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Health Literacy for Health Behaviour Change—A Study of Cancer Survivors in Nairobi Support Groups

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Abstract

With the increase of Non-Communicable Diseases (NCDs), Health literacy has emerged as a strategy in improving patient self-care behaviour resulting in reduced morbidity and mortality. As such policy documents have been developed resulting to the integration of patient education in health management systems. This study was conducted with the purpose of assessing specific ways in which health literacy has influenced health behaviour change amongst cancer survivors. Through a survey, a sample of 115 cancer survivors in Nairobi County was interviewed with the use of Semi structured questionnaires and data analyzed using SPSS. Results indicated that most of the respondents were motivated to practice health behaviour due to direct health and medical benefits. In addition, many expressed their confidence in their ability to keep up with health practices inculcated through the health literacy program. However, existing socio-economic challenges delayed the taking up of health practices. This study concluded that health literacy generally produces positive results when articulated in an environment that takes into consideration social and economic factors that could influence individual health habits.

Keywords

Health Literacy, Health Behavior

1. Introduction

Non-communicable diseases (NCDs) such as cancer, have seen an upsurge over the last decade accounting for 71% of deaths globally (World Health Organiza-*First author.

tion, 2020). In Kenya, an estimated 47,887 new cases of cancer annually with a mortality of 32,987 were reported in 2018 (National Cancer Institute, 2022). As a means of mitigation, health professionals have promoted health literacy as a tool of improving patient self-care behaviour and adoption of healthy lifestyles that ultimately reduce adverse effects of non-communicable diseases such as cancer. This has primarily been through; designing health education materials, group discussion forums, doctor-patient discussion sessions, community health volunteer-patient discussion and support discussions on a regular basis (Robat Sarpooshi et al., 2020).

In this view, the government of Kenya through the Ministry of Health has developed policy documents that outline the need to promote positive health behaviour through the use of available information resources that educate individuals on health practices (Ministry of Health, 2012, 2014). To this effect, several nonprofit organizations have supported this strategy and facilitated the rollout of health literacy programs for cancer patients, both at health facility and community levels. By working through organized groups commonly referred to as support groups, these organizations create opportunities for regular dialogue between cancer health care professionals and patients undergoing cancer management (Batterham et al., 2014). Through this interrelationship, cancer patients not only receive social support, but are presented with the opportunity of accesing correct and updated health information.

Despite this globally accepted approach in cancer management, there is need to understand how health literacy information influences specific health behaviour amongst beneficiaries. This paper presents findings on specific health behavior amongst a sample of cancer support group members who were regular recipients of health literacy.

1.1. Social Groups Influence on Health Behaviour

The study of human behaviour has been an area of interest for a wide spectrum of researchers in both social and physical sciences. Sociologists define human behaviour as a set of actions produced from an individual's interaction with their social environment (Fabrigar, 2017). It focuses on people's deliberate actions in regards to their health status taking into account the different dimensions of health-related practices such as; disease prevention, early treatment of disease and finally disease management (Amzat & Razum, 2014). In this process, cognitive determinants beyond the self are engaged with the potential to shape and pattern adoption of certain actions, which promote or compromise an individual's health (Short & Mollborn, 2015). These cumulative actions produce experiences that bear positive or negative effects on their health and wellbeing. Examples of actions describing health behaviour pertain to practices related to; sleep, diet, sexual behaviours, physical exercise, medication adherence. Factors influencing health behaviour could emanate from the self or within the social environment of the individual (Short & Mollborn, 2015). Of the two factors, social determinants have been defined as the most powerful because they interact with other factors within social settings such as work places, institutions or neighborhoods which offers a significant influence in the development or maintenance of health behaviour (Swain, 2016, 2017). These factors are associated with social structures and networks such as neighborhoods, community groups in which individuals belong to and regularly interact with or receive information from (Rothman et al., 2017). These interactions have the capacity to influence health behaviour of individuals, as well as support long term behaviours (Conner & Norman, 2017). This study focused on social networks such as cancer support groups that provide health literacy information, as well as social support to members in the utilization of health behaviours that contribute to their wellbeing (National Cancer Institute, 2019). Despite health behaviour receiving acknowledgement as critical component of non-communicable disease intervention, its validity as an outcome has not always received scrutiny. In most cases, processes related to intervention in disease management receive more focus than understanding the end result which is health behaviour (Cohn, 2014). It was of interest to this study to understand how this information was utilized and reinforced by support groups, that act as social networks with the potential to create desired behaviour changes.

1.2. Health Literacy Influence on Health Behaviour

Health literacy is linked to the awareness, motivation, and competence of people in accessing, understanding, appraising, and applying health information (He et al, 2016). Several studies indicate the relationship between health literacy and health behaviour. Aaby et al. (2017) reported on a study of cardio vascular ailments and related this to the ability of patients to understand health information. Results suggested significant associations between health literate patients and; better weight control, the ability to actively engage with healthcare providers and abstinence from smoking. Cherik et al. (2018) also conducted a study on diabetic patients and determined that health literacy played a critical role in advocating for better health and wellbeing. This was related to delayed diabetic complications amongst health literate patients which were otherwise commonly experienced. A similar study was conducted in Denmark and results indicated that diabetic patients with little or no health literacy were least likely to engage in health practices like exercise, proper dietary habits (Friis et al., 2016). The above studies provide evidence on the effectiveness of health literacy as being measured upon an individual's execution of positive health behaviours (Conner & Norman, 2017). On the other hand, this means that mere provision of health literacy information does not guarantee its utilization by all recipients, since this information may not be processed or understood as intended (Nanna & Egbert, 2009). This could be experienced in instances health care workers may not have the time to explain health information due to overwhelming number of patients to attend to, while in other cases a patient's literacy levels may influence the quality of information, they are able to process. In this view, it is important to ensure that health literacy is provided in a practical and effective manner and results in anticipated health behaviour outcomes.

2. Theoretical Model

This study was be guided by the theory of planned behaviour and the health belief model which are health promotion theories. These theories are based on the principle that individuals strive to improve themselves and achieve wellbeing through the use of positive resources. Such resources include professionals, existing social networks, and information hubs that all contribute to motivating an individual into changing of health behaviour (Seibt, 2008). As such, these theories can be used in explain the outcome of deliberate health interventions such as health literacy programs and the outcomes on the health behaviour of support group members.

2.1. Theory of Planned Behavior

The theory of planned behaviour (TPB) was developed as a model of predicting and explaining behaviour building. This theory borrows from the theory of reasoned action, which assumes that humans engage in rational thoughts before undertaking actions of behaviour (Croyle, 2005). The theory of Planned Behaviour further postulates that individuals are more likely to engage in behaviour that they have belief in and have control over. Their level of control can be measured by the opportunities and resources to perform a behaviour, for example; time, money, information and knowledge, skills, cooperation of others. As such, the intention of pursuing a healthy behavioral course is determined by; the attitude towards the proposed behaviour, subjective norms and the perceived level of control of the intended action (Icek, 1991).

2.2. Health Belief Model

This model was developed with the view of understanding why people accepted or rejected disease prevention strategies or screening tests. This model proposes that an individual perception on the risks, costs, susceptibility and severity of the disease influence their accepting or rejecting screening tests (Jones et al., 2015). It is based on the understanding that the probability of an individual engaging in a health action is higher if they expect positive results and are confident in their ability to succeed (Boskey, 2020). This model was relevant to the study since it takes into account how individual behaviour is influenced by confidence in enhanced well-being as a result of healthy behavior.

2.3. Theoretical Principles Guiding Study

Principles from the theory of planned behaviour and health belief model were merged to provide a background for this study. These two frameworks demonstrated an interactive relationship between intrapersonal factors and behaviour, revealing dynamic factors that may influence individuals in engaging or abstaining from behaviour, despite receiving similar information. In this study, health lite-

racy information acts as a resource which can empower an individual to make decisions influencing their behaviour. In addition, it gives them the confidence needed to succeed following an action. However, for this to be achieved, an individual must conceptualize and process information before execution of an intended action (Marcus, 2014). This means that health literacy is not an end in itself but rather a process defining the interaction of knowledge and self to produce a behaviour change. Figure 1 summarizes the theories discussed in the study.

3. Methods

This study employed a quantitative research approach to understand the health behavior of cancer survivors in support groups that received health literacy in Nairobi County. The study site was identified due to its advanced cancer diagnostic and treatment facilities and host to cancer patient support programs that offer health literacy education in addition to other forms of support (Wambalaba et al., 2019). Ethical approval was sought from Kenyatta University Ethical Review Committee and The National Commission for Science, Technology and Innovation (NACOSTI). A semi structured questionnaire was used for data collection from a sample of 115 cancer survivors in Nairobi County. All data was cleaned, entered and analyzed in SPSS V 25.

4. Results

4.1. Importance of Health Behaviour

In this study, health behaviours measured were; diet, exercise, adherence to cancer treatment and management. Measurement of these variables was based on subjective sources, relying on respondent self-reporting. As presented in **Table** 1, most of the respondents (58.2%) mentioned that the primary reason for adhering to health behaviours was that it resulted to *reduced hospital visits*, while 31.6 percent were keen on *general improved well-being*. On the other hand, 7.2 percent perceived the most important reason for practicing health behaviour was to *comply with the doctor's direction* while 3 percent did it for *social acceptance*.

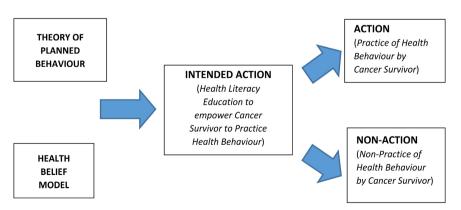


Figure 1. Model summarizing of study.

Table 1. Most important reason for practicing health behaviour.

Frequency*Percentage			
Most Import	ant reason for Practicing Health behaviour	Frequency	Percentage
Valid	Reduced Hospital Visits	67	58.2
	Improved Wellbeing	36	31.6
	Social Acceptance	3	3
	Compliance with doctors' advice	8	7.2
	TOTAL	115	100

These results indicate that most respondents were motivated to practice health behaviour due to direct health and medical benefits. Similarly, 77.6 percent of respondents felt in full control of the health behaviour choices they made, while 18.2 percent rated themselves as being in moderate control of their health behaviour as shown in **Table 2**. Only 3.2 percent percent perceived themselves as having little control while 1 percent did not have control of their health behaviours.

4.2. Nutrition and Diet

In this study respondents were asked to state the frequency of health activities they undertook in the different frequencies namely; "regularly", "sometimes" or "rarely". The practice of good dietary practices was regularly adhered to by 36 percent of respondents while 59 percent sometimes adhered to a good diet as shown in **Table 3**. Only 5 percent of respondents said that they did not adhere to proper nutrition and diet as encouraged during the support group meetings. A graphical presentation of this findings in shown in **Figure 2**.

4.3. Regular Exercise

In this study, 42 percent engaged in physical exercise on a regular basis while 40 percent sometimes maintained a physical exercise program. On the other hand, 7 percent rarely engaged in exercise while 11 percent said they never exercised as presented in **Table 4** and **Figure 3**.

4.4. Use of Alcohol

The abstinence from alcohol and drugs is a health practice recommended amongst cancer survivors. As indicated in **Table 5** and **Figure 4**, 89 percent of respondents had a regular practice of abstaining from use of drugs and alcohol, 11 percent abstained sometimes implying that they indulged in the use of alcohol some times.

4.5. Adherence to Treatment

In this study, 82 percent of respondents adhered to medication and treatment

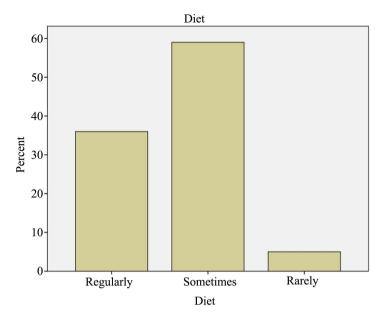


Figure 2. Practicing of proper diet and nutrition.

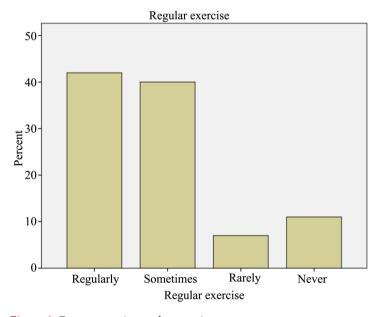


Figure 3. Engagement in regular exercise.

Table 2. Perceived level of Control on Health behavior.

	Frequency*Percentage			
Level of Con	trol on Health behaviour	Frequency	Percentage	
	Full Control	89	77.6	
X7 1: 1	Moderate Control	21	18.2	
Valid	Little Control	4	3.2	
	No Control	1	1	
	TOTAL	115	100	

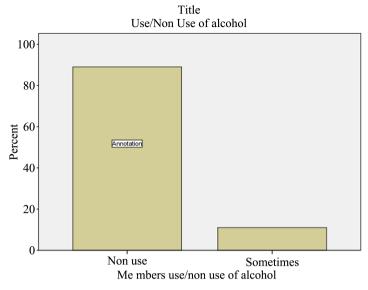


Figure 4. Use/non-use of alcohol.

Table 3. Practicing of proper diet and nutrition.

	Frequency*Percentage			
Proper Diet	and Nutrition	Frequency	Percentage	
	Regularly	41	36	
Valid	Sometimes	68	59	
	Rarely	6	5	
	Total	115	100	

Table 4. Practice of physical exercise.

	Frequency*Percentage			
Engaging in F	Physical Exercise	Frequency	Percent	
	Regularly	48	42.0	
77 1.1	Sometimes	46	40.0	
Valid	Rarely	8	7.0	
	never	13	11.0	
	Total	115	100.0	

Table 5. Practice of abstinence from alcohol.

Frequency*Percentage		
Use of alcohol and drugs	Frequency	Percentage
Sometimes	13	11
Never	102	89
Total	115	100

which involved; attending chemotherapy sessions, radiotherapy, taking medication and attending medical appointments as required, while 13 percent sometimes followed through with their treatment routines. Only 4 percent rarely adhered to treatment while 1 percent said they did not adhere to treatment. Those who adhered to treatment said they viewed it important since they hoped to regain their strength back, wanted to live longer, and had noticed an improvement while others hoped that the cancer would be cured. Respondents who said that they sometimes adhered to treatment attributed their irregularity to; busy schedules that made them skip doctor follow up appointments, the cost of treatment was high, a renewal of physical strength thus no need to keep some appointments, the completion of "major" treatment regimens thus giving a sense of wellness to the patient. A few said they sometimes skipped some treatment because of the negative side effects. However, only 3 percent said they rarely maintained their treatment patterns citing reasons such as; fearing the side effects of treatment or preferred to try out alternative herbal treatments. Table 6 and Figure 5 presents these findings.

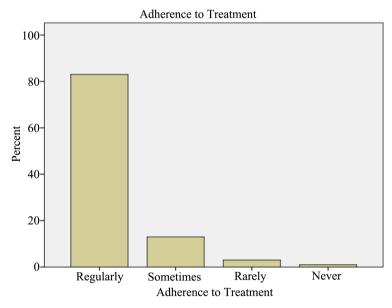


Figure 5. Adherence to treatment.

Table 6. Adherence to treatment.

Frequency*Percentage			
Adherence to Treatment	Frequency	Percentage	
All the time	94	82	
Sometimes	15	13	
Rarely	5	4	
Never	1	1	
Total		100	

5. Discussion

5.1. Importance of Health Behaviours and Social Support

In this study, health behaviours measured were; diet, exercise, adherence to cancer treatment and management. Measurement of these variables was based on subjective sources, relying on respondent self-reporting. Results indicate that most of the respondents were motivated to practice health behaviour due to direct health and medical benefits. This is reflected in previous studies that indicate that patients with long term illnesses who adhere to dietary and physical exercise requirements and as a result reported to have general well-being (Jayasinghe et al., 2016). In relation to the measure of control in practicing health behaviour, most respondents were confident in their abilities. In as much as individual will power is essential in making promoting positive health behaviour, the role of social reinforcements cannot be ignored. Wilf et al. (2019) conducted a study on diabetic patients that acknowledged the role of spouses in increased ability to manage self-care habits. As such the family, support group, neighborhood and other social environments can be enablers to exuding confidence in individual health decisions. These networks have the capacity to influence health behaviour of individuals, as well as support long term behaviours (Conner & Norman, 2017).

5.2. Nutrition and Diet

Proper nutrition and diet are considered essential elements in the health literacy program and the rigors involved in cancer treatment demand a healthy body to withstand the effects of cancer treatment regimes. This requires a comprehensive understanding of required food groups, recommended foods after treatment side effects (American Cancer Society, 2021). In this study respondents were asked to state the frequency of health activities they undertook in the different frequencies namely; "regularly", "sometimes", "rarely" or "never". Only 5 percent of respondents said that they did not adhere to proper nutrition and diet as received during the support group meetings unlike most of the respondents Further probes in this indicated that some of the reasons for not adhering to dietary advice was because some of the respondents could not afford proper nutrition, while others depended on family members to cook and could not always dictate the quality of meals, unavailability of some of the food options in some locations was also mentioned, while some alluded to preferring to maintain food options that they were used to regardless of their nutritional value. Understanding the reasons for adhering to proper diets should be of concern to all health care providers in health literacy programs. Toles & Demark-Wahnefried (2008) mention that health practitioners generally notice a sense of eagerness amongst most cancer survivors on acquiring knowledge about diet and nutrition. This could be due to the higher risk of comorbidities thus calling for increased attention on nutrition and diet. As such, there is need for regular evaluation of patient adherence to proper diet and provision of practical assistance. In addition, social support systems such as support groups should be used as forums to evaluate individual progress and discuss challenges to maintaining healthy diet programs.

5.3. Regular Exercise

Engagement in physical exercise has been regularly discussed in health programs as a strategy of increasing and maintaining vitality. Previous studies associate physical exercise with positive mental health outcomes and has been used to alleviate negative mood disorders associated with cancer treatment (Liska & Kolen, 2020). In this study, those who engaged in regular physical exercise said that they walked a lot and engaged in physical activities at home as a way to get fit. Those who did not regularly engage in physical exercise mentioned reasons such as; lack of morale, lack of time, absence of necessary equipment, not having an exercise partner, exercise not a priority as compared to diet, viewing exercise as a requirement for those who were fat or overweight. Previous studies have identified similar challenges in regular exercise amongst patients with NCDs. Albelbeisi (2021), who carried out a study on patients with Non-Communicable Diseases in Palestine, noted that although most (92.0%) of participants believed that by adhering to physical activity they would be in a position to manage their diseases and reduce comorbidities, a number still did not engage in physical exercise citing lack of exercise equipment and social support. These findings are further corroborated by the National Cancer Institute (2019), which revealed that not many of cancer survivors' exercise on a regular basis, despite evidence that points at the role of physical activity improving physical strength, endurance and daily energy levels. Despite these challenges the importance of regular exercise cannot be undermined as noted by a number of key informants who emphasized that cancer survivors should be more careful about their weight and physical status as compared to before in order to avoid developing other ailments. This calls for deliberate efforts in improving the level of involvement of patients in physical activity. It is thus suggested that exercise programs should be designed and fit to a patient's abilities and needs such as age, type and staging of cancer (National Cancer Institute, 2019). More so, public awareness on the importance of physical exercise amongst survivors in support groups can provide social impetus to support individuals and programs designed to facilitate exercise.

5.4. Use of Alcohol

The abstinence from alcohol and drugs is a health practice recommended amongst cancer survivors. In this study, 89 percent of respondents had a regular practice of abstaining from use of drugs and alcohol, 11 percent abstained sometimes. When asked on which drugs and alcohol the respondents used, many mentioned the use of *local legalized brands of alcohol*. The abstinence from alcohol and drugs has been promoted amongst cancer survivors as one strategy of healthy behaviours. Ji et al. (2021) notes that young adult cancer survivors are

more likely to use alcohol, drugs or engage in prescription abuse due to more demanding physical and mental demands. In this study, 24.5 percent of respondents were between the ages of 20 - 30 years, while 48 percent were between the ages of 31 - 40. These age brackets are considered young adults who are in the economically and socially active population segments of the community. This may lead to the assumption that they are more vulnerable to greater physical and psychological demands that may lead to drug and alcohol abuse as a means of coping. The use of alcohol was also described as more likely to occur amongst support group members who did not disclose their health status and therefore lacked social support. A number of respondents linked this behaviour to a sign of denial that requires counselling and psychosocial support. Roan (2020), discusses the issue of denial and notes that some cancer survivors indulge in the use of alcohol in an attempt to normalize their lives prior to cancer diagnosis. This may be pre-empted by the feeling that an individual has been forced to give up a lot as they attempt to improve their health and as such the use of alcohol or drugs may come not only as a welcome solace, but as a means of asserting individual freedom despite struggling health conditions.

5.5. Adherence to Treatment

Non adherence to treatment is sometimes experienced amongst patients in long plans such as in cancer treatment. Bowman et al., (2017) reported that at least 50% of cancer survivors adhere to treatment while the rest who do not, attributing it to patient related, health system related or therapy related factors. In some cases, patients may experience unfavorable side effects of treatment, lack finances to access treatment or the health facilities may lack essential treatment for the cancer survivor's (Ingwu et al., 2019). This is evident amongst some respondents in the study who mentioned experiencing negative side effects while others feared such side effects preferring to try herbal medicine instead. Health care providers are often aware of the likelihood of cancer patients practicing non adherence especially after completing chemotherapy sessions as mentioned by Stump et al., (2019). In addition, such patients are more likely to be practicing other unhealthy behaviour as they feel justified to control their health seeking options. In such cases, such patients may opt to forfeit a treatment course without full knowledge of the implications involved. Lu et al. (2021), describe these perceptions as misguided since the risks of comorbidities are higher amongst cancer patients who did not adhere to treatment as compared to those who did. However, findings from this study indicated a general motivation amongst most cancer survivors, to adhere to treatment due to improved physical health and the desire to regain vitality.

5.6. Challenges in Adopting Health Behaviour

In view of the above findings, it is evident that support group members are well acquainted with behaviour practices related to nutrition, exercise, use of alcohol

and drugs as well as adherence to treatment. However, although most of them endeavored to maintain these practices, a few found it difficult to maintain these health patterns and allude that to various factors as indicated in Table 7. Amongst the most common reason mentioned by most respondents behind noncompliance to recommended health practices was the *lack of finance to purchase healthy foods and treatment*. Some other respondents referred to *lack of personal discipline, motivation, positive thinking and morale* as behind their non-engagement in healthy exercise. A few support group members said that the effects of treatment and associated comorbidities pushed them away from *exercise* and sometimes towards *use of alcohol as a means of coping*.

The existence of such challenges as above, present obstacles towards progressing to adoption of healthy behavior as shown in Figure 6. With this in mind, Young (2014) notes that health care providers should tailor lifestyle recommendations to individual evaluations rather than present blanket recommendations. This can be possible following a socio-economic assessment of support group members and a redesigning of lifestyle recommendations based on existing practical situations. Bailey (2017) recommends that both health practitioners and patients should plan for health behaviour and discuss not only the action plan but also anticipated barriers that may impede the success of the action plan. This in effect creates a "protection" against anticipated distraction or derailment from the process of behaviour change. The above-mentioned challenges also point at the relationship between emotional and physical health. Respondents mentioned feelings such as; lack of motivation, depression and lack of positive thinking as challenges in effecting healthy behaviour practices. Niedzwiedz et al., (2019), mentions that cancer survivors may undergo psychological and emotional distress as a result of learning about their diagnosis or even as a result of physical changes experienced from their condition. However, Niedzwiedz et al., (2019) further notes that these emotional experiences can be redirected to positive energy and action for renewed health decisions.

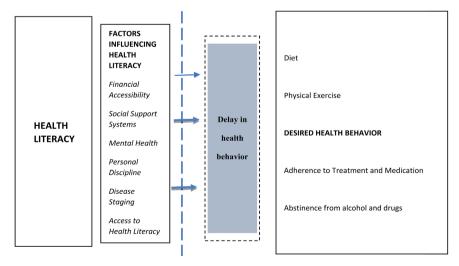


Figure 6. Association between health literacy and health behavior.

Table 7. Reasons for non adoption of healthy behavior.

Reasons given for not adopting healthy behaviour		
Lack of finances	Feelings of depression, lack of motivation	
High cost of healthy food, medication, cost of treatment	Stress and the challenge of long working hours	
Use of alcohol to help forget pain, cope with side effects of cancer treatment	Related comorbidities that make exercise difficult	
Peer pressure	Lack of positive thoughts especially during late survival stage	
Lack of social support to reinforce good behaviour, stigma and isolation		
Lack of personal discipline and failure to plan		
Ignorance of good health practices		
Exercise is hard especially when one chemotherapy		
Lack of exercise equipment		
Lack of funds, time, commitment		

6. Conclusion

It can therefore be deduced that health literacy generally results to positive health behaviour but is dependent on favorable social and economic environments. In addition, health literacy exists as a process that cannot be complete unless the recipient makes rational health decisions, hinged on a person's feelings, beliefs and perceptions that draw confidence on the justification of healthy behavior.

6.1. Recommendations

The Ministry of Health Cancer Program should identify suitable mechanisms of encouraging patient self-monitoring and self-reporting of key aspects of health behaviour as encouraged through the health literacy program.

Health care programs should also ensure that they initiate community-based health behaviour programs for patients as an extension of the health literacy package.

6.2. Areas for Further Research

The need to conduct an in-depth qualitative investigation on the social and economic factors delaying or impeding health behaviour as well as potential agents of mitigation.

With the scaling up of digital technology, it would also be of interest to find out how digital platforms can be effective in promoting self-care habits amongst cancer survivors in support groups. This could be in the form of digital reminders for medication, appointments, exercise.

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Conflicts of Interest

The authors declare that there were no competing interests involved in this study.

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