while those that are purely being motivated by extrinsic motivation may not be learn as well. Those who are amotivated, of course, wil not be capable of learning at all (Courtney, S., 2018).

The additional burden for learners who are patients is their own disease; grouped together under the category of illness-related factors (Lane, D. S., & Evans, D., 1979). In the cancer context, this included the type of cancer, stage of cancer, severity of its symptoms and the stage of the patient’s treatment. All these will have an impact on the educational level of the patient ((Lane, D. S., & Evans, D., 1979).

Figure 2 below illustrates the conceptual framework of the study.

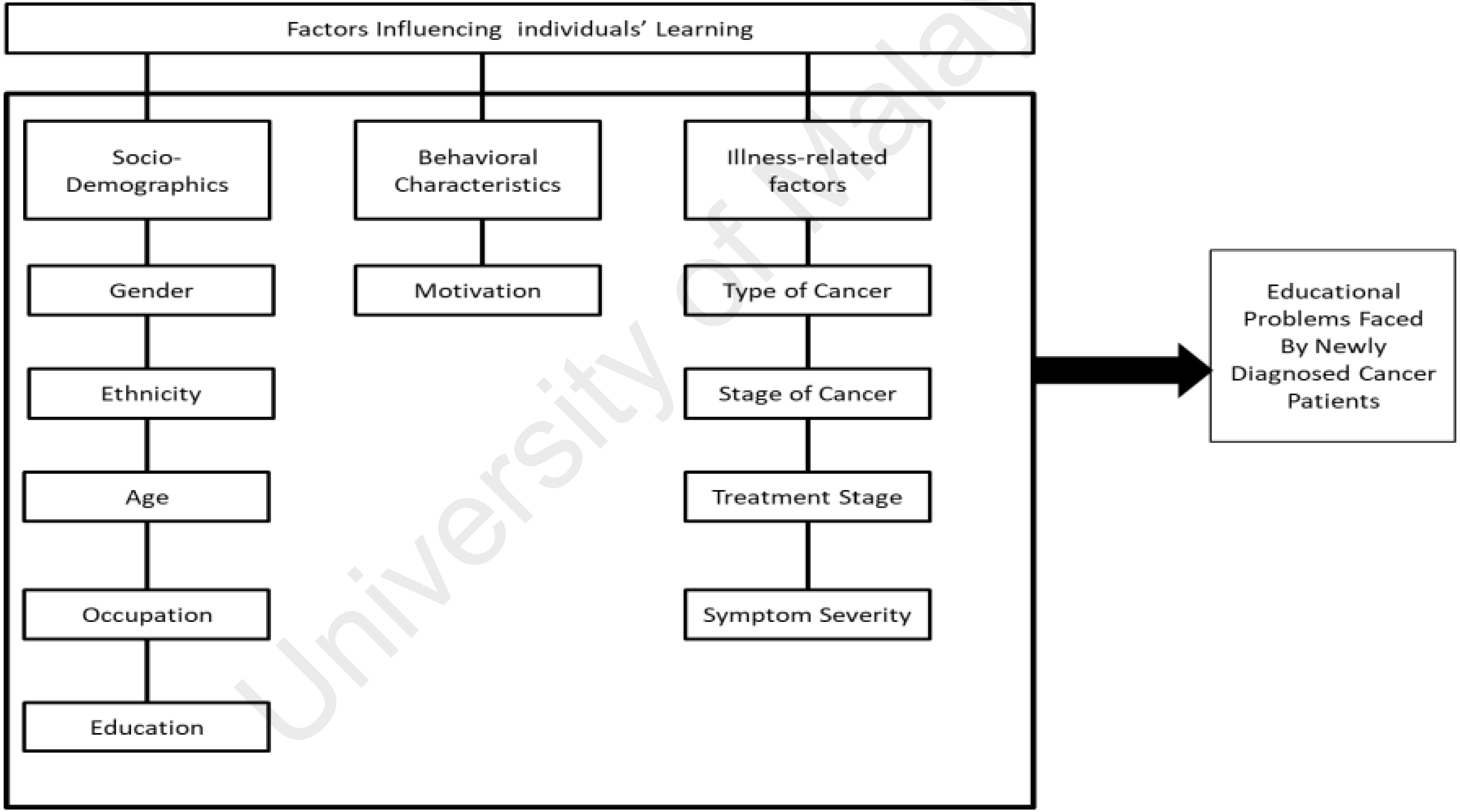


Figure 2: Conceptual Framework of the Study

CHAPTER 4: METHODOLOGY

4.1 Study Design

The study was of qualitative design, using a narrative approach. This study consisted of individual in-depth interviews. During this time of the Covid-19 pandemic, in line with safety measures, these interviews were carried out via Zoom (a web-based Video Conferencing application, available at https://zoom.us)

4.2 Study Area

The study area for this study was in National Cancer Society Malaysia, Kuala Lumpur

4.3 Study Duration

The duration of the study was about 12 weeks, beginning from May to August December 2020. Data collection was carried out in the months of May, June and July 2020.

4.4 Study Population

The study population was newly diagnosed cancer patients (within 6 months of diagnosis) residing in Kuala Lumpur. The patients could be those followed up by oncologists in public or private hospitals. The researcher clarifies here that all the patients were on active treatment but this study was not an interventional study and thus did not have a possibility of interfering with their treatment regimen

4.5 Inclusion and Exclusion Criteria

Inclusion criteria

i) Participant is newly diagnosed with cancer within the past 6 months

ii) Participant is able to speak and converse clearly in Bahasa Malaysia or English

iii) Patient does not have a history of previous cancer diagnosis and treatment.

Exclusion criteria

i) Participant has diseases which affect their mental capacity premorbidly such as a mental disability or vascular dementia.

ii) Participant is being treated by psychiatry for acute mental health issues such as severe depression or severe anxiety disorder.

iii) Participant refuses to participate in the study.

4.6 Sample and Sample Size

The sample consisted of cancer patients who had been diagnosed and sought any kind of support through one of the National Cancer Society of Malaysia Kuala Lumpur's support channels, namely i) support groups; ii) Cancer Information System (CIS), iii) attendance to wellness classes or workshops for cancer patients; iv) counselling or clinical psychology support; or v) peer support counselling . Patients who consented were be recruited and in-depth interviews carried out with them consecutively one after another to compare the data obtained and ensure saturation of information.

4.7 Sampling Technique

The sampling technique for this study was by quota sampling, where patients were sampled according to groups depending on their type of cancer in order to get as many diverse and complete views as possible. For this study, these sub-groups were for patients with i) breast cancer; ii) colon cancer; iii) women's cancers (cervix, ovary); v) men's cancers (prostate); and vi) young people with cancer.

Within each group, care was also taken to attempt to ensure as different a set of representation (in terms of socio-economic status, gender, ethnicity) reflecting these differences as far as possible. This was done to ensure the maximum variation of sampling so that there would be as wide a heterogeneity as possible.

Participants for each sub-group continued to be recruited until data saturation was obtained. The entire study participants were considered completed when data saturation was reached for all groups.

4.8 Recruitment and Data Collection Procedure

All cancer patients seeking any form of support services through one of the National Cancer Society of Malaysia Kuala Lumpur’s support channels, namely i) support groups; ii) Cancer Information System (CIS), iii) attendance to wellness classes or workshops for cancer patients; iv) counselling or clinical psychology support; or v) peer support counselling were sent a recruitment brochure explaining in depth the study and its requirements. They were invited to participate in the study. Those who were interested were given a contact number of a study team member who assessed whether they fit the inclusion and exclusion criteria, answered any queries they may have had and obtained informed consent. Those who declined or were unable to participate were thanked. Once confirmed, participants were called to schedule their availability for in-depth interviews as well as to aid them in downloading and configuring their device to be able to handle the Zoom interview.

Participants were called from the NCSM office in Kuala Lumpur for the in-depth interview session. Each interview lasted a maximum of 120 minutes. The in-depth interviews were carried out in either Bahasa Malaysia or English and was handled by a trained member of the study team who is also a cancer survivor (as well as being a trained peer support team member at the National Cancer Society of Malaysia). The interviewer was chosen specifically as they have particularly been trained to be empathetic and have skills in motivational interviewing as well as coping skills. The interviewer was provided with an interview guide (Attached in the Appendix) which provided them with questions to be covered as well as being briefed on the methodology of conducting an in-depth interview. Both interviewer as well as the participant were provided with a stipend to recompense them for their time.

4.9 Research Instrument

The interviewer used a formulated interview guide which was pilot-tested on a three different individuals to ensure the scope of the questions being asked is on point (attached in the Appendix). At the beginning of the interview, the interviewer covered a series of questions on demographics of the patient and an overview of their illness including the patient describing how and when they were diagnosed, where are they seeking treatment and also what is their current stage of treatment. Following this, the interviewer asked open and explorative questions to the participant in order to obtain their complete answers. The questions were clustered around five arcs. The first arc consisted of questions to the patient in terms of learning needs during diagnosis. The second arc consisted of questions around how these learning needs were fulfilled, while the third arc asked the participant to evaluate on whether how fulfilled they were with the information given to them . The fourth arc concerned questions about the patients' continous learning needs, if any, throughout their treatment journey and the fifth arc elicited suggestions from the patient on how the need for a learning programme for diagnosed cancer patients. All the questions were open-ended and the interviewer continously strove to obtain complete opinion from the participant, prompting them when necessary.

4.10 Reliability and Validity

Validity was established from the wide sampling involving as heterogenous a sample as possible, with diversity in each of the sub-groups in terms of the participants with various types of cancer as elaborated above. Reliability was established from the running of in-depth interviews for each sub-group completely first before embarking on the next sub-group. Thus, the interviews of the groups ran consecutively one after the other. In this manner, the data from each sub-group acted to verify the information of the previous group via the ongoing input process. Data analysis for each sub-group was also carried out immediately once that sub-group was completed so that the collated analysed data was available for the study team to benchmark as they began on the next sub-group.

4.11 Data Analysis

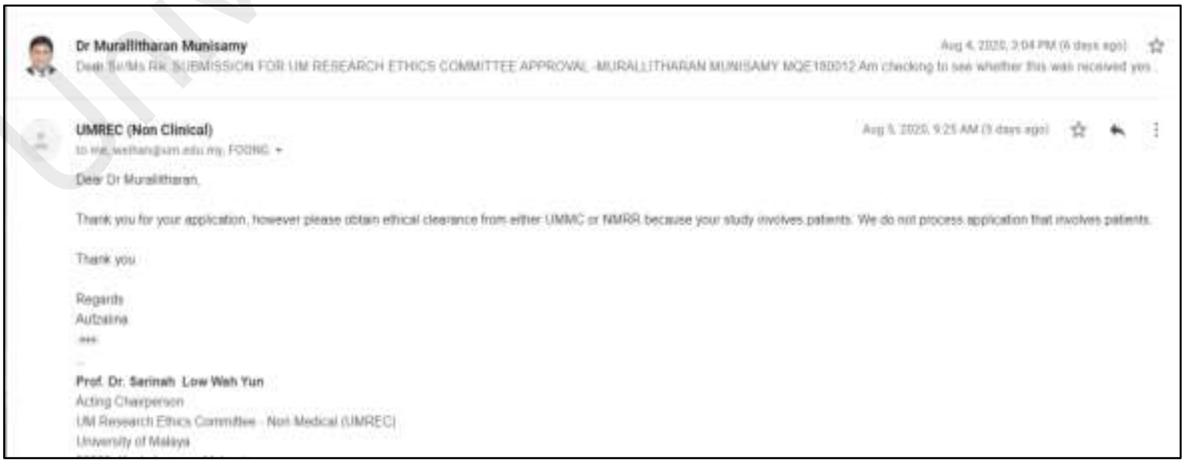
The in-depth interview sessions was conducted in English or Bahasa Malaysia Interviews were recorded electronically and transcribed verbatim into English as required. Each participant was labelled with an individual number according alphabetical order of their names and the written transcripts were labelled following these numbers.

An iterative approach was used to thematically analyse transcripts. Two members of the study team read and re-read the transcripts independently to familiarize themselves with the data and developed a framework for coding the interview data. The transcripts was then be independently analysed by the two members of the study team to find significant ideas and opinions using systematic and comprehensive coding. The coded data was summarized to determine code frequencies and then grouped by similarity into themes and sub-themes. Study supervisors provided oversight to verify findings and ensure consistency between the findings. Comparisons between the participants answers' was then be carried out, with patterns and associations being found and explanations for the findings generated before final categorization and conceptualization completed.

4.12 Ethical Considerations

At the ground level, a submission for support and approval to conduct the study was made to the National Cancer Society of Malaysia's Research Ethics Committee (NCSMREC) and their approval was obtained (attached in the Appendix).

At the same time, ethical approval for this study was also sought from the University Malaya Research Ethics Committee (UMREC) and an application made (attached in the Appendix). However, due to the concern about the use of a patient population for the study, UMREC informed the researcher that it would not be able to process such an application for ethical approval.



Dr Murallitharan Munisamy Aug 4, 2020, 3:04 PM (6 days ago)
Dear Sir/Ms Re: SUBMISSION FOR UM RESEARCH ETHICS COMMITTEE APPROVAL -MURALLITHARAN MUNISAMY MQE180012 Am checking to see whether this was received yes ...

UMREC (Non Clinical) Aug 5, 2020, 9:25 AM (5 days ago)
to me, weihan@um.edu.my, FOONG

Dear Dr Muralitharan,

Thank you for your application, however please obtain ethical clearance from either UMMC or NMRR because your study involves patients. We do not process application that involves patients.

Thank you

Regards
Aufzalina
***
--
Prof. Dr. Sarinah Low Wah Yun
Acting Chairperson
UM Research Ethics Committee - Non Medical (UMREC)
University of Malaya

Figure 4: Response from UMREC

Despite this being a ‘patient’ population i.e. consisting of those who have been diagnosed with cancer, as mentioned earlier this is a qualitative non-interventional study focusing on their educational needs and is thus not treatment based.

Remaining consistent with international research and ethics procedures, the Informed Consent of each participant was obtained along with confidentiality and privacy measures to ensure that their data is safeguarded and not utilized for any purpose outside the purpose of this study.

4.13 Data Storage

Recordings of interviews, which were in digital format, were stored in a secure password-protected hard drive maintained only for this purpose and destroyed upon completion of the thesis/related publications in the time frame legally allotted for this purpose (not less than five years). Data sheets and other hardcopy material pertaining to the study were stored securely within a locked cabinet in the National Cancer Society Malaysia offices and stored for the legal duration required (five years). Personal data will remain disaggregated from interview data on hardcopy or electronic files to ensure security. All hardcopy information and data analyzed on a computer, will be destroyed after the storage duration, unless required

4.14 Data Access

All medical and research records for this survey would be maintained appropriately in compliance with the principles of good clinical practice, regulatory and institutional requirements for the protection of confidentiality of participants. The study team members will have access to the records. The ethics committee(s), institution authorities, or regulatory bodies may inspect all documents and records required to be maintained for the purposes of quality assurance reviews, audits, inspections, and evaluation of the study safety and progress. This will include, but not limited to, medical records (if captured appropriately) for the participants in this study. Participants or their legally acceptable representatives would not be given direct access to the personal information and study data as to protect confidentiality and privacy of other participants. They would be informed of the final survey findings and / or any publication via email.

CHAPTER 5: RESULTS AND DISCUSSION

5.1 Sample Characteristics

The characteristics of the sample were divided into two different categories: i) respondents' demographic and the clinical characteristics. Each different category is described in detail below.

Respondents' Demographic

A total of 23 respondents who fit the inclusion criteria and consented participated in the study. The participants were labelled in alphabetical order of their names from R1 to P23. The majority of the sample consisted of females, with them making up close to 70% of the study population. More than half of the respondents were of Malay ethnicity with Chinese making up the second largest number of respondents. In terms of age, slightly more than half of the sample consisted of individuals between the ages of 50-69 years of age. The smallest number of respondents consisted of those from the 20-29 age group. There were no respondents who were younger than 20 years old. Almost half of the respondents were those who had completed at least diploma/degree level of education. Only 3 of the participants were those who only had completed primary level education. The breakdown of the socio-demographics of the sample is as detailed in the following table.

Table 5.1 Sample sociodemographic characteristics

Sociodemographic variables (N=23)	n (%)
Gender	
Male	7(30.4)

Female	16 (69.6)
Ethnicity	
Malay	12(52.2)
Chinese	8(34.8)
Indian	2(8.7)
Others	1(4.3)
Age	
20-29	2(8.7)
30-49	5(21.7)
50-69	13(56.6)
70 and above	3(13.0)
Education	
Primary education	3(13.0)
Secondary education (Completed Form 5)	4(17.3)
Diploma/Degree	11(48.0)
Postgraduate	5(21.7)

Of the respondents, the largest proportion consisted of breast cancer patients, while the smallest proportion consisted of young people living with cancer. Most of the patients (34.8%) were those who had been diagnosed 5-6 months ago; while those diagnosed within 1-2 months ago made up the second largest proportion of patients. 91.4% of the patients were in Stage 2 or Stage 3 of disease and the same percentage of patients were on active cancer treatment, ranging from surgical treatment, chemotherapy, radiotherapy or targeted therapy. 65.2% of the patients were being treated in public sector hospitals including Ministry of Health hospitals or Ministry of Education hospitals. The breakdown of the clinical characteristics of the sample is as detailed in the following table.

Table 5.2 Sample clinical characteristics

Clinical characteristics (N=23)	n (%)
Type of cancer	
Breast Cancer	8(34.8)
Colon Cancer	5(21.7)
Women's Cancers	2(8.7)
Prostate Cancer	6(26.1)
Young People with Cancer	2(8.7)
Duration of Living with Cancer	
<1 month	2(8.7)
1-2 months	7(30.4)
3-4 months	6(26.1)
5-6 months	8(34.8)
Stage of Disease	
Stage 1	1(4.3)
Stage 2	10(43.4)
Stage 3	11(48.0)
Stage 4	1(4.3)
Stage of Treatment	

Have not started active Cancer Treatment	1(4.3)
On Active Cancer Treatment	21(91.4)
Completed Active Cancer Treatment	1(4.3)
Treatment Centre	
Public Sector	15(65.2)
Private Sector	8(34.8)

5.2 Themes of the findings

The findings from the respondents pertaining to the study could be divided into 3 major themes which encompassed the provided input. Each of the themes and their respective sub-themes are as described in the table below:

Table 5.3 Themes and sub-themes of the findings

Theme 1	Awareness about Disease-Related Educational Needs
Sub-themes	i) Educational needs at Diagnosis ii) Ongoing Educational Needs iii) Emotional and Psychosocial Management Need
Theme 2	Current Delivery of Disease-Related Educational Needs
Sub-themes	i) Self-related issues ii) System-level delivery

Theme 3	Expectations of Disease-related Educational Needs
Sub-themes	i) Fulfillment of Disease-related Educational Needs ii) Suggestions of Disease-related Educational Needs

5.3 Awareness About Disease-related Educational Needs

There were three sub-themes within this theme which were educational needs at diagnosis, ongoing educational needs; and emotional and psychosocial management needs.

5.3.1 Educational needs at Diagnosis

At the moment of the diagnosis of their disease, all 23 respondents perceived that they were inadequately equipped with information about their disease. More than half of the respondents (17/23) felt that the most important thing they needed to learn was what had caused the disease while the majority of the others (5/23) felt that the most important thing that they needed to learn about was what was the prognosis or probably outcome of the disease. All participants, however, were unanimous in stating the need to learn about how their disease was going to be treated. They felt that by learning about how they were going to be treated, they would be able to get better control about the disease, feel more hopeful that there was some plan to ‘fight’ the disease and also gain understanding of the journey they would have to go through in managing the disease.

“ When the doctor told me I had cancer, I immediately began to cry. All I could think of my daughter had not even finished university yet, and I wouldn’t be able to see her graduate. I was going to die (I thought). It was burning inside me…. I needed to learn how to treat this condition immediately….” (Respondent 12)

Other areas in which respondents felt they needed to learn about besides how to treat the cancer was also i) how and what they needed to eat; ii) how to prevent the cancer from worsening; iii) how and what medicine they needed to take include supplements, traditional medicine and even alternative medicine.

" I remember seeing somewhere cancer patients should not eat chicken. The moment the doctor told me I had cancer, I needed to know whether I could eat chicken (or any meat) or not…" (Respondent 19)

Some of the respondents shared that they were too 'numb' or 'blur' when the news of their diagnosis was broken to them by the healthcare professionals. However within the space of one or two days, they declared that they also had these informational needs arising within their mind to be answered. All 23 respondents agreed that the were many commonalities within their informational needs at the moment of diagnosis. They also felt that addressing these needs should be a component of their holistic cancer treatment process.

5.3.2 Ongoing Educational Needs

21 of the respondents who were on active cancer treatment affirmed that they continued to have many informational needs even after their diagnosis. While during diagnosis their informational needs clustered around how they were going to be treated and what the outcome was going to be; their subsequent informational needs were dependent on the different procedures that they were about to undergo. For example, those who were going for chemotherapy expressed that they needed to learn of the side-effects of the medication that they were going to be on.

"…. I had been given this medicine which they said was for my cancer but I was so worried to take it because I had been told (by someone) that these drugs would cause a lot of side-effects and I should not take them every day…." (Respondent 7)

"…. I had stomach pain and diarrhoea two days after radiotherapy. I was so worried that it was due to the side effects of the treatment. I tried calling the radiotherapy department but it was a Sunday so no one answered and the next day, I went to the breast clinic and waited for 3 hours to check with the doctor…." (Respondent 14)

Respondents also voiced their opinion that after a few months of having the disease, they already had a lot of questions on a multitude of topics pertaining to their cancer and needed someone to go through the questions with them to give them the answers. Only 1 respondent said that she was content with the doctor's explanations during diagnosis and follow-ups and did not really have any need for further information. Two issues which were continuously recurring from the participants' interviews. The first was their repeated assertions of the need for receiving some sort of education on what complementary or alternative medicine that they could take, especially since they received a lot of contradictory advice on this matter.

"… my GP told me I must take vitamins during my cancer treatment. Every day one friend or another will tell me about some new supplement. After a few months when I see the government doctors treating me, and got so many of them… each them tell me different things whether can or cannot… I now just gave up and not taking any supplements…" (Respondent 9)

The second was that almost half the respondents voiced out that they had concerns over their activities related to daily living. Many of them expressed that they were keen to learn about the modifications they needed to implement in terms of their daily lives, and not directly related to clinical care. This included queries on what they could and could not eat; whether and when they could go back to work, should they stay out of crowds in between chemotherapy treatment cycles; when would they be able to exercise and how much they would be able to do; and whether after surgery should they be able to carry small children.

"… I really loved to eat durians and I was worried whether it would be too hot for me. I won't be able to see my doctor till two months more and I am tensed whether or not I can eat (durians) or not…. Everyday people are buying and eating in the house, why they didn't tell me whether or not I can eat?" (Respondent 22)

Some of these questions seemed to be minor in nature; but when asked to enumerate on how many questions they had in total at any one time, most of the respondents said that they had between 20 to 25 such questions in a week. Three respondents even had a specific notebook for which they wrote down questions and looked for answers to these questions when they went to see their doctors or other healthcare professionals.

The concern for most of them were that the difficulty in getting these questions answered since there were gaps (about 2 months on average) between them seeing their healthcare team meant that they had a lot of uncertainty, which subsequently caused a lot of anxiety for them in their daily lives. On top of their existing concerns about their cancer and treatment, this was an added psychological burden.

" As it is every day I wake up in the morning not knowing whether tomorrow I am going to be alive or not. I am not sure whether the chemo(therapy) will manage to kill the

cancer cells. I am unsure whether the cancer will come back after treatment…. also now I must worry about whether I can drink soya bean, can I walk in the sun, can I eat meat…. So many things that I might just die from worry rather than the cancer…" (Respondent 5)

5.3.3 Emotional and Psychosocial Management Needs

Another area of educational need that was highlighted by almost 80% of the respondents (18/23) was in the areas of emotional and psychosocial management. The respondents all had experienced varying degrees of psychological stress and disease especially during their early days and weeks after diagnosis. For at least half of them (12/23) anxiety, depression and other emotional-control issues continued to be of major concern even in their current daily lives. Some kind of formal education programme that would help provide techniques on how to reduce stress, control and manage their emotions and enable them to deal with anxiety was vocalised by almost all of them (22/23).

" Some days, I get up and cry. Some days, I just feel so angry. I shout at my daughter and son for no reason. After that I am so disgusted with myself for doing that to them. But I not it's just me hitting out…. I wish someone would teach me how to control all these…." (Respondent 1)

"My doctor told me I might feel depressed. She told me to see a psychologist… get an appointment if I was feeling down…. I got an appointment to see (the psychologist) but it's in 2 months…. So I am just googling and watching videos online to see how to calm myself down, how to improve my mood…." (Respondent 16)

Curiosity also proved to play an important role in the mental makeup of the respondents. About a third of the respondents (7/23) reported that they were very curious about their disease and spent a lot of time searching online and offline for various informational material. Among material that they reported searching for was i) alternative therapies; ii) new treatments for their cancer; iii) calming techniques; and iv) motivational strategies. 5/23 of the respondents mentioned that they were not so good at electronic media/internet so they did similar searches but offline, talking to friends, neighbours and even acquaintances as they searched for information on these similar topics. Most respondents (18/23) stated, however most of the time they became frustrated and even more upset as they were not able to find relevant, useful knowledge which they could use for themselves, especially in the areas of mental health. Most often than not, they shared, these were offered as paid services by professionals rather than educational knowledge that they could learn and subsequently practice by themselves.

“ No one is willing to teach me to handle my anger, or my confusion…. All they ask is that we go to the counsellor for sessions… each session is RM 100 something…. Sometimes I wonder can’t anyone teach me how to do this myself. Isn’t that better? (Respondent 10)

20/23 of the respondents felt that they needed to be given some sort of educational module on the various social aid available, be it from the government or from other sources. No one, they alleged, ever shared on what aid could be accessed by them. This was something that was most often picked up by them on the fly, and was especially difficult for those who attested to being in the lower socio-economic groups. 17/23 respondents identified with having financial hardships which has been worsened by the Covid-19 situation and now, their cancer as well. They felt that a great burden would be lifted if they could be provided with material on what type of financial aid was available and how to apply and receive it. This, they felt, would be tremendously helpful since they would then be able to reduce their stress levels and impact their mental health as well as being an important step in them being able to be better equipped to deal with their cancer treatment.

"My cancer diagnosis on top of this entire Corona (Covid-19) thing has been a nightmare…. my son also lost his job and is staying with us. Sometimes I get wassap (WhatsApp messages) that this office is giving financial aid, so I drop everything and run there…. but usually this is old information…(or even) fake news… but I drive Grab so now I lost that day's income. Can't the hospital tell us what (aid) to get and where to get it? " (Respondent 3)

5.4 Current Delivery of Disease-Related Educational Needs

This theme contained within it two sub-themes namely about self-related issues and system-level delivery.

5.4.1 Self-related issues

Almost all the respondents (22/23) had severe complaints about being not able to understand the terminology and language used when explaining their disease to them. Only 3/23 of the respondents worked in a job that was healthcare or healthcare-related; and even these three individuals mentioned that they could not understand totally the information being provided to them. 16/23 of the individuals had received higher education but the comments on difficulties in understanding proved to be similar from them as well.

“ I never even went to science stream before. I went to the arts stream. Suddenly the doctor was explaining all these terms in some science language. Some colo something something oma and what cell… I was lost already…. My wife had to stop and ask the doctor again, sorry doctor is this cancer?” (Respondent 4)

A major part of them (15/23) also acquiesced that they were quite overwhelmed over the diagnosis and merely nodded when asked on whether they understood the terms, stages of treatment and other medical information being passed on to them by the doctor or nurse. One respondent said that when he got up the next day, he could not even remember a single thing due to this. Another respondent was the only one of the whole group sampled who recalled writing down everything that was said during the consultation and was able to recall it up to the period of this interview. Four of the participants agreed that the trauma of the entire process may also have contributed to them being unable to remember information pertaining to the disease.

“I don’t even want to remember I have cancer! How (do) you want me to remember about the treatment and all the things to do?” (Respondent 13)

Other than the confusion of receiving information in scientific terms that they could not understand, some respondents also stated that they had a language barrier. 6/23 of the respondents professed to be poorly proficient in Bahasa Melayu or English and this was a barrier for them in terms of receiving and understanding the information provided to them. Interestingly, 5/23 of the patients who spoke Malay as their first language also reported similar language barriers. They said that the doctors did speak to them in Malay but the terms they used were still in English and so they did not manage to understand what was being said to them.

“ The doctor was a nice young Malay guy who was respectful to me. He spoke Malay, but he kept on telling me the terms in English. I kept on having to interrupt him and ask him what this meant, then he would stop, think and tell me in a way I could understand… but after a while I think he got irritated, so I also stopped asking…” (Respondent 11)

5.4.2 System-level delivery

More than half of them (15/23) declared that they recall having being given some kind of information about the symptoms of their disease; i.e what kind of health problems they were expected to have because of the cancer itself by a healthcare professional during their diagnosis. However, on average, this information was shared as part of the consultation, and lasted less than fifteen minutes. Only 2 respondents who were followed-up in the private sector had a different experience where the doctor spent more than half-an-hour with them during that session and subsequently had another session with them after a week to discuss and share information more completely to them.

“ My doctor was nice, but the small room itself had two other patients and two nurses. She was trying hard to manage all of us. She took some time to tell me and drew a little on a paper to explain something. But it was hot, noisy and loud. She was talking to me while filling in forms, arranging other dates for my treatment and also signing other patients’ forms.” (Respondent 20)

Some respondents (7/23) raised their concern that the doctors or nurses who discussed their condition with them did not have a prepared manual or scheme to follow when they were providing information to the respondents during their diagnosis. 19/23 respondents shared that during the entire information provision process, their doctors often went back and forth between explanations, which the respondents felt may have confused them as well. There were also concerns on whether there were things that they may have missed out in discussing with the respondents about their disease.

" I don't want to blame the doctors lah, pity them. They are running around and doing so many things and then need to explain to us also. But my doctor kept on saying, haiya lucky I remember, and then would add one more point…. and then again he did it, and again…" *(Respondent 17)*

Respondents also shared that very few of them (4/23) received brochures or other material on their disease. Amongst those who did, this were not brochures done by the hospital but from some other organisation including cancer societies or support groups. Most of the doctors merely mentioned to them that you can google and look for more information. Only one of the respondents followed-up in private said that the doctor gave her a printed page with different websites and what could be found on them. However, 7/23 of the respondents also recall that within the same conversation or at a different follow-up date, the doctors would be quite sceptical if they asked them questions based on Internet sources. Some of the respondents shared that when they did have and ask questions during follow-up sessions, the doctors would answer one or two questions and then go on as they were rushing for other patients.

" Very confusing lah. First they (doctor or nurse) told me uncle if don't know anything can search from Internet. Then next appointment I brought one list of questions I not sure (was unsure) of from the Internet, the doctor scold (ed) me. He said why you go and search the Internet. So much of false news lah, then you are confused, how?"
(Respondent 15)

During follow-up sessions also, respondents shared that there was no new information shared with the patients. In fact, most of them (18/23) thought that information about their progressive stage of treatment, if shared with them at that time, would have been of benefit. Respondents remarked that at follow-up sessions, doctors would merely check if they had any questions but not share new information.

" At follow-up, they (doctor) would ask if got questions. If not, that was it." (Respondent 2)

Respondents who had peer-support services in the hospital that they were being treated in had a huge number of additional benefits in terms of information provision. 5/23 of the respondents received peer-support, which was hospital-based. They were usually offered peer support right after they met the doctor/nurse before they went to collect medication or sometimes these peers (these are usually cancer patients who have finished treatment and work as volunteers) gave them a separate appointment which they then attended. Respondents reported that the peers were able to give them much more time, describe the terms and details about the treatment process in language that they could understand and also were able to be contacted outside the appointment times to clarify any and all questions they had.

" My peer counsellor has been more like a sister to me… or even a mother. She helped us so much with the whole process of treatment. The first time, I spent 2 hours as she patiently explained all the things to me about my cancer. She calls me every two weeks to see if I need something and I can ask her all the things I need" (Respondent 6)

5.5 Expectations of Disease-related Educational Needs

This theme contained within it two sub-themes namely fulfilment of current disease-related educational needs delivery and suggestions of disease-related educational needs.

5.5.1 Fulfillment of current Disease-related Educational Needs delivery

This sub theme of discussion centred around the respondents' thoughts on whether they felt their educational needs had been fulfilled throughout their cancer treatment journey, functioning as a subjective assessment of sorts. About two-thirds of the respondents (16/23) felt that they had received some sort of education, whether it was in person or by being given printed material which they could read. However, with the exception of the respondents who had been able to access peer-support, most of them were ambiguous on how effective these interventions had been.

In terms of those respondents provided with printed educational material, they felt that most of the time, brochures and other printed material were just provided without explanation. Another criticism was that for some of them, the brochures themselves were difficult to understand and most of the time, respondents reported they kept it at home without really reading it.

" They (healthcare team) told me outside the door (of the consultation room) there would be a rack with brochures and booklets. They told me to take what I wanted and everything I needed would be there. When I went (to the rack) I couldn't even find one in English, but there was some in Chinese… I don't read Chinese…" (Respondent 18)

The respondents also were very appreciative of the time that healthcare professionals who were treating them took to explain things to them, but raised concerns that it was difficult for them to understand and remember most of the things told to them at diagnosis. At least half the respondents voiced out that these professionals' tasks was not to 'teach' them and because they were forced to also take on this role, they couldn't perform their clinical tasks properly. Some respondents also stated that because these professionals were not trained to 'teach' the patients, they were not able to do it in a proper way as well, and if the task of educating patients was going to be handled by the treating healthcare professionals, they needed to be trained on how to carry it out properly.

" I am a retired teacher for more than 30 years. I pity the doctors and nurses who have to give the information for us to remember when I try to put myself into their shoes. In one session they try to teach us, they also have no clue how to teach and what material can share and cannot share…. It's no wonder that patients can't learn…" (Respondent 21)

5.5.2 Suggestions of Disease-related Educational Needs

A common suggestion that many of the respondents had (19/23) was to have a structured set of educational modules for different types of cancer, which could be provided to the doctors or nurses so that they could use those modules to teach the patients. Continuing along this context, each lesson in the module was suggested to have limited content and be relevant for the patient's following type of treatment. 5/23 of the respondents suggested that this kind of educational module could be provided through their phones, even perhaps through social media channels such as WhatsApp.

In this way, respondents felt that they could be provided with a form of continuous education.

"Why don't they send some video or picture (infographic or poster) through WhatsApp every day. WhatsApp is free and all of us use it. I get so much of helpful information from WhatsApp. That way, I can remember also and can check back if I forget." (Respondent 23)

Another suggestion that more than a third (7/23) of the respondents shared was on the need to have a specific person carrying out the tasks of educating patients, and the thought that this needed to happen at their clinical appointment time. In this way, respondents felt that they would have the time to engage patients individually and cater to their learning needs. Respondents did understand about the challenges in having such personnel, especially amongst Ministry of Health under-staffing conditions, but shared ideas on how retired nurses could be offered some sort of allowance to come back and do these tasks,.

Respondents also felt that as their treatment was ongoing, so should their learning about the changing conditions. Merely one session at diagnosis and subsequently at follow-ups would not be adequate, they felt, to be able to cover the wide spectrum of topics and information that needed to be shared. One respondent even raised the issue of using evaluations so that the educators could assess on whether patients actually understood the material that was being provided or taught to them.

22/23 respondents agreed that improving delivery of educational information pertaining to their cancer was extremely important for them in order to be able to manage their disease well over the long run.

“ I also have diabetes and am seen in a university hospital. Every now and then I have to attend sessions with the diabetes nurse educator. She teaches me and checks on different things concerning my diabetes to see whether I know how to give my insulin, for example, or how to check my feet to see there are no wounds…. Everything is planned and regular… she showed me she even has a book with schedules when she has to teach me what… cancer must have this too...” (Respondent 8)

5.6 Discussion

This study explored the educational needs of newly diagnosed cancer patients in learning about cancer. From the study, it was determined that newly diagnosed cancer patients had certain educational needs at the point of diagnosis, different ongoing educational needs during their treatment process; and educational needs in terms of their emotional and psychological management. The fulfilment of these educational needs which were looked at partially fulfilled due to inherent challenges within patients themselves as well as challenges in the current delivery mechanism from the health system. Newly diagnosed cancer patients also have certain expectations of how delivery solutions of their educational needs should be structured as well as specific suggestions on what these delivery solutions should look like. The following paragraphs will analyse and offer an interpretation of the results obtained in the study as well as to offer recommendations for future research and policymaking in this arena.

5.7 Analysis of the Results

The respondents of the study were mostly aware that they needed some form of education during their treatment journey. As a matter of fact, they were also able to distinctly separate these educational needs separately into different segments; based on where they were in the treatment journey as well as separating out different components such as emotional and psychosocial management.

Knowles' Adult Learning Principles (Knowles, 1980) outlines that one of the key learning principles for adults is that they learn best when they have a perceived need.

This input from the respondents validates the principle. When the respondents i.e. patients realised that this was part of them being able to fight their disease, they immediately perceived of the need to learn. This would enable them to be able to readily learn, as corroborated by even those who were initially distraught by the bad news given to them that they had cancer, but rebounded quickly to see that this was a critical step for them in managing the disease.

Table 5.2 Knowles Adult Learning Principles (Knowles, 1980)

Principle	Description
1	Adults learn best when there is a perceived need
2	Teaching of adults should progress from the known to the unknown
3	Teaching of adults should progress from the simpler concepts to more complex topics
4	Adults learn best using active participation
5	Adults require opportunities to practice new skills
6	Adults need the behaviour reinforced
7	Immediate feedback and correction of misconceptions increases learning

The premise from this study that patients wanted to learn because they perceived the need to learn is, in fact similar to results of studies conducted in other settings. In a survey of 100 patients who were hospitalised in a US hospital with an infection caused by a serious multi-drug resistant organism, for example, 98% of the study participants thought that patient's role in learning about their disease was important (Gudnadottir, U. et al, 2013). In addition, 94% of the patients thought that learning about their disease would definitely help them in making choices that would improve their care (Gudnadottir, U. et al, 2013).

However, many of the respondents balanced this perceived need by many different self-limitations. First amongst this was the challenge of dealing with complex terminology and the fact that they had no background in the area of medicine, especially in cancer. These findings are valid and indeed have a strong theoretical foundation when looked at through the lens' of Ausubel's Assimilation Theory (Ausubel, D., 1985) and Vygotsky's Zone of Proximal Development (Chaiklin, S., 2003).

By their own admission, many of the respondents have no existing cognitive structure containing within it medical or even cancer related 'material'. Thus, exactly as Ausubel (Ausubel, D., 1985) theorises, it is difficult to incorporate new unrelated material as it will be a challenge to incorporate them into the existing cognitive structure. Specific anchoring ideas which are tailored to each individual patient is probably necessary in order to facilitate learning to occur for this patient. Similarly, applying Vygotsky's ideas of the Zone of Proximal Development into this study context reveals that the existing knowledge levels of the respondents i.e. patients were very far away from the 'new' knowledge being provided to them and so it was challenging for them to be able to learn (Chaiklin, S., 2003).

The findings that patients find it difficult to learn due to the lack of an existing framework of similar knowledge has also been reported in multiple other studies, as this correlated closely with the concept of health literacy- defined as how much individuals are able to find, conceptualise and understand information in a manner than enables them to make appropriate health decisions (Graham, S., & Brookey, J., 2008). Even the newly published Malaysia National Health and Morbidity Survey 2019 that similar conditions exist in the Malaysian setting with more than a third of Malaysian patients having low levels of health literacy (Institute for Public Health (IPH), 2020).

Respondents also reported challenges in understanding the language in which the information was delivered. This had two contexts; one where the respondent could not understand the language used to provide the learning; and second, where the respondent could not understand the context of the learning being provided, even when it was being provided in a language they understood. Freda, M. C. (2004) elaborates on this in her literature review where she expounds on various issues in patient education, citing both language and cultural context as patient education barriers similar to the findings in our study. While Freda says language issues are something which are inherently easily explainable, cultural contextual barriers are something which are not so easily elaborated on. ‘Culture’ is the shared practices, beliefs, customs and values of a particular group; and she contends that the ‘healthcare group’ already has a different ‘culture’ with the explanations from their contexts not easily understood by someone outside their culture such as a patient, for example (Freda, M. C., 2004).

More than a few respondents disclosed how they had little time and no structured delivery programme from their healthcare professionals. This is also a problem discovered in many other settings where healthcare professionals are not trained to teach or equipped to carry out patient education, in addition to being disincentivised to carry out the task (Farahani, M. A, 2013). In this Iranian qualitative study, for example, nurses reported that they were not given any sort of training or taught to understand patient educational needs; as well as work-related factors such as staff shortages and de-prioritisation of patient education delivery as challenges they faced at a system-level to provide education (Farahani, M. A, 2013). Although provider-side input was not obtained in this study, inferring from the respondents reflection leads the researcher to also postulate on whether similar conditions also abound here in the Malaysian setting, especially when it comes to cancer.

Another system-level barrier in terms of education for the patients seemed to be in terms of the provision of printed education material which respondents reported had difficulty understanding. New published work in patient education today also discusses the concept of readability, which discusses how capable patients are of comprehending patient education material (Jabbour, J. et al, 2017). Readability is a concept which measures how easily an individual can read and understand the written word and can be measured through mathematical formulas. Unsurprisingly, most material produced for patients are often unreadable by patients. In a cancer context, for example, a study in which 135 radiation-oncology related patient education materials were downloaded from 5 major professional websites and assessed for readability level found that only 1 out of the 135 was within readability recommendation levels (Prabhu, A. V. et al, 2016). Even though this study did not assess the readability of the printed material provided to the patients, deriving from their input it is not an impossibility that the readability of these material was far beyond their ability to read and understand.

Reid, J.C. et al (1995), contend that there is actually a dynamic pendulum between the readability of patient education material and the reader’s own characteristics which impeded the learning process. In the study they carried out, 26 adults with diabetes mellitus could only recall 8 out of 108 ideas in a commonly used diabetes pamphlet (Reid, J.C. et al, 1995),. The authors of that paper theorised that even when the readability of the material was appropriate, there was a challenge for patients who lacked cognition and memory skills (Reid, J.C. et al, 1995). This also has a strong theoretical underpinning when the idea of Pintrich's Metacognitive Knowledge Theory (Pintrich, P. R., 2002) is applied where the learner's own cognitive processes are critical in enabling them to learn. From the demographic variables of this study such as age, and the illness levels of the patients, it could be contended that their learning was also somewhat impeded due to challenges in their metacognition.

One of the shining examples of successful patient education in the context of this study was in terms of the glowing reports from respondents who had access to peer-support services where cancer patients who had completed treatment helped guide the respondents in terms of their educational needs. This is in keeping with the Bruner's concept of instructional scaffolding (Olson, D. R., 2014). In the context of the respondents' experience, the peer supporters functioned to guide the learner (respondent) to move along and expand their ZPD in terms of their cancer knowledge (Olson, D. R., 2014). Vygotsky also refers to a similar theoretical construct which may accurately depict the peers as being More Knowledgeable Others (MKOs), functioning to guide the respondent along their learning journey (Chaiklin S., 2003).

Respondents' input on suggestions to improve the learning delivery and what they learn included i) having a structured set of educational modules which was simple and continuously delivered; ii) use of e-media as a form to deliver content; iii) have specific trained professionals to deliver the learning which needed to be ongoing. The input from this study has been found in other settings, where patients were found to have preferred internet-based educational material which were short and available in multiple formats including in written form, video form and even face-to-face delivery (Gudnadottir, U. et al, 2013).

Various studies have investigated the use of 1-to-1 teaching for patients and found it not to be cost-effective; however, the use of group teaching seems to highly effective and cost-efficient as well (Rodgers, C.C et al, 2016). The use of videos to teach has also been found to be effective for patient education, especially for populations that are of low-literacy (J. Yap et al, 2019) . The effectiveness of video-based delivery of education; however needs to be balanced by the use of facilitators who can then clarify and answer questions compared to when videotapes are played in waiting rooms, which then have been found to be ineffective (Freda, M. C., 2004).

In a cancer-specific context, for example, a systematic review reviewing the effectiveness of patient-based educational interventions to improve cancer-related pain found that multiple educational interventions including the use of videos and booklets together; education or coaching programmes, face-to-face sessions, written material; video-taped material and/or phone calls were all effective in their respective settings (Oldenmenger, W. H., 2018). The authors of the review concluded that well-designed multi-modal educational interventions for patients' are effective when tailored based on the preference and ability of patients (Oldenmenger, W. H., 2018). Like in this study, patient preferences seem to be an important element of provision of patient education; and needs to be considered especially when it is to be effective.

CHAPTER 6 RECOMMENDATIONS AND CONCLUSION

6.1 Study Recommendations

From this study, one large recommendation that arises is the need for more research into developing structured, guided patient education modules in cancer in a Malaysian context.

Development of such patient education needs to fall back on the still highly relevant principle of adult education as first postulated by Knowles (Knowles, 1980). First, adult learners must always be appraised of the need for them to learn, and this is never more relevant in a disease management context. Patients need to be understand of the concept of Therapeutic Patient Education , where education forms an important component of the holistic treatment of a patient especially in chronic disease such as cancer (World Health Organization, 1998).

Second, the rules of teaching such as performing basic assessments in terms of evaluating existing knowledge levels before teaching the learner; and concepts such as progressing from simple concepts to complex topics should continue to hold true and be applied especially in the patient education context. The use of tools to assess cancer-specific literacy; or readability, for example can easily be used to guide the patient’s learning process.

Third, adult learning is closely linked to experiential learning. Patient education should thus be carried out in a similar manner. Rather than carrying out a face-to-face talking session as is the current practice, interactive, engaging sessions in which the patients are also participative needs to be created.

Fourth, adults require opportunities in which to practice new skills. Patients need to be provided opportunities in which they can do so. For example, teaching and observing them on how to count their medication or tick off a checklist of symptoms to watch out for are essential parts of ensuring that they are successfully engaged in learning.

Fifth, adults need behavioral reinforcement. Follow-up sessions should be used as an avenue to reinforce skills and knowledge taught in previous sessions and the use of e-media can also be used to modulate this.

Sixth, learning is increased in adults when immediate feedback and corrections of misconceptions are carried out in a routine manner. The practice of getting patients to restate what they have been taught as well as what they already know of this topic helps to address the huge issue of misconceptions, pseudoscience and fake news prevalent in the healthcare landscape as well as to strength the learning being provided.

Unfortunately, while the principles of education are easily translatable into the patient education context, there remains a huge burden in terms of the resources required to adequately design, deliver and evaluate such educational interventions within the clinical landscape.

This requires a reallocation of resources, both fiscal and in terms of human resource to be able to provision and provide patient education in a manner than it can be effective. The management of life-long chronic disease patients has evolved to encompass multiple dimensions beyond clinical therapeutics. Patient education is one of those components, needing adequate resources, time and research to properly be developed and delivered in order to be effective.

6.2 Strengths of the Study

This study is one of the first studies exploring the educational needs of newly diagnosed cancer patients in the Malaysian setting. Since there are no structured patient educational models in cancer, this study is especially relevant in exploring the landscape and seeking to understand on whether this patient population's educational needs are being taken care of. In addition, the design of the study has been carried out to intentionally rope in as diverse a population of cancer patients as possible from different types of cancers; as well as using sub-groups to ensure that the input of different groups are able to be triangulated across the disease spectrum. The use of maximum variation sampling also ensures that the study attempts to cast a wide net in terms of respondents' and their input, thus increasing the validity. All these measures work in tandem to reduce the inherent biases of the study and increase its validity and reliability.

6.3 Limitations of the Study

As this was a qualitative study, there were some inherent design shortcomings which were a weakness of the study. The findings of this study cannot be extended to wider populations since these findings cannot be quantifiably assessable and thus it cannot be dismissed that these findings are merely due to chance. For example, since this study was only carried out in an urban setting, the findings from it may not reflect the ideas and input from cancer patients in a rural setting. In addition, analysis of qualitative data may be ambiguous due to the subjectivity in terms of interpretation of the language of the respondents in terms of their intended meaning.

6.4 Conclusion

In conclusion, newly diagnosed cancer patients in the Malaysian urban setting have multiple educational needs, which are being fulfilled in part. There are multiple challenges which are present and may act to impair the provision of effective delivery of solutions which can help to completely fulfil the educational needs of these patients. Further comprehensive research is needed to be able to determine exact needs of various populations of different cancer patients in different settings; develop specific tailored educational interventions to fulfil their needs and sustainably deliver them in a system-wide setting for the entire Malaysian population afflicted by cancer.

REFERENCES

American Academy of Family Physicians. (2000). AAFP core educational guidelines: Patient education. *American Family Physician*, *62*(7), 1712-1714.

Ausubel, D. (1985). Learning as constructing meaning. *New directions in educational psychology*, *1*, 333.

Atkinson, R. C., & Shiffrin, R. M. (1968). Human memory: A proposed system and its control processes.

Brady, E. M. (1984). Demographic and Educational Correlates of Self-Reported Learning among Older Students. *Educational Gerontology*, *10*, 25-38.

Bhoo-Pathy, N., Yip, C. H., Peters, S. A., Kimman, M., Sullivan, R., Jan, S., ... & Balete, S. L. (2017). Policy and priorities for national cancer control planning in low- and middle-income countries: Lessons from the Association of Southeast Asian Nations (ASEAN) Costs in Oncology prospective cohort study. *European Journal of Cancer*, *74*, 26-37.

Chaiklin, S. (2003). The zone of proximal development in Vygotsky's analysis of learning and instruction. *Vygotsky's educational theory in cultural context*, *1*, 39-64.

Chelf, J. H., Agre, P., Axelrod, A., Cheney, L., Cole, D. D., Conrad, K., ... & Villejo, L. (2001, August). Cancer-related patient education: an overview of the last decade of evaluation and research. In *Oncology nursing forum* (Vol. 28, No. 7).

Courtney, S. (2018). *Why adults learn: Towards a theory of participation in adult education*. Routledge.

Darkenwald, G. G., & Hayes, E. R. (1988). Assessment of adult attitudes towards continuing education. *International journal of lifelong education*, *7*(3), 197-204.

Davis, T. C., Crouch, M. A., Wills, G., Miller, S., & Abdehou, D. M. (1990). The gap between patient reading comprehension and the readability of patient education materials. *J Fam Pract*, *31*(5), 533-538.

Davy, C., Bleasel, J., Liu, H., Tchan, M., Ponniah, S., & Brown, A. (2015). Effectiveness of chronic care models: opportunities for improving healthcare practice and health outcomes: a systematic review. *BMC health services research*, *15*(1), 1-11.

Faury, S., Koleck, M., Foucaud, J., M'Bailara, K., & Quintard, B. (2017). Patient education interventions for colorectal cancer patients with stoma: A systematic review. *Patient education and counseling*, *100*(10), 1807-1819.

Farahani, M. A., Mohammadi, E., Ahmadi, F., & Mohammadi, N. (2013). Factors influencing the patient education: A qualitative research. *Iranian journal of nursing and midwifery research*, *18*(2), 133.

Freda, M. C. (2004). Issues in patient education. *Journal of Midwifery & Women's Health*, *49*(3), 203-209.

Gudnadottir, U., Fritz, J., Zerbel, S., Bernardo, A., Sethi, A. K., & Safdar, N. (2013). Reducing health care-associated infections: patients want to be engaged and learn about infection prevention. *American journal of infection control*, *41*(11), 955-958.

Graham, S., & Brookey, J. (2008). Do patients understand?. *The permanente journal*, *12*(3), 67.

Harvey, P. W., Petkov, J. N., Misan, G., Fuller, J., Battersby, M. W., Cayetano, T. N., ... & Holmes, P. (2008). Self-management support and training for patients with chronic and complex conditions improves health-related behaviour and health outcomes. *Australian Health Review*, *32*(2), 330-338.

Howell, D., Harth, T., Brown, J., Bennett, C., & Boyko, S. (2017). Self-management education interventions for patients with cancer: a systematic review. *Supportive care in cancer*, *25*(4), 1323-1355.

Horner, S. D., Surratt, D., & Juliusson, S. (2000). Improving readability of patient education materials. *Journal of community health nursing*, *17*(1), 15-23.

Institute for Public Health (IPH), National Institutes of Health, Ministry of Health Malaysia. (2020). National Health and Morbidity Survey (NHMS) 2019: Vol. I: NCDs – Non-Communicable Diseases: Risk Factors and other Health Problems

Jabbour, J., Dhillon, H. M., Shepherd, H. L., Sundaresan, P., Milross, C., & Clark, J. R. (2017). Challenges in producing tailored internet patient education materials. *International Journal of Radiation Oncology• Biology• Physics*, *97*(4), 866-867.

Koo, M., Krass, I., & Aslani, P. (2006). Enhancing patient education about medicines: factors influencing reading and seeking of written medicine information. *Health expectations*, *9*(2), 174-187.

Knowles, M. S. (1980). The modern practice of adult education.

Krau, S. D. (2011). Creating educational objectives for patient education using the new Bloom’s Taxonomy. *Nursing Clinics*, *46*(3), 299-312.

Lane, D. S., & Evans, D. (1979). Measures and methods in evaluating patient education programs for chronic illness. *Medical Care, 17*(1), 30-42.

McGrath, C., Palmgren, P. J., & Liljedahl, M. (2019). Twelve tips for conducting qualitative research interviews. *Medical teacher, 41*(9), 1002-1006.

McGowan, P. (2011). The efficacy of diabetes patient education and self-management education in type 2 diabetes. *Canadian Journal of Diabetes*, *35*(1), 46-53.

Newman, E. J., & Loftus, E. F. (2012). Updating Ebbinghaus on the science of memory. *Europe's Journal of Psychology*, *8*(2), 209-216.

Olson, D. R. (2014). *Jerome Bruner: The cognitive revolution in educational theory*. Bloomsbury Publishing.

Oldenmenger, W. H., Geerling, J. I., Mostovaya, I., Vissers, K. C., de Graeff, A., Reyners, A. K., & van der Linden, Y. M. (2018). A systematic review of the effectiveness of patient-based educational interventions to improve cancer-related pain. *Cancer treatment reviews*, *63*, 96-103.

Pintrich, P. R. (2002). The role of metacognitive knowledge in learning, teaching, and assessing. *Theory into practice*, *41*(4), 219-225.

Prabhu, A. V., Hansberry, D. R., Agarwal, N., Clump, D. A., & Heron, D. E. (2016). Radiation oncology and online patient education materials: deviating from NIH and AMA recommendations. *International Journal of Radiation Oncology* Biology* Physics*, *96*(3), 521-528.

Polishchuk, D. L., Hashem, J., & Sabharwal, S. (2012). Readability of online patient education materials on adult reconstruction web sites. *The Journal of arthroplasty*, *27*(5), 716-719.

Reid, J. C., Klachko, D. M., Kardash, C. A. M., Robinson, R. D., Scholes, R., & Howard, D. (1995). Why people don't learn from diabetes literature: influence of text and reader characteristics. *Patient education and counseling*, *25*(1), 31-38.

Ritsema, T. S., Bingenheimer, J. B., Scholting, P., & Cawley, J. F. (2014). Peer Reviewed: Differences in the Delivery of Health Education to Patients With Chronic Disease by Provider Type, 2005–2009. *Preventing chronic disease*, *11*.

Rodgers, C. C., Laing, C. M., Herring, R. A., Tena, N., Leonardelli, A., Hockenberry, M., & Hendricks-Ferguson, V. (2016). Understanding effective delivery of patient and family education in pediatric oncology: A systematic review from the Children's Oncology Group. *Journal of Pediatric Oncology Nursing*, *33*(6), 432-446.

Sweller, J. (2011). Cognitive load theory. In *Psychology of learning and motivation* (Vol. 55, pp. 37-76). Academic Press.

Lindner, H., Menzies, D., Kelly, J., Taylor, S., & Shearer, M. (2003). Coaching for behaviour change in chronic disease: a review of the literature and the implications for coaching as a self-management intervention. *Australian Journal of Primary Health*, *9*(3), 177-185.

Vallis, M., Lee-Baggley, D., Sampalli, T., Shepard, D., McIssaac, L., Ryer, A., ... & Manley, S. (2019). Integrating behaviour change counselling into chronic disease management: a square peg in a round hole? A system-level exploration in primary health care. *Public health*, *175*, 43-53.

World Health Organization. (1998). *Therapeutic patient education: continuing education programmes for health care providers in the field of prevention of chronic diseases: report of a WHO working group* (No. EUR/ICP/QCPH 01 01 03 Rev. 2). Copenhagen: WHO Regional Office for Europe.

Yap, J., Teo, T. Y., Foong, P., Binte Hussin, N., Wang, H., Shen, T., & Yeo, K. K. (2019). A randomized controlled trial on the effectiveness of a portable patient education video prior to coronary angiography and angioplasty. *Catheterization and Cardiovascular Interventions*.