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Original Research

Perception and Belief of Dietary Intake among Newly Diagnosed with Gynaecologic Cancer in Malaysia: A Qualitative Study

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Background: Gynaecologic cancers (GC) experience unintentional weight loss and inadequate oral intake even before treatment. Cancer patients are at risk of accessing inaccurate advice and misleading information due to the prevalence of misinformation regarding nutrition and cancer in the media. This study aimed to obtain a comprehensive understanding of the perception and belief of dietary intake among newly diagnosed with GC in Malaysia.

Methods: We conducted in-depth qualitative interviews with 12 GC respondents from three major ethnicities and continued until the saturation point was reached. A semi-structured interview guide is employed. The interviews were audio recorded and verbally transcribed. Thematic analysis with theoretical saturation was applied to data analysis.

Results: The majority of patients interviewed reported that they made dietary modifications following their GC diagnosis, such as healthy eating, and began taking supplements. Their belief and perception of dietary intake were influenced by the impact of diagnosis, uncertainty, and fear of cancer progression and empowerment through nutrition. The cultural influence and access to resources and information might affect their dietary intake. There was evidence of navigating information overload from various sources after newly diagnosed GC. They felt a dilemma in food choices, balancing emotional and nutritional needs. The multidisciplinary support systems and healthcare delivery approach were useful.

Discussion and conclusion: The perception and belief of dietary intake among newly diagnosed with GC in Malaysia is diverse and can vary greatly depending on individual experiences, beliefs, and situations. They may attempt to restore some control over their health in the face of a cancer diagnosis. All respondents admitted that they changed to a healthy diet after being diagnosed with GC. The healthcare profession might benefit from current qualitative research to better understand more patients and increase the quality of

oncology dietetic service and decision-making. Hence, effective dietary interventions and support strategies could be established for this population.

Introduction

Gynaecologic cancers (GC), a group of cancers, are the top 10 cancers in Malaysia [1]. Cancer-related pathophysiological alterations result in dysgeusia and poor appetite in cancer patients, leading to insufficient oral intake, cancer cachexia with wasting, anorexia, and systemic inflammation [2]. A previous study found that about 57.3% of GC patients were malnourished even before any treatment [3]. Furthermore, the dietary consumption of GC patients may be influenced by the psychological stress and trauma associated with the diagnosis [4].

Dietary changes before treatment might impact a patient's nutrition status and cause further nutrition depletion even malnutrition [3]. Few studies found that malnourished surgical cancer patients had more postoperative complications, longer hospital stays, experienced higher postoperative readmission rates, had lower quality of life, and even death [5]. Hence, the exploration of the perception and belief of dietary intake in newly diagnosed GC is essential.

With more people being diagnosed with cancer due to earlier identification, there is increased interest in the potential for lifestyle factors, such as food, to minimize the late and long-term impacts of cancer [6]. Cancer patients are at risk of accessing inaccurate advice and misleading information due to the prevalence of misinformation regarding nutrition and cancer in the media and online [7]. Qualitative research is particularly well-suited for exploring perceptions and beliefs, especially in complex and sensitive contexts such as dietary intake among individuals newly diagnosed with gynecologic cancer. To our knowledge, the dietary behavior of Malaysian breast cancer [17] and colorectal cancer [8] only were explored. However, the information about perception and belief of dietary intake in newly diagnosed GC has remained lacking in Malaysia. This study aimed to obtain a comprehensive understanding of the perception and belief of dietary intake among newly diagnosed with GC in Malaysia.

Materials and Methods

Study Design

Semi-structured, face-to-face in-depth interviews were conducted to address the research aims and objectives. The potential respondents were selected from the female ward, Institut Kanser Negara, Putrajaya. Those newly diagnosed with GC (the diagnosis should be dated no more than 90 days from the beginning of the study), and consented were included while those who were not diagnosed with GC were excluded. The GC patients were screened by the principal investigator in the ward. Then the principal investigator approached the potential respondents and explained the study before consent. Potential respondent was allowed to ask the principal investigator if there was anything that was not clear. After the potential respondent was properly satisfied and understood this study, she was given sufficient time to consider or discuss it with family members before signing the consent form and return to the investigator. After consented, the respondent was arranged for an in-depth interview (IDI) session. Interviews were conducted between May 2023 to October 2023.

Study Tool

The interview guide was semi-structured and the questions were open-ended to guide the conversation to gather information from a respondent. A survey of the literature and the

researchers' clinical experience in the field were used to develop an interview guide. The validity and reliability of the semi-structured interview guide were checked by a gynaecologist, two dietitians, and three GC patients (Malay, Chinese, and Indian). There were probes throughout the interview for respondents to raise unforeseen topics, as well as flexibility to follow such leads. Respondents were allowed to contribute further reviews and comments to acquire more in-depth insights.

Analysis Plan

The interviews were done by a single researcher to ensure uniformity in data gathering. The interviews lasted around one hour and were audio-recorded. The semi-structured, in-depth interviews are widely used as an interviewing format in qualitative studies, whether with individuals or groups. These interviews were conducted only once, with an individual or a group, and often last 30 minutes to more than an hour [9]. The respondents were sampled carefully and purposefully until saturation was reached. The saturation point was the same themes coming out repeatedly during the data analysis. Reflexive notes were made throughout the analysis to document the thoughts. An audit trail was kept to ensure that the method was followed. All interview transcripts were professionally transcribed verbatim and reviewed for accuracy to ensure a thorough record of respondents' input. This was followed by identifying emerging themes (reduction) in the data and conducting hermeneutic contemplation. The goal of these interviews was to delve into the patient's experiences with their illnesses and uncover the themes that influenced their perception and belief about dietary intake. In-depth interviews were chosen as the strategy because they give more information about people's complex thoughts than group discussions do [9]. Two researchers identified major themes using qualitative thematic content analysis.

Results

Saturation was seen after analysis of twelve IDI sessions. The consented respondents aged range from 44.9 to 74.8 years old. Six of them were Malays, 4 Chinese, and 2 Indian. Majority of the respondents (n=10) were married with only 2 singles. Seven of the respondents were still working four were unemployed and one was pensioner. Table 1 shows the sociodemographic characteristics of respondents.

Code	Age (years)	Ethnicity	Marital status	Education level	Employment
R1	50.6	Malay	Married	Secondary	Businesswoman
R2	46.9	Chinese	Single	Tertiary	Executive
R3	47.8	India	Single	Secondary	Salesgirl
R4	63	Chinese	Married	Primary	Housewife
R5	55.1	Malay	Married	Secondary	Housewife
R6	59.1	Malay	Married	Secondary	Businesswoman
R7	44.9	Malay	Married	Tertiary	Teacher
R8	62.3	Chinese	Married	Secondary	Housewife
R9	52.1	India	Married	Tertiary	Lecturer
R10	51.2	Malay	Married	Secondary	Housewife
R11	74.8	Malay	Married	Tertiary	Pensioner
R12	52.3	Chinese	Married	Tertiary	Lecturer

Table 1. Sociodemographic Characteristics of Respondents.

The majority of patients interviewed reported that they made dietary changes after being diagnosed with cancer, such as reducing carbohydrate and fat intake, increasing fiber and

wholegrain intake, and starting to take supplements. From the analysis of responses, this study was able to identify eight themes that might affect their perception and belief of dietary intake, including the impact of diagnosis, uncertainty, and fear of cancer progression, empowerment through nutrition, cultural influence, access to resources and information, navigating information overload, balancing emotional and nutritional needs as well as support systems and healthcare delivery approach.

Impact of Diagnosis

Patients experienced shock, anxiety, disbelief, and sadness after being diagnosed. A cancer diagnosis often brings about significant emotional stress. Poor oral intake upon diagnosis due to loss of appetite, emotional stress, and the intention of limiting food intake to healthy eating.

‘I felt lost and down after the doctor broke the news (diagnosed cancer). I changed my dietary habits.’ [R2, 46.9 years old]

‘When the doctor told me mostly is cancer. I get shocked and lose my appetite after that.’ [R4, 63 years old]

‘I changed my diet pattern straight away to more healthy eating after being diagnosed with cancer..’ [R5, 55.1 years old]

Nutrition-related misconception

Patients diagnosed with gynecologic cancer (GC) often face various nutrition-related misconceptions, which can significantly impact their dietary behaviors and overall health. Patients might seek immediate and sometimes unreliable dietary advice in an attempt to regain control over their health. They attempted to manage or limit nutritional intake. They were clueless about the correct dietary consumption.

‘Cancer patients must avoid those toxic foods because those foods make cancer grow..’ [R1, 50.6 years old]

‘after being diagnosed, I’m lost. I no dare to simply eat.. cancer is very scary..’ [R2, 46.9 years old]
‘because.. (think)… I’m scared… the wound is not healing. I’m a cancer patient with a wound. I need to control my dietary intake, isn’t I?’ [R3, 47.8 years old]

‘I have no idea what’s correct diet after knowing I got cancer’ [R8, 62.3 years old]

Empowerment through Nutrition

Patients perceived nutrition as important to optimize their health. Proper nutrition is essential for a stronger body in response to oncology treatment.

‘I change my diet pattern straight away.. be healthy eating.. because I want to be stronger for treatment..’ [R5, 55.1 years old]

‘since I was diagnosed and before treatment started. I controlled my diet and tried to become healthier..’ [R9, 52.1 years old]

‘proper dietary intake is important for cancer patients especially before and during treatment.’ [R11, 74.8 years old]

Cultural Influence and Tradition Belief

Patients' perceptions of nutritional consumption are influenced by cultural preferences and traditional beliefs. Patients made dietary changes to regain health by consuming particularly nutritious foods with a cultural influence and traditional beliefs.

'In Malay culture, I must 'pantang' those foods which are 'toxic' to the human body, especially after surgery..' [R1, 50.6 years old]

'My 'sinseh' book (Tradition Chinese medicine) said cancer patients need to have 'clear' food.. [R12, 52.3 years old]

'I started to have herbal soup to make my body stronger.. replenish my energy (qi) before treatment. I made red dates and goji water as drinking water every day. [R4, 63 years old]

Access to Resources and Information

Patients reported a few resource and information accesses after being diagnosed. Most of them relied on the information from caretakers and healthcare providers. Following a diagnosis of GC, some patients actively seek cancer diet-related information on the internet and make dietary changes.

'Auntie old already. I don't know how to search for information using my handphone.. so my kids help me search all the information on the internet' [R4, 63 years old]

'That information was informed or updated from my family members, friends, cancer patient, and neighbor….' [R5, 55.1 years old]

'I started to have special supplement after reading the cancer diet-related website' [R6, 59.1 years old]

'I met and discussed with a dietitian once. then I got ask nurse and doctor on diet for cancer…' [R7, 44.9 years old]

'my daughter registered for me for 1 online class.. the professor from overseas teaches us how to eat for cancer patients..' [R11, 74.8 years old].

Navigating Information Overload

After being diagnosed with GC, patients' minds became overloaded with formal (healthcare provider) and informal (cultural practice) information. Overwhelming and confusing interpretation of full information influenced patients' decision to modify their dietary habits.

'After being diagnosed with cancer, many people told me that cancer patients need to 'pantang' but healthcare personnel said healthy eating and adequate oral intake. I'm confusing' [R2, 46.9 years old]

'I'm losing weight after practicing 'pantang' which was recommended by media social and friends.. so, I started to wonder if what I practice now is correct. [R6,

59.1 years old]

Balancing Emotional and Nutritional Needs

Patients' dietary habits have been affected by emotional stress following a diagnosis. Some patients attempted to eat nutritious foods but were hampered by their cancer-related symptoms.

'Before this, I liked to drink coffee… but they said can't take coffee at all. I'm stressed and worried if I continue to take coffee' [R2, 46.9 years old]

'I felt so depressed after my cancer diagnosis. I am aware that I need to eat properly but I lost my appetite at all..' [R4, 63 years old]

'I know I need to eat more to build my nutrition but I am unable to finish my meals. I feel full easily. My tummy is distended.' [R10, 51.2 years old]

Support Systems and Healthcare Delivery Approach

The patient felt helpless and forlorn. They require social and emotional support following cancer diagnosis. For the healthcare delivery approach, some favoured individual consultation whereas some preferred group consultation. They preferred a multidisciplinary clinical approach to an unimodal one.

'I joined cancer group so I can get moral support and know more from others cancer patient experience..' [R9, 51.2 years old]

'hmm… if ok, I wish to have individual consultation with my kids together…' [R5, 55.1 years old]

'I prefer group consultation so that I can know better how others handle the condition… how's treatment like…. Sometimes I think I need a counselor or ustazah for moral or religious support..' [R7, 44.9 years old]

'I wish to have multidisciplinary support from the hospital.. like an oncologist, dietitian, pharmacist, and physiotherapy.. because everyone has their expertise.. a better approach… not doctor alone..' [R12, 52.3 years old]

Discussion

The perception and belief of dietary intake among newly diagnosed with GC in Malaysia is diverse and can vary greatly depending on individual experiences, beliefs, and situations. In GC patients, dietary adjustments were driven by their diagnosis. This qualitative study explored and found several themes that might influence their dietary perceptions, including the impact of diagnosis, uncertainty, and fear of cancer progression, empowerment through nutrition, cultural influence, access to resources and information, navigating information overload, balancing emotional and nutritional needs as well as support systems and healthcare delivery approach.

The initial diagnosis might cause shock, anxiety, and disbelief. Patients may experience a wide range of emotions, including anxiety, despair, frustration, and concern about the future [10]. The sudden discovery and stress of a GC diagnosis can have a significant effect on an individual's perceptions of dietary intake [11]. Some people may be driven into adopting healthy eating habits, whilst others may experience changes in appetite or food preferences as a result of emotional or physical conditions [12]. The fear of cancer progression frequently persists, impairing a patient's capacity to embrace the new life after the diagnosis. Managing this fear and apprehension can be a continuous challenge [13].

Following a cancer diagnosis, the patient agreed that empowerment via nutrition is important. Many patients perceive nutrition as a tool that they're able to actively rely on to improve their health during treatment and recovery [14]. They may interpret it as an attempt to restore some control over their health in the face of a cancer diagnosis. Malaysia's three main ethnic groups are Malay, Chinese, and Indian. Every ethnic group encounters its traditional eating habits and cultural patterns [15]. Cultural influence and beliefs were influential in dietary decision-making, which may explain why patients focused on specific food items rather than food patterns [16]. Cultural stigma associated with cancer may lead to the adoption of specific dietary restrictions believed to improve outcomes. Traditional beliefs about the healing features of certain foods or their impact on well-being might impact dietary choices [15]. Malaysian dietary patterns are frequently determined by cultural preferences, which could determine how individuals perceive their eating habits following a cancer diagnosis [17].

Patients frequently turn to the internet and social media for information, where they may encounter misinformation, unverified claims, and anecdotal advice presented as fact. Well-meaning friends, family, or even non-specialist healthcare providers may offer dietary advice based on myths or outdated information [17]. Patients might possess different degrees of understanding regarding the association between nutrition and cancer. Some individuals might actively look for information on dietary changes that could alleviate their disease, while others might depend on medical advice or cultural practices [18]. Patients' perceptions concerning and approaches to dietary intake might be influenced by access to nutritional guidance, and the accessibility of particular foods or dietary supplements [19]. Patients who have been diagnosed with cancer have to cope with information overload. Patients are frequently overwhelmed with health-related and cancer-related nutrition information about their disease, treatment options, and possible outcomes [20]. This can be overwhelming and perplexing, resulting in variable levels of perception and decision-making capacity.

A patient's perception of nutrition is significantly influenced by emotions. Specific foods may provide comfort to certain individuals, while stress, anxiety, or depression associated with the disease might trigger others to experience problems with changes in appetite [21]. Moreover, to cope with the emotional and psychological toll of the diagnosis, patients frequently seek help from family, friends, support groups, or psychological specialists [22]. Multidisciplinary support from healthcare practitioners, dietitians, family, and friends can have a significant effect on the way patients perceive and handle their dietary needs [23]. Positive reinforcement and guidance may be applied to promote adherence to recommended dietary modifications [24].

Empathy, effective communication, and tailored assistance are critical in supporting GC patients as they pass through this challenging process [25]. The current qualitative exploratory study allowed for the exploration of previously unexplored factors on the perception and belief of dietary intake as well as modifications following GC diagnosis. Our study, one of the first in Malaysia's cultural contexts, provides significant insight into how cultural beliefs influence various kinds of dietary changes. Qualitative research supports researchers and healthcare professionals in understanding and insight into what drives patients' behavior. Moreover, the current study is chosen to explore the perceptions and beliefs of dietary intake among newly diagnosed gynecologic cancer patients because it provides a comprehensive, detailed, and nuanced understanding of their experiences, which is essential for developing effective support and intervention strategies. It is also used for evaluating patients' perceptions and beliefs of dietary intake in Malaysians who have recently been diagnosed with GC. The healthcare profession and dietitians might benefit from current qualitative research to better understand more patients and increase the quality of oncology dietetic service and decision-making. Current qualitative research has limitations such as possible small sample sizes and potential answer bias. The current qualitative research is a perspective-based method of research, the responses given are not measured so the statistical representation is not part of the qualitative research process. Moreover, qualitative research is not able to verify the results objectively against the scenarios stated by the respondents.

In conclusion, the actual experiences perceptions and beliefs of dietary among newly diagnosed with GC in Malaysia could provide useful insights for establishing effective dietary interventions and support strategies for this population. Understanding these perceptions and beliefs is critical for healthcare practitioners to provide individualized guidance, support, and interventions that are compatible with the needs and cultural backgrounds of GC patients.

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Conflict of Interests

The author has no relevant financial or non-financial interests to disclose.

Ethics Approval

The study was reviewed and granted approval by the Medical Research Ethics Committee (MREC) Malaysia with identity number NMRR ID-23-00437-FRD IIR.

Consent to participate

Informed consent was obtained from all individual participants included in the study.

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