

## Disclosure of Diagnosis and Prognosis Information of Cancer in Jordan: Comparative Analysis

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### Abstract

There is no common disclosure practice among healthcare providers when it comes to cancer diagnosis, whether to tell or not to tell. The lack of a clear policy for healthcare practitioners, who face this dilemma every day in their professional practice, further complicates the situation. The aim of this review is to attempt to look into what governs the public attitude towards disclosure in Jordan as an example of what may affect attitudes in developing countries. Also brings some data from national research among physicians and patients as well as from public surveys to describe the changing attitude over the years with a comparative analysis of the Western literature, A search was done via MedLine for all publications related to this review objective were included emanating from Jordan and western countries (USA, Australia and UK). The findings showed that Western countries have high levels of reported disclosure compared to Jordan, which has a slight growth in disclosure due to some obstacles in the sociocultural constructs lacks patient education resources and low health literacy.

***Key words: Cancer, decision making, information provision, Jordanian, physicians***

## Introduction

Cancer is a complicated illness, represents a significant event that changes individuals' life trajectory. Cancer meant death, usually perceived by patients as highly stressful, resulting in fear, shock, depression, and unresolved denial (Jaiswal & Breitbart, 2014). There is no agreement among health care providers on a unified disclosure practice, either to say it or not. This is a complex issue due to the lack of evidence Policy for healthcare practitioners, who each face this issue a day in their clinical practice (Ni & Alræk, 2017).

Disclosing a terminal diagnosis or prognosis to their patients, clinicians have been described as intermediaries or "master of ceremonies" to the transition from health to life-threatening illness and for some, death (Wolfreys, 2016). Disclosure and truth-telling can be overwhelming emotionally for patients as well as for health care providers, who have a prior belief that there is no cure and death is linked to cancer (Rozveh et al., 2017). In most of these clinical situations, the family's request for non-disclosure of diagnosis or prognosis to the patient is the most contradicting and at the same time, the most difficult to manage. To appropriately respond to this request, physicians need to deeply understand the sociocultural background of such an attitude (Paternotte et al., 2015).

Disclosing the diagnosis or prognosis to cancer patients in Jordan can be a serious challenge to the physician in his daily clinic practice. The public attitude towards disclosure is still conservative, and in order to appropriately deal with such an attitude, physicians and nurses need to much understand its sociocultural background (Al Qadire, 2018).

This paper attempts to look into what governs the public attitude towards disclosure in Jordan as an example of what may affect attitudes in developing

countries. Also brings some data from national research among physicians and patients as well as from public surveys to describe the changing attitude over the years with a comparative analysis of the Western literature.

### **Disclosure of Cancer in Jordan VS Western Countries**

Many researchers have referred to a different perspective on the importance of disclosing cancer in their various studies. The following studies have been selected to compare disclosure in Jordan and western countries (USA, Australia and UK).

Studies by (Obeidat and Khrais, 2015), (Obeidat and Khrais, 2016), (Al Qadire, 2018) and (Borgan et al., 2018). All of these studies were conducted for Jordan. According to Obeidat and Khrais (2016) was conducted a study to determine the attitude of Jordanian physicians toward disclosure of cancer information, comfort and use of different decision making approaches, and treatment decision making by used A descriptive comparative research design ,a convenience sample of 86 Jordanian medical , radiation oncologists and surgeons practicing mainly in oncology setting. The result of this study show that almost 91% of all physicians indicated that the doctor should tell the patient and let him/her decide if the family should know of an early stage cancer diagnosis. Similarly, Al Qadire (2018) conducted a study to explore Jordanian public preference on cancer diagnosis disclosure and the type of information they need by used A descriptive cross-sectional survey design and the sample consisted of 485 participants. The result of this study show 421 (86.8%) participants wanted to be informed of the diagnosis if they developed cancer. However, Obeidat and Khrais (2015) was conducted study to determine Jordanian women's attitudes toward disclosure of breast cancer information and their information needs by used descriptive comparative research design among 156 Jordanian women who had a confirmed first time diagnosis of breast cancer. The

result of this study show the vast majority of patients wanted to know whether the diagnosis was breast cancer (92%) and the stage of the disease (78%) and information about spread of the disease and chances of cure was of highest importance for the majority of the patients (88 % and 85 %).

Borgan et al. (2018) was conducted study to explore the truth disclosure Practices of physicians in Jordan, a developing country. By used A descriptive cross sectional survey design and sample consisted of 240 physicians. The findings show that 77 % of physicians opted for a usual (Tell) policy. Surprisingly, specialists were more likely to have adopted a (Do not Tell) policy compared to non-specialists (34 % and 19 %), non-disclosure was primarily motivated by request from the patient's family (71 participants, 54 %). Most respondents opt to disclose the truth; However, the vast majority of these respondents make exceptions and instances of non-disclosure are primarily motivated by sociocultural constructs.

Obeidat and Khrais (2016) indicated that almost 48% of the participating physicians reported using shared decision making as their usual approach for treatment decision making; The cultural norms, in which patients are not accustomed to being involved in medical decision making, are rooted deep in Jordanian society and may be responsible for Jordanian patients' willingness to play a passive role in treatment decision making. Al Qadire (2018) was found that people with a high monthly income requested more information, while the inhabitants of the southern region needed relatively less information than others related to economic status of participants.

On the other hand, other studies were conducted for western countries ; (Enzinger et al., 2015), (Chittem and Butow, 2015) and, (Munro et al., 2015) .Both Enzinger et al. (2015) and Munro et al.(2015) have supported disclose information for patient.

According to Enzinger et al. (2015) conducted a study in New York to determine how prognostic conversations influence perceptions of life expectancy (LE), distress, and the patient-physician relationship among patients with advanced cancer. That used multicenter observational study of 590 patients with metastatic solid malignancies with progressive disease after one line of palliative chemotherapy, undergoing follow-up to death. The results showed that 71% wanted to be told their LE, but only 17.6% recalled a prognostic disclosure by their physician. Similarly, Munro et al. (2015) conducted a study to identify disclosure patterns among patients with cancer and to determine the factors associated with disclosure among 120 Patients who had received a diagnosis of either lung, colorectal or skin cancer in UK. The findings showed that the majority of patients (95%) found it helpful to disclose information and did so to a variety of social targets, with the highest levels of disclosure being reported to medical personnel. Additionally, Chittem and Butow (2015) Using the snowball method, 14 Australian (Western: 9, non Western: 5) oncologists to explore differences in the attitudes and practices of Western born and non Western born oncologists in Australia when faced with a nondisclosure request. The results showed that six main themes emerged from the study: (1) Barriers to truthful communication, (2) an ethical and moral dilemma, (3) high costs of nondisclosure, (4) cultural influences on interpretation and understanding of requests for nondisclosure, (5) emotional impact of bad news on patients, families and oncologists, and (6) truthful disclosure as a gentle balancing act.

### **Discussion of Findings**

The aim of this paper was to discuss seven published studies and compare the disclosure in Jordan versus in the western countries (**Table 1**). Jordanian researchers referred to several reference points related to the issue of patient disclosure.

According to Obeidat and Khrais (2016) indicated for important facts that the Jordan Ministry of Health website lacks patient education resources and low health literacy has been implicated as one of the major barriers for the successful implementation of shared decision making in clinical practice. This barrier is inconsistent with the results of the Al Qadire (2018) study it was found that the majority of Jordanians opted strongly for disclosure of cancer diagnosis, with high information needs about all aspects of cancer and its treatment. In the same way, Obeidat and Khrais (2015) indicated to the majority of Jordanian women wanted information about breast cancer diagnosis, chances of cure and treatment side effects.

Another obstacle to disclosure in Jordan is the sociocultural constructs and fear of psychological consequences is the most common reason for nondisclosure is a direct request to the respondent from the patient's family, without the patient's consent. This finding provides first-hand evidence of the strong presence of family centered care in Jordan (Borgan et al., 2018).

In comparison to western countries, the findings showed that high average levels of disclosure were reported to 'family' and 'friends' social subgroups expands the earlier work that has emphasized the importance of informal helpers and confidants. Higher levels of disclosure were also associated with higher levels of social support, confirming suggestions that social support systems provide an important context for disclosure (Munro et al., 2015). Also, western oncologists felt there were high costs of nondisclosure to patients and their families, they agreed that there were cultural influences on interpretation and understanding of requests for nondisclosure, they observed an emotional impact of bad news on patients, families and oncologists, and they believed that truthful disclosure was a gentle balancing act (Chittem& Butow, 2015). Additionally, the increased optimism treatment in western country for some

cancers due to advances in surgical and radiation methods and the beginning of medical oncology gave more treatment options and increased survival in many cancers; This in turn provided the momentum toward disclosing diagnoses to patients (Enzinger et al., 2015).

### Conclusion

Attitudes are steadily passing, although their growth has been slow in many non-Western countries, including Jordan. Public education and partial cultural openness due to the communication revolution, and worldwide globalization are having some effect in changing a few aspects of the sociocultural constructs in Jordan. Socially sanctioned roles in the patient provider relationship in non western countries, whose cultures are mostly family centered, are different from those in western countries (autonomous, self determinate patients and authoritative physicians).

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**Table 1. Summary of Studies that used in comparative analysis**

<b>Authors/ Years</b>	<b>Objectives</b>	<b>Approach/ Design/ Sample</b>	<b>Setting</b>	<b>Summary of Findings</b>
<b>Enzinger et al., (2015)</b>	-To determine how prognostic conversations influence perceptions of life expectancy (LE), distress, and the patient-physician relationship among patients with advanced cancer.	-Quantitative - prospective study (cohort ) - 590 patients with advanced cancer patients with metastatic solid malignancies and progressive disease after one line of palliative chemotherapy	New York (USA)	-Prognostic disclosure was not associated with worse patient-physician relationship ratings, sadness, or anxiety in adjusted analyses.  - Prognostic disclosures are associated with more realistic patient expectations of LE.
<b>Obeidat, R., &amp; Khrais, H. I. (2015).</b>	To determine Jordanian women’s attitudes toward disclosure of breast cancer information and their information needs.	-Quantitative method - descriptive comparative research design - A convenience sample of 156 Jordanian women	Jordan	-The majority of Jordanian women wanted information about breast cancer diagnosis, chances of cure, and treatment side effects
<b>Chittem&amp; Butow, (2015)</b>	- To explore differences in the attitudes and practices of Western-born and nonWestern born oncologists in Australia when faced with a nondisclosure request.	- Using the snowball method, 14 Australian (Western = 9, non Western = 5) oncologists .	Australia	- All oncologists felt that the family request for nondisclosure was difficult, with many cultural and emotional nuances to take into consideration. Some immigrant Australian oncologists who had a similar cultural background as the patient/family, felt they could better understand the desire for nondisclosure.

<p><b>Munro et al.(2015)</b></p>	<p>-To identify disclosure patterns among patients with cancer and to determine the factors associated with disclosure</p>	<p>-Quantitative method -descriptive research design - A convenience sample of 120 cancer patients.</p>	<p>London, UK</p>	<p>- The majority of patients (95%) found it helpful to disclose information and did so to a variety of social targets, with the highest levels of disclosure being reported to medical personnel</p>
<p><b>Obeidat, R., &amp; Khrais, H. I. (2016).</b></p>	<p>-To determine the attitude of Jordanian physicians toward disclosure of cancer information, comfort and use of different decision-making approaches, and treatment decision making.</p>	<p>-Quantitative Method -A descriptive, comparative research design was used. - convenience sample of 86 Jordanian medical and radiation oncologists and surgeons practicing mainly in oncology was recruited.</p>	<p>Jordan</p>	<p>- Almost 91% of all physicians indicated that the doctor should tell the patient and let him/her decide if the family should know of an early-stage cancer diagnosis. - Physicians provide abundant information about the extent of the disease, the side effects and benefits of the treatment, and details of the treatment procedures</p>
<p><b>Al Qadire, M. (2018).</b></p>	<p>-To explore Jordanian public preference on cancer diagnosis disclosure and the type of information they need.</p>	<p>- Quantitative Method - A descriptive cross-sectional survey design was used. -The sample consisted of 485 participants who were conveniently selected from the Jordanian public.</p>	<p>Jordan</p>	<p>- This study marks a point of change in public thinking about health issues. Jordanian public preferred to be fully informed of their cancer diagnosis. - They wanted information about their prognosis, treatment and the available</p>

				supportive services.
<b>Borgan et al. (2018)</b>	-To explore the truth disclosure Practices of physicians in Jordan, a developing country.	- Quantitative Method - A descriptive cross-sectional survey design was used - The sample consisted of 240 physicians from four major hospitals in Amman, Jordan.	Jordan	- Most respondents opt to disclose the truth; however, the vast majority of these respondents make exceptions. -Instances of non-disclosure are primarily motivated by sociocultural constructs.