



Research Article

# Assessment of Patient's Knowledge about their Cancer Diagnosis and Stage of their Disease and its Implications

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**Citation:** Al Bahrani BJ, Al Lawati AS, Shuja TM, Mehdi I (2023) Assessment of Patient's Knowledge about their Cancer Diagnosis and Stage of their Disease and its Implications. J Oncol Res Ther 8: 10167. DOI: 10.29011/2574-710X.10167

**Received Date:** 16 April, 2023; **Accepted Date:** 26 April, 2023; **Published Date:** 29 April, 2023

## Abstract

**Introduction:** The knowledge about cancer diagnosis, proposed treatment, and expected outcomes is vital for decision-making and adherence to treatment. Cultural and social beliefs toward cancer influence perceptions and attitudes, selection of treatment, and the outcome. A diagnosis of cancer is a life-threatening experience of an uncertain situation prompting emotions of uncertainty, anxiety, helplessness, despair, hopelessness and fear of death. The information is very valuable to manage the situation, allowing to gain a sense of control about decisions. Information is a cognitive activity of intellectual perception and a means of coping, reducing stress and managing emotions. **Patients and Methods:** This is a prospective analysis conducted between July 2022 to December 2022, at a tertiary cancer facility. The patients were evaluated for their awareness of diagnosis of malignancy, and the stage of disease. The main information retrieved was the knowledge about the cancer diagnosis and stage of the disease. The knowledge of disease and stage of disease were analysed in relation to age, gender, education level, and stage of disease. **Results:** A total of 221 adult cancer patients were questioned, 97 male and 124 females. The age ranged from 16 to over 75 years. The patients who were aware of their disease and diagnosis were males 80.41% and females 67.74%. The ratio of patients who are unaware of their disease increases with age, 3.4% at age <20 and 35.6% with age >70 years. The knowledge of diagnosis was inversely related to education level. The university and college educated people has the higher rates of knowing their diagnosis (96.6% and 89.1%), while less educated people have lower rate of knowledge about their diagnosis (67.8%% to 76.3%). The percentage of patient's knowing diagnosis and stage of disease, decreases with advancing stage of disease. All 100% cases knew about their diagnosis having stage I disease, while only 63.6% of stage IV knew about their diagnosis. About 47.5% had knowledge of disease stage, 51.1% didn't know the stage. Patients on curative neo-adjuvant chemotherapy, only 17.6% were unaware of diagnosis, while patients in incurable disease group having palliative intent chemotherapy 67.8% were unaware of diagnosis.

**Discussion:** The evidence shows that cancer patients have substantial information needs both during and after treatment, which often remain unresolved. Unmet information needs are frequently associated with lower quality of life, and increasing anxiety and depression. Our study signifies the effect of age, gender, disease stage and education on knowledge of patients about their cancer diagnosis. If a patient is not aware of diagnosis it erodes trust, and negatively impact patient-physician relationship, and acceptance of treatment influencing compliance and outcome. It also reportedly has an influence on survival. This is clinical experience that the patient is usually aware; getting information from surrounding (cancer department, display signs), lateral information from staff or other patients.

**Keywords:** Royal hospital; Knowledge of cancer diagnosis; Information on cancer diagnosis; NOC Oman

## Introduction

Cancer is a leading cause of morbidity and mortality across the globe [1]. Knowledge about cancer, treatment, and outcomes is critically important for decision-making and adherence to proposed treatment [2]. Cultural and social beliefs of the patient and family toward cancer influence perceptions and attitudes, selection of treatment, and the likely outcome [2,3]. Additionally, knowledge and perception toward cancer have been found to substantially influence help-seeking in patients [4,5]. However, late diagnosis and treatment remains significant barrier to improving outcomes, coupled with poor knowledge influencing the ability to seek treatment [2,6,7].

A diagnosis of cancer implies a life-threatening experience that brings a confusing and uncertain situation prompting emotions and feelings like uncertainty, anxiety, helplessness, despair, hopelessness and fear of death [7]. The effort in accepting the diagnosis is combined with feelings of anger, a sense of unfairness, stigma and a complete loss of hope. Patients have concerns for the unpredictable nature of cancer, and cancer recurrence. The information is very important to handle the situation, allowing to gain a sense of control about decisions [3,6,7]. Information is a cognitive activity of intellectual understanding, and is also a means of coping, reducing stress and managing emotions [2].

Patients should receive all the relevant information about their malignant disease, stage of disease, potential benefits and expected side effects of the proposed management strategy [4]. They must understand it by satisfying their queries and give their consent before start of treatment. This relevant and comprehensible information is a moral, legal, and ethical requirement for patients so as to acquire enough knowledge permitting them to be involved in shared decision making [3]. This helps to comply with the treatment plan, to make them aware of potential side-effects and to understand what to do in case of adverse side-effects [3]. A well informed patient is more satisfied with management, have a better perception of control of situation, and experience a better quality of life [3,4,6].

The meaning and role of information in cancer patients is clearly associated with gaining control in a seemingly uncontrollable situation [3]. Information is helpful in strengthening the treatment decision, and also in terms of learning how to handle the disease and knowing what consequences from the potentially life-threatening diagnosis and the ensuing treatments. The need to be selective about what information to hear and trust is a means of managing emotion and gaining control.

There are several potential barriers to provision of relevant and understandable information. Medical information has become more complex, health care providers communication skills vary; and written, standardised information is not always available. There is not always enough time, and interruptions are frequent [4]. Moreover, denial, fatigue, distress and anxiety are common among cancer patients impairing the ability to comprehend the given information. Even when adequate information is provided, patients do not necessarily feel adequately informed or satisfied with the information, or gain enough knowledge to make treatment decisions or to follow instructions from health care personnel [4]. This probably explains why approximately half of the complaints from patients and relatives concerns poor communication between HCP, patients and relatives [8]. An important challenge for HCP when providing information is that there is no established method for evaluating whether patients are well informed or satisfied with the information they have been given [3].

The European Organization for Research and Treatment of Cancer (EORTC) has developed a new 25 item self-report questionnaire QLQ-INFO25 to measure how cancer patients perceive the information they receive. It measures how much information patients perceive to have received about their disease, medical tests, treatment, help and support available; whether written or audio-visual information has been provided; whether they are satisfied with the amount of information; whether they would like to receive more or less information; and whether the information has been helpful. The EORTC QLQ-INFO25 has been used in studies of patients with various cancer types, and patients from several different countries (Sweden, Spain, Germany, United Kingdom, Austria and Taiwan) and has proven to have good internal consistency and good test-retest reliability [3,5,9,10]. Given the construct of QLQ-INFO25, the scores may reflect the level of knowledge about disease and treatment.

There is paucity of studies on knowledge and belief of cancer patients related to their diagnosis. The purpose of this study was to assess the knowledge of cancer patients about their diagnosis and stage of disease.

## Patients and Methods

This was a prospective analysis conducted between July 2022 to December 2022. The patients were evaluated for their awareness of diagnosis of their malignancy, and the stage of disease.

The patients were interviewed in the absence of any attendants to ensure the accuracy of information without any influence. The main information retrieved was the knowledge about the cancer diagnosis and stage of the disease. The other information collected from patients Electronic Medical records through Al Shifa 3 system

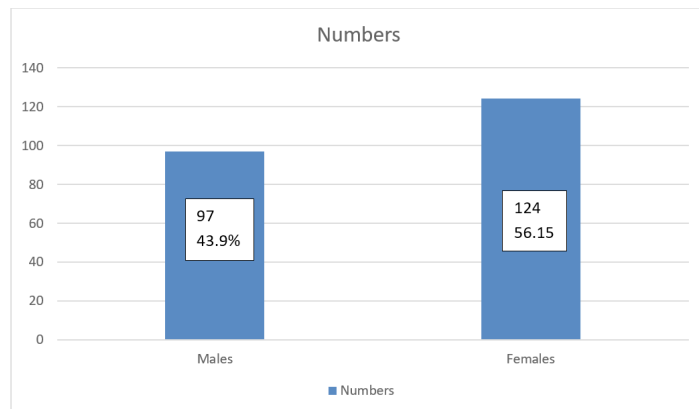
were age, gender, marital status, education level, site of disease, diagnosis, stage, and type of treatment received. The patients who were not mentally competent, or could not understand the questions, and could not respond were excluded.

The knowledge of disease and stage of disease were analysed in relation to age, gender, education level, and stage of disease.

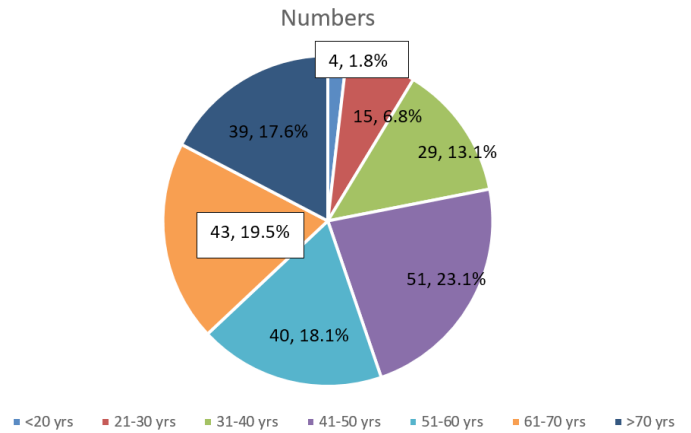
**Results**

This was a prospective analysis conducted between July 2022 to December 2022. The patients were evaluated for their awareness of diagnosis of their malignancy, and the stage of disease. A total of 221 adult cancer patients were examined and questioned, 97 male and 124 females (Figure 1). The age ranged from 16 to over 75 years. Figure 2 shows the age distribution; 23% between 41-50 years, 19.5% between 61-70 years, 18.1% between 51-60 years, 17.6% more than 70 years of age and 13.1% between 31-40 years of age. Thirty-one (14%) were single and 190 (86%) were married). The cases were cancer breast (55), Colorectal (53), Stomach and Esophagus [15], Prostate (14), Lung (12), Germ cell tumour (11), and soft tissue sarcoma (10) [Table 1].

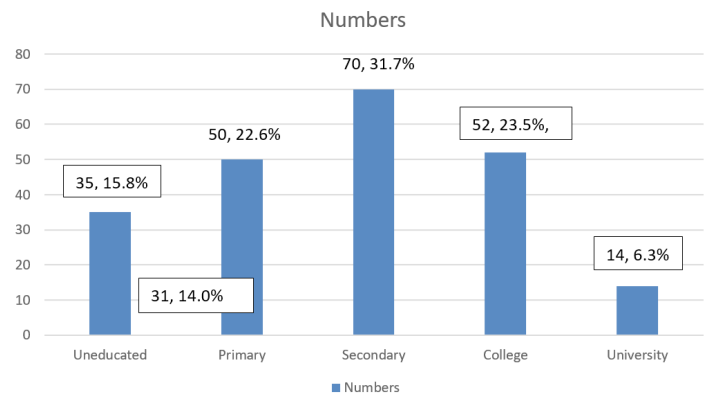
The education level wise distribution of these patients is shown in figure 3. Their level of education was uneducated (35, 15.8%), primary (50, 22.6%), secondary (70, 31.7%), college (52, 23.5%), and University (14, 6.3%). Stage wise the patients were stage I (8, 3.6%), stage II (22, 10%), stage III (62, 28.1%), and stage IV (129, 58.3%); shown in figure 4.



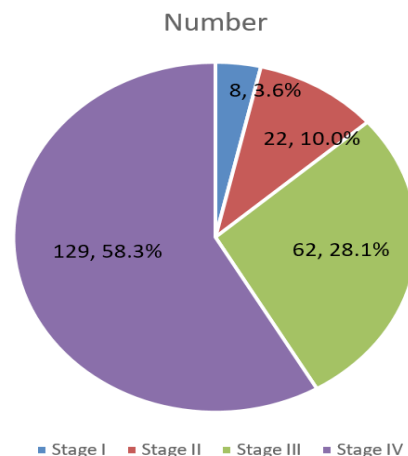
**Figure 1: Gender of patients**



**Figure 2: Age of Patients.**



**Figure 3: Literacy level.**

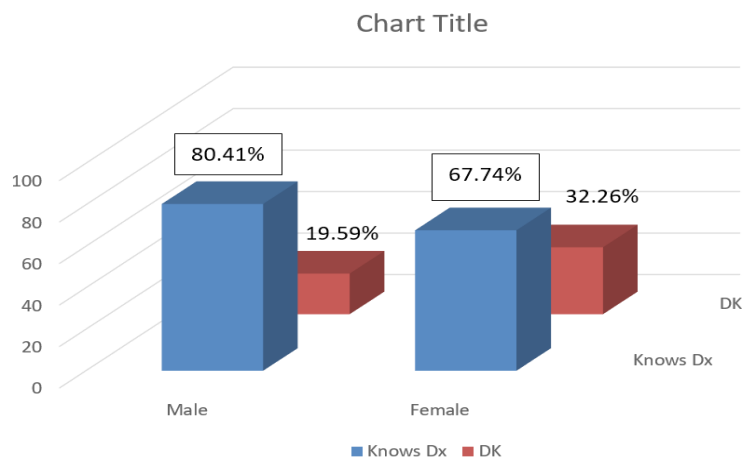


**Figure 4: Stage Distribution**

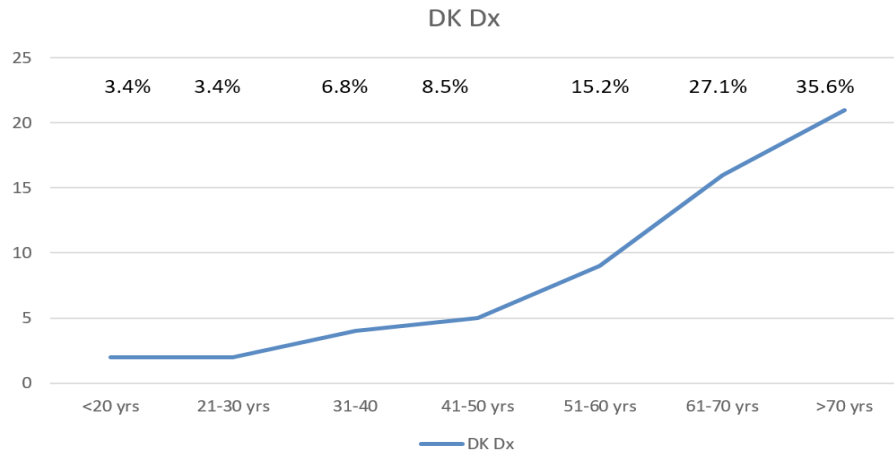
No.	Tumour	Number	No.	Tumour	Number
1	Breast	55	13	Head and Neck	4
2	Colo-Rectal	53	14	Hepatocellular carcinoma	4
3	Esophagus and stomach	15	15	Osteosarcoma	4
4	Prostate	14	16	Cervix, Endometrium	3
5	Lung	12	17	Thymus	2
6	Germ cell tumour	11	18	Adrenal Carcinoma	1
7	Soft tissue Sarcoma	10	19	Choriocarcinoma	1
8	Pancreas	8	20	Melanoma	1
9	Renal cell CA	6	21	Nasopharyngeal CA	1
10	Gall bladder, Cholangiocarcinoma	5	22	Urinary Bladder	1
11	Glioblastoma Multiforme	5	23	SCC perineum	1
12	Ovary	4			

The patients who were aware of their disease and diagnosis were males 80.41% and females 67.74%, while 19.59% males and 32.26% females were unaware of their diagnosis (figure 5). The ratio of patients who are unaware of their disease increases with age, 3.4% at age <20 and 35.6% with age >70 years (figure 6). The knowledge of diagnosis was inversely related to education level. The university and college educated people has the higher rates in terms of knowing their diagnosis of malignancy (96.6% and 89.1%), while uneducated, primary educated and secondary educated people have comparatively lower rate of knowledge about their diagnosis (76.3%, 67.8%, and 71.2%) (figure 7).

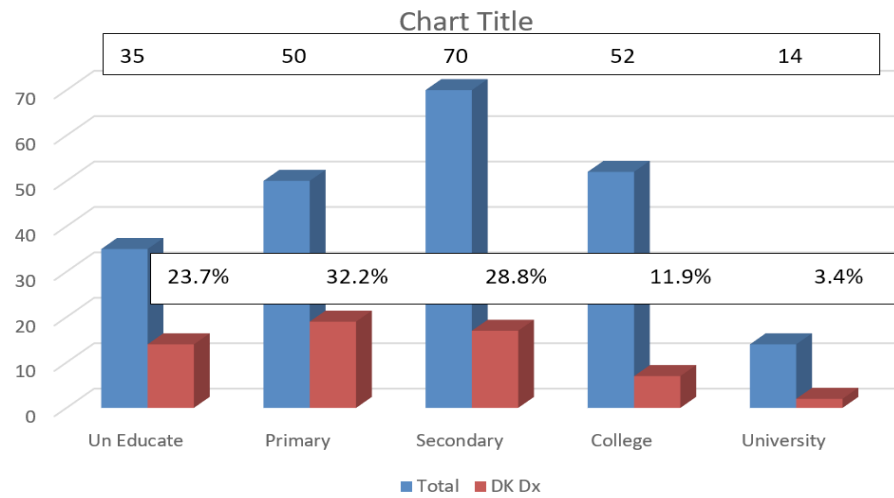
The percentage of patient’s knowledge about diagnosis and it’s relationship with stage of disease, decreases with advancing stage of disease. All 100% cases knew about their diagnosis who has stage I disease, while only 63.6% knew about their diagnosis who has stage IV disease (figure 8). As per stage of disease 47.5% had and knowledge of disease stage, 51.1% don’t know stage, and 1.4% don’t want to know (Figure 9). The knowledge of cancer is also influenced by treatment type (table 10). Patients on curative neo-adjuvant chemotherapy, only 17.6% (16/75/91) were unaware of diagnosis, while patients in incurable disease group having palliative intent chemotherapy (80/38/118) 67.8% were unaware of diagnosis (Figure 10).



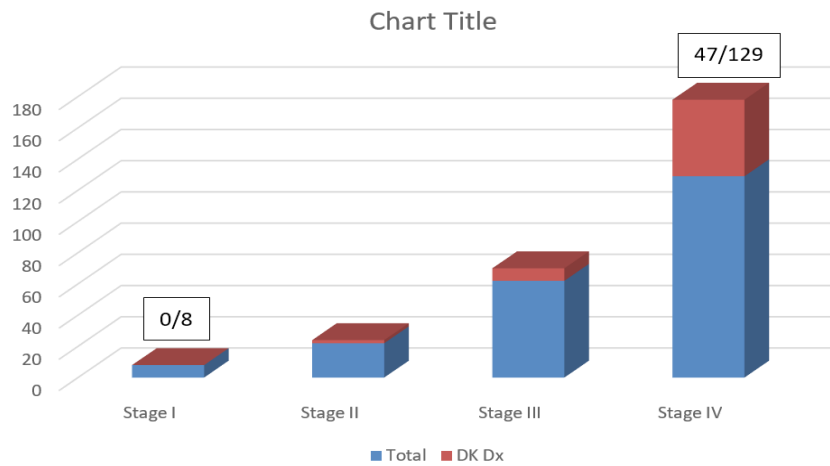
**Figure 5:** Gender and knowledge of cancer diagnosis.



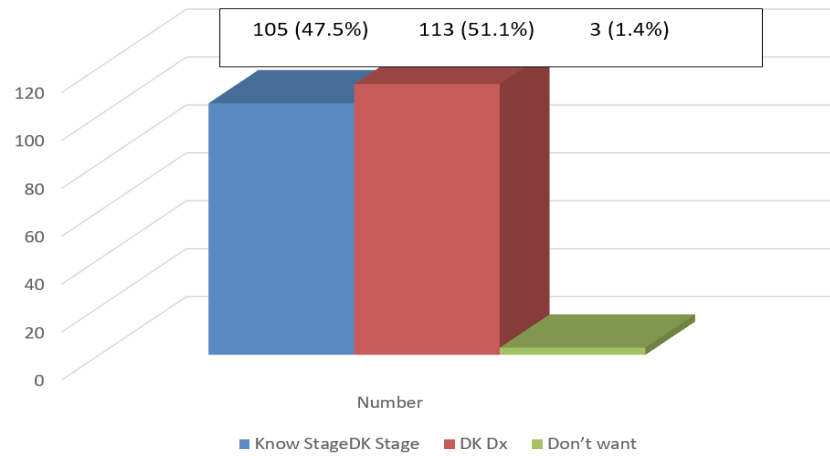
**Figure 6:** Age and Knowledge of Cancer Diagnosis.



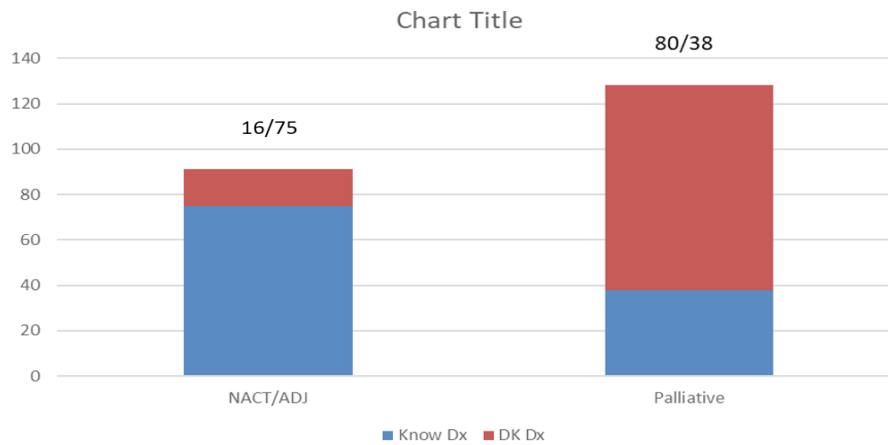
**Figure 7:** Literacy and Knowledge of diagnosis.



**Figure 8:** Stage of disease and Knowledge of Diagnosis.



**Figure 9:** Knowledge of Stage of disease.



**Figure 10:** Treatment and Knowledge of Diagnosis.

## Discussion

During the past few decades, notions about cancer have changed remarkably due to progress in diagnostics and management options. Knowledge about cancer, treatment, and likely outcomes is critically important for decision-making and adherence to the treatment [2,4,5]. Reportedly 61% cancer patients have satisfactorily adequate knowledge, 86% have modest belief, and nearly 54% have indeterminate opinion about cancer [11-13]. There is a link between educational level and cancer knowledge, while males showed a more significant positive attitude than females [2,11,12].

The evidence shows that cancer patients have substantial information needs both during and after treatment, which often remain unresolved [13]. The needs relate to medical information of disease, treatment options, psychosocial support and health behaviour. The information given have to be understood for effective handling the disease and its potential consequences. Patients' anxieties for information are often not resolved by an increased amount of information [3]. There is a need for provide emotional support and respect for patient autonomy. The evaluation of one's behaviour and the information received is closely linked to how the disease progresses [14]. The studies have found that half of the cancer survivors were unsatisfied with the received information regarding side effects and medication, medical examination results, treatment options, social issues, and health promotion [14]. Unmet information needs are frequently associated with lower quality of life, and increasing anxiety and depression. Indeed, receiving health information influences perceptions, a feeling of being in control, a better understanding of the illness, and an overall positive effect on disease perceptions [2,3,15].

The type of information conferred needs to be carefully selected. Personal and contextual characteristics should be taken into account when evaluating patients' desires for information and their behaviours for seeking or avoiding information. The desire for information may well complement the future physician-patient relationship. Half of the patients avoid to converse about their disease, while males have a more positive attitude toward cancer than females [2,3]. The fear, frightful attitude, lack of awareness, and social stigma lead to negative attitude and belief toward cancer. Patients residing in urban areas and higher literacy levels have a better understanding toward cancer influencing their dealing with diagnosis, and management decision for cancer [11,12,15].

One third of patients believe cancer is an old age disease, are unaware of the warning signs of cancer, and believe that cancer can spread by a biopsy [2,9,15,16]. Nine out of 10 patients have the awareness that smoking can cause cancer, one third know the role of dietary factors [8]. Some patients still think that cancer is a communicable disease, while majority do not believe that there is a

familial or genetic association of cancer [3,17]. About 88% patients are aware that surgery, radiation therapy, or chemotherapy are the treatment options for cancer. Nearly 29% think it is incurable, and 55% believe that cure depends on stage of disease. One third believe that chemotherapy or radiation therapy are painful management strategies. A majority (68%) have the opinion that screening can lead to early detection [2,4,18]. A majority believe that disclosing cancer diagnosis will ruin their relationship [3,19].

Uninformed patients carry a higher risk of treatment related complications [7,16,19]. Physicians usually not give enough time and opportunity to explain about the disease and answering queries [7]. A patient may feel respected and appreciated when the physician spends more time and attention and give a better awareness for the disease, realistic expectations, management plan, and toxicity profile [3,7]. A continuous patient education along the patient's journey should be an important part of the treatment [7,15,19].

Information needs may vary by age cohort in terms of the role and meaning of information, in different stages of the disease. Information has generally been seen as important for the health-related quality of life of patients with cancer [3]. Western countries and culture practise patient autonomy, whereas in developing countries, the patient's family plays a vital role in treatment decisions [2,15,16]. A study of medical students and law students indicate that all future physicians and 95.8% of future lawyers would respect the right of cancer patient to know his diagnosis. However, the right of a cancer patient to be informed about poor prognosis is respected by significantly fewer future physicians (74%) and future lawyers (82.2%). Still fewer future physicians (66.9%) and future lawyers (54.2%) would respect the right of a cancer patient not to know his diagnosis. The right not to know about prognosis was respected by 80.3% of future physicians, but only 62.5% of future lawyers [20]. However, other studies have found cultural differences in the desire for information, expectations of information provision, and role in medical decision-making [11]. Culture, age, education, stage, being on chemotherapy and gender all influence the knowledge of cancer diagnosis and stage [11]. Decision to provide information should be patient-centered and careful communication. It must be built on respect, sensitivity, composure, partnership, honesty, astuteness, curiosity, and tolerance. The information the providers deliver needs to be as specific as possible to the individual patient and family situation and sensitive to the preferences of the patients in accessing and receiving their medical information [11].

One of the ethical issues is when family members of a cancer patient request that certain information be withheld from the patient. At some point the family intercepts the physician and requests not tell the patient about the diagnosis. Honouring this request makes health professionals complicit in the deception, a

very uncomfortable position for health care providers. On one hand, the patient's right to self-determination (ethical principle of respect for autonomy) has become so strongly entrenched in health care system and health care providers recognize that they are being asked to violate a clear ethical principle [9,16]. At the same time, maintaining a therapeutic alliance with the patient's family is important because an unhealthy relationship with the patient's family can impede quality of care and promote unhealthy physician family relationship. Moreover, family members often act as substitute decision makers, having the right to make many health care decisions on behalf of patients. Health care providers are thus often feels pressured to honour the request respecting the substitute decision maker's authority. The family's pleas may be very emotional, making it harder for health care providers to go against their wishes. All health care providers are primarily obligated to promote the interests of their patients over the interests of others. That means your obligations to your patient must take priority over your obligations to the patient's family members. A meta-analysis of 23 trials Informing cancer patients of their diagnosis may not have a detrimental effect on their quality of life or on their symptoms of fatigue, pain, dyspnoea, insomnia, appetite loss, physical function, role function, cognitive activity, and emotional function, and may in fact have beneficial effects in terms of vitality and social function [10].

The patient does have a right to know his or her diagnosis, for two main ethical reasons: First it is the patient's information, so the patient is entitled to that information; and secondly there will always be more decisions to make, even if the disease is terminal, so the patient needs to be informed of diagnosis and prognosis if he or she is going to make those decisions (like consent for further tests or procedures or consent for palliative care) [14, 16]. Additionally, information disclosure prevents the health care team from having to lie to or deceive the patient, most patients desire to be informed about their diagnosis and prognosis, and open disclosure helps to maintain a trusting therapeutic relationship.

Does this mean that health care providers should totally ignore the family's pleas and disclose the diagnosis to the patient? The answer is not a clear No. First, the patient's family members will know the patient better than their health care providers and have a legitimate concern and clear perception about how harmful the information might be to the patient. Second, there are often cultural factors at play in these situations. Some cultures do not subscribe to the individualistic concept of patient autonomy like Western health care and in these cultures it is standard practice for family members to take over all decision making for a sick patient. Third, although most patients do want to know about their diagnosis some of them will not tolerate it psychologically [12,14,20].

A reasonable compromise approach can be used to resolve these issues between the competing values. Endorse apprehensions of the family but clarify to them that the patient has every right to know if he wishes to know. Explain that the conversation will be conducted with sensitivity and compassionately. Ensure them that the diagnosis will not be enforced upon the patient. Secondly ask the patient if he wants the test results revealed to him or to his family. If he wants to know, make sure how much detail he wants and needs to know. Make sure the family members are present for support (unless the patient doesn't want it). Thirdly If the patient wants to know, explain the diagnosis gradually and clearly. Select careful words like growth or tumour instead on cancer. Give the patient ample chance to ask questions. Fourthly wherever feasible describe the treatment options and plans. Never leave the patient with the impression that there is nothing more left to do [11,12,14,20].

Our study signifies the effect of age, gender, disease stage and education on knowledge of patients about their cancer diagnosis [4,15]. It appears that older patients are less aware of cancer diagnosis. It is likely to be the respect and concern in culture for older members and keep them comfortable and cheerful. Females are also taken extra care in the culture and mostly in society the males are the decision maker. Higher the education level, better the awareness of cancer diagnosis due to education, and access to information material. The majority of patients with stage IV incurable disease are not aware of diagnosis and stage, while early stage curable disease diagnosis is known to most patients. This is from family request, pressure, and with holding information by the family [11, 20].

If a patient is not aware of diagnosis it erodes trust, and negatively impact patient-physician relationship, and acceptance of treatment influencing compliance and outcome. It also reportedly has an influence on survival [11]. This is clinical experience that the patient is usually aware; getting information from surrounding (cancer department, display signs), lateral information from staff or other patients.

### **Limitations**

The study's main limitations is small sample size, a higher exclusion rate, and a cross-sectional nature of our analyses. All these factors lead to selection bias and causality. A longitudinal design could shed light on the changes of information acquisition and needed information assistance as patients cope with the disease in different phases (early stage, advanced or remission). Patients who did not volunteer to participate were not tracked, and it is possible that we only included the most motivated and well-informed patients. Another limitation is the imbalance of cancer types. Breast and colon cancer patients comprised a large



percentage of the sample; consequently, cases were too few for focused analyses with different types of cancer. Future studies can benefit from comparing self-reported clinical information with information from patients' medical records, limiting the analyses to a specific diagnosis and stage.

## Conclusions

Information is never a simple or enough, but essential way of gaining sense of control of a apparently overwhelming situation. Information seeking and avoidance are both means of feeling comfortable with the selected treatment, and is a means for a patient to strengthen relationship with the physician. The unmet need for information cannot be answered by a simple increase in the amount of information provided. Emotional support and respect for patient autonomy also play a major role. The behaviour and the information required change over time as the illness evolves, making it a challenge to document unmet information needs and satisfaction with information. Health knowledge and informational deficits about the disease should be measured in a more inclusive and comprehensive way. Due to a rising incidence of cancer, a health awareness campaign needs to be adapted to target the issues. Cancer patients need to made aware of the cardinal signs of cancer and improvise their approach toward cancer. Cancer care programs should involve both cancer patients and their caregivers because the understanding of family members is of utmost importance to combat cancer. It is implied that the role of information, medical or otherwise, in cancer should be seen as a coping tool influencing patient's understanding of the disease and managing emotions. Information disclosure must be understood as essentially enmeshed in the cancer patient's journey and in his interactions with healthcare providers, physicians, and cancer care services.

**Funding:** The study was not funded by any grant or sponsors

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