Original Article :

Patients' Disclosure Preferences when Hypothetically Diagnosed with a Terminal Illness

Sharifah Alsayed[1], Farhan F. Alshammari[2]*, Abdalkarem F. Alsharari[3], Fuad H. Abuadas[3], Fouzia, Mahboub[1], Eddieson, Pasay-an [2], Zayed D. Alsharari[4], and Ebaa M. Felemban[5]

1. College of Nursing, King Saud bin Abdulaziz University for Health Sciences, Saudi Arabia.

2. College of Nursing, University of Hail, Saudi Arabia.

3. Nursing Department, College of Applied Medical Sciences, Jouf University, Saudi Arabia.

4. Faculty of Applied Medical Sciences, University of Tabuk, Saudi Arabia.

5. Nursing Department, Faculty of Applied Medical Sciences, Taif University, Saudi Arabia.

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Corresponding Author:
Abdalkarem F. Alsharari
Nursing Department, College of Applied Medical Sciences,
Jouf University, Saudi Arabia. Phone: +966557470077 Email: afalsharari@ju.edu.sa

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Abstract

Background & Aims:

Breaking bad news to patients is a challenge for physicians, nurses, and other healthcare professionals in various clinical settings. This study aims to explore patients' preferences when being told about an emerging life-threatening terminal illness, such as cancer, and to determine specific factors that can affect individuals' responses upon the disclosure of the disease and its prognosis.

Methods:

We employed a quantitative-cross sectional design using a convenient sample. A total number of 814 participants responded to an online survey invitation from four major cities in Saudi Arabia. Descriptive analysis was used to represent the socio-demographic characteristics of the participants, and the Chi-square ($\chi 2$) test was performed to analyze the differences in the disclosure preferences.

Results:

Most participants preferred to be directly informed

الملخص

الخلفية و الاهداف :

إبلاغ المرضى بالتشخيص المرضي في حالة الاصابة بمرض عضال يشكل تحدي للأطباء والممرضين وغيرهم من المتخصصين في مجال الرعاية الصحية في مختلف البيئات السريرية. تهدف هذه الدراسة إلى استكشاف ما يفضله المرضى عندما يتم إخبارهم عن مرض عضال ناشئ يهدد الحياة مثل السرطان،

طريقة البحث :

تم استخدام تصميم مقطعي وصفي باستخدام عينة ملائمة. استجاب ما مجموعه ٨١٤ مشاركا لدعوة استطلاع عبر الإنترنت من أربع مدن رئيسية في المملكة العربية السعودية. واستخدم التحليل الوصفي لتمثيل الخصائص الاجتماعية - الديمغرافية للمشاركين، وتم إجراء اختبار تشاي سكوير لتحليل الاختلافات فيما يفضله المرضى عند الكشف عن المرض وتشخيصه.

النتائج :

فضل معظم المشاركين أن يكونوا على علم مباشر بالتشخيص الناشئ (٨٥,٧٪)، ورغبوا في أن يكونوا مع أسرهم عند الكشف عن المرض (٩٨,٣٪)، وفضلوا المشاركة بشكل فعال في خطة صنع القرار والعلاج. وأشارت المشاركات إلى أن النساء أكثر حرصا على الكشف عن التشخيص من الذكور وكما أشارت النتائج ايضا الى ان المشاركين المتزوجين كانوا أكثر حرصا على الكشف عن التشخيص

about an emerging diagnosis (85.7%), wished to be with their family upon the disclosure of the disease (98.3%), and preferred to be actively involved in the decision-making and treatment plan. Female participants noted to be keener for a diagnosis disclosure than males $\chi2(2) = 18.7$, $p < .01$, and the same observation seen in singles compared to married participants, $\chi2(4) = 10.91$, $p < .05$.

Conclusion:

This study investigated public responses and preferences when being told about a terminal medical diagnosis. Healthcare providers are advised to plan ahead and make a strategy to report bad news to lessen the psychological burden on patients and their families.

Keywords:

Breaking bad news, disclosure preferences, terminal illness, Saudi Arabia

من غير المتزوجين.

الخلاصة:

حققت هذه الدراسة في الاستجابات والتفضيلات لدى المشاركين عند الكشف عن المرض وتشخيصه الطبي النهائي. بناءا على ذلك ينصح مقدمو الرعاية الصحية بالتخطيط للمستقبلي ووضع استراتيجية للإبلاغ عن الأخبار السيئة لتخفيف العبء النفسي على المرضى

Introduction

Revealing the truth to a patient will support the whole process in instituting an optimum trust between healthcare providers (HCPs) and their patients [1]. As such, this enables patients and their families to be prepared, involved and make informed decisions that confine with their belief system, values, and cultural norms [2]. However, telling the truth can result in unexpected responses or reactions by patients and their families. Thus, this needs proper involvement of psychological, emotional, and spiritual support. Because when bluntly telling the truth can result in denial, frustration, and anger, which could affect patients' comprehension, decision-making abilities and consequently disrupt any proposed treatment options suggested by their HCPs [2].

While telling the truth might be difficult on the part of the HCPs' side, the need to strategize how to inform should be of utmost concern. Such consideration, therefore, includes communicating the needed information and the proper channels for communicating it [3]. Telling the truth encompasses disclosure of the diagnosis, the disease prognosis, treatment options, as well as the impact of the disease on the affected patient's social and work life [4-6]. Preferences refer to whether a person (e.g., patient) likes to be informed of their terminal disease findings. While responses

pertain to psychological and emotional reactions of a person when informed about a life-threatening terminal diagnosis [5, 6].

Previous studies on disclosing unfavorable medical diagnosis or prognosis have been explored in a variety of cultures and contexts [6, 7]. The communication process and who should be involved differs from various countries, and this can be greatly influenced by people's sociocultural backgrounds. For instance, the family involvement and needs for information and being updated about a critically sick family member is of great importance for Saudi families [7]. Because once fulfilled, it can relieve the family distress, otherwise, it may produce distress among the family, and create an untrusted relationship with the medical team [7]. In the Asian perspective, physicians have to struggle to disclose the truth to the patient and family members [4], while most physicians in North America and Europe can clearly and directly tell the diagnosis [8-10]. While telling the truth is an ethical responsibility, it is the ways of saying that can impact the responses [11]. As such, the traditional beliefs of the American physicians that disclosing diagnosis can likely harm and is distressing to patients. Also, the assumption that disclosing the diagnosis can result in unwarranted psychological stress [12, 13]. It can be argued, however, that not telling the truth can result in prohibiting the patient from participating in treatment options due to lack of information on the disease prognosis [14], thus, disclosing the information must be customary[15]. In this context, the patients themselves are allowed to participate in their treatment options.

With the similar assumption of the previous study, the disclosure preferences of the public seemed unclear and that the need for further information must be undertaken[16]. To date, there have not been published studies concerning the population of the Kingdom of Saudi Arabia (KSA) on their disclosing information preferences and responses when being told about an emerging terminal illness. This topic is of great interest to be explored among such populations with very strong religious backgrounds and very strong family connection bonds. Therefore, the disclosure preferences and responses of patients when newly diagnosed with a life-threatening disease are of paramount importance in the Saudi context. As such, it gives a better understanding to HCPs on the perceptions and preferences of patients and their families, and it could facilitate ways to communicate such sensitive and life-changing health information to the concerned individuals. Indeed, knowing the insights and preferences of such vulnerable people makes the difficult task of breaking bad news, and com-

municating other vital information about the emerging health issue, much easier for HCPs [17]. It is evident that when appropriate strategizing communication skills and techniques are deployed when breaking bad medical news to patients and/or their families, it is more likely to increase the patients' acceptance of the new reality, convey trust, and enhance positive two-way communications [2]. From a workplace safety perspective, it could prevent violence against medical staff, allow HCPs to deescalate a violent person, and deal with difficult people 18. We can also argue that it saves a lot of time too for all parties and shortens the length of hospital stay for hospitalized patients. However, to better understand these subjective individuals and collective thoughts and perceptions, which are significantly shaped by demographical and psychosocial factors, we need to study the communities where we practice.

This study aims to explore the preferences, attitudes, and responses of individuals from the population when hypothetically diagnosed with a life-threatening terminal illness. Cancer was used in this paper to serve this purpose since it is a widely known terminal illness among the public. Some reports indicate a dramatic increase in the incidence of cancer in the past decade in KSA, which could be due to the revolutionary change in socioeconomic status in the country. This necessitates the establishment of a national plan to combat this surge [17]. The current study aims to answer the following research questions; a) What are the disclosure preferences, attitudes, and responses of individuals when hypothetically diagnosed with a life-threatening terminal illness? b) What are the differences in participant's disclosure preferences based on their demographic and professional characteristics?

Materials and Methods

Design

This was a cross-sectional study using an online survey questionnaire to collect data from the public about their preferences and responses related to the disclosure of sensitive medical information in case they have been diagnosed with a terminal disease such as cancer.

Population and Sampling

The sample calculation using G*Power 3.1.9.4 software (2019) indicated that for proportions difference between two independents proportions assuming a significance level (α) of 0.05, a medium effect size, and a power of 0.80 would require a minimum sample size of 776 participants. Therefore, additional participants (814 participants) were approached to participate in the study to increase the power for additional analyses.

A convenient sample of 814 people who live in the KSA was recruited. In particular, the sample was taken from the following major cities; Jeddah, Riyadh, Makkah, and Hail. These locations have large cities with semi-dense areas. The inclusion criteria were as follow; an adult person living in KSA, able to communicate in Arabic and/or English, able to respond to an electronic invitation link on a mobile phone or a computer. However, medical professionals, the pediatric population, inpatients, and individuals with other comorbidities such as stroke, end-stage renal failure, and psychological disorders were discouraged not to participate in the survey.

Recruitment Strategy

This research used an online survey questionnaire developed via the google-forms platform to collect the data. The questionnaire included an informed consent at the beginning of the survey to inform participants about the purpose of the study, its benefits and risks, and why it was being conducted. If agreed, they could proceed to answer all items, otherwise, they could exit the survey without providing information. The primary investigator's contact information was provided in case some clarifications or questions arise by the participants to ease communication. When all the items were answered, a debriefing and a confirmation to participate statement appeared to users. After submitting, a thank you letter with a link is shown. Users were encouraged to share the link with those they knew, within their locality as potential participants, to invite them via social media applications. The data collection period extended from November 2019 until January 2020.

The development of the study data collection tool

The study used a questionnaire to collect data, which was developed by the researchers' following an extensive review of published research. The final questionnaire consists of 3 main parts. The first part is the participants' demographic characteristics: age, gender, marital status, nationality, educational level, and economic status. The second part includes hypothetical scenario items, it is further divided into three subsections: disclosure preference (9 items), a preferred pathway of disclosure (4 items), and participants' attitude toward disclosure (14 items). The third part consists of four items concerning non-disclosure reasons. The Likert scale items in this questionnaire consist of three levels (1) disagree, (2) neutral, and (3) agree.

Both Arabic and English versions of the questionnaires were developed by translating the final English copy into Arabic using a two-way translation by two independent (native Arabic) translators, who have med-

ical backgrounds and experience in the subject. Furthermore, the questionnaire underwent validity and reliability tests as follows; firstly, the researchers invited five panels of experts who are known for their expertise in the subject area of community nursing care. One member of the panel is an associate professor who has extensive experience in the field of psychometric validation and tool development. The panel advised some modifications to the items, some wording, and other remarks to enhance the tool, which all were adapted into the final copy. Secondly, the tool was subjected to the content validity index (CVI). The questionnaire obtained an overall CVI score of 0.72 for relevance and a CVI score of 0.70 for clarity, indicating a high level of content validity. Overall, the questionnaire yielded a reliability coefficient of 0.78.

Finally, the tool was piloted among 30 participants, who met the inclusion criteria but were excluded from the current dataset, to assess the suitability of the items to the culture, clarity of language, time management, and foresee any unexpected issues. As a result, minor wording and text adjustments were made. Overall, the questionnaire yielded a reliability coefficient of 0.78.

Ethical Consideration

This study was approved by the institutional review board (IRB) of the Health Affairs Directorate of Hail region, KSA (IRB log number: 2020-13). Participation was voluntary and no personal data were recorded or kept during the data collection process. Informed consent was attached to the electronic form during data collection.

Statistical Analysis

The research data were coded, cleaned, and entered for analysis using SPSS version 24 (Armonk, NY: IBM Corp. USA). Descriptive analysis using the frequency and percentage were used to represent the socio-demographic profile of the respondents and the items related to the disclosure of the terminal illness as perceived by the participants. In addition, a Chi-square ($\chi 2$) test was performed to analyze the differences in participants' disclosure preferences based on demographic and professional characteristics.

Results

Participants' Socio-demographic Characteristics

A total of 814 participants completed the study, among which 534 were females (65.6%). Participants' age varied between 17 and above 60 years of age; 43.4% were in the category of 21-30 years. The majority of participants (93.4%) were Saudis. The highest educational level was divided into four categories: Intermediate school, secondary school, undergraduate (Bache-

lor's degree), and postgraduate level of education (Master's or Doctorate). The majority of the participants (85%) fall within the Undergraduate educational level. More than half of the participants (55.5%) were single. In addition, the majority of the participants (85.1%) reported they had no terminal illness, and only one-third (30.5%) of them knew someone with a terminal illness.

Terminal Illness Disclosure Preference

When the study participants were asked about their disclosure preferences of a hypothetical diagnosis and prognosis of a terminal illness, the majority of participants (85.3%) preferred the direct disclosure of the terminal illness diagnosis (85.3%), and the disease prognosis (77.5%). However, a small proportion of the participants favored the non-disclosure option of the diagnosis (2.7%), and the disease prognosis (7.2%). Regarding the preferred level of disclosure (full or partial), most respondents (84.3%) preferred full disclosure. On the other hand, approximately half of the participants (51.3%) expressed interest in obtaining more information about the expected length of survival.

Most participants (78.7%) preferred to be actively involved in the decision-making and treatment plan of their disclosed terminal illness. Less than half of the participants (39.3%) did not like to be involved in the decision-making and treatment plan and preferred a healthcare specialist to decide their treatment course instead of them. Besides, a small proportion (14.7%) preferred to delegate the treatment plan decisions to a family member (Table 1).

Table 1. Descriptive statistics (participants' response frequencies) of diagnosis and prognosis disclosure preferences (N = 814).

Disclosure Preferences	Agree, % (N)	Neutral, % (N)	Disagree, % (N)
I would like to be informed about terminal illness diagnosis	85.3(694)	12(98)	2.7(22)
I would like to obtain information regarding my diagnosis of a general nature but not in detail (partial disclosure).	72.1(587)	12.3(100)	15.6(127)
I would like to be given all information regarding my diagnosis (full disclosure).	84.3(686)	11.2(91)	4.5(37)
I would like to obtain information on the expected prognosis and complication of terminal illness	77.5(631)	15.2(124)	7.2(59)
I would like to obtain information on the expected side effects of the terminal illness treatment plan	82.2(669)	10.9(89)	6.9(56)
I would like to be told about my prospects of the expected length of survival eventually	51.2(417)	20.1(164)	28.6(233)
I would like to decide on my terminal illness treatment plan	78.7(641)	16.2(132)	5(41)
I Would like specialists to decide on my terminal illness treatment plan (Instead of mine)	39.3(320)	34.5(281)	26.2(213)
I Would like the family to decide on my terminal illness treatment plan (Instead of mine)	14.7(120)	30.1(245)	55.2(449)

Desired pathways of disclosure

Regarding the desired pathway of disclosure, the majority of participants (N=702, 86.2%) indicated that they preferred to have a face-to-face disclosure of the diagnosis and/or the prognosis of their terminal illness, while others (N=107, 13.1%) desired a telephone disclosure. Likewise, a large proportion of the participants (80.5%) indicated their preference to be notified of their terminal illness directly by a healthcare specialist first, while (51.2%) wished to be told by a family member first.

Participants attitude toward terminal illness disclosure

Regarding positive and negative consequences of disclosure represented by the expected participant attitudes, the majority of participants agreed that disclosure would yield positive outcomes (82.8% improve understanding of the disease, 78.1% enhance the communication between patient and health care providers, 76.9% increase the trust relationship between patient and health care providers, 75.1% improve patient cooperation, 73.3% increase commitment to the treatment plan, and 60.4% reduce confusion). On the other hand, some participants indicated that disclosure would yield negative consequences (46.3% increase level of stress, 37.8% may lead to depression, 12.7% lack of commitment to the treatment plan, and 9% provoke suicidal ideation). Almost one-third of participants (N=263, 32.3%) indicated that males have a greater disclosure tolerance than females, while (N=143, 17.6%) indicated that females have a greater tolerance. Approximately half of the participants (46.3%) agreed that disclosure would eventually improve patients' quality of life (Table 2).

Table 2. Descriptive statistics of the participants' attitude toward disclosure (N = 814).

Participants' attitude	Agree, % (n)	Neutral, % (n)	Disagree, % (n)
Disclosure of terminal illness diagnosis will increase my level of stress	46.3(377)	39.4(321)	14.3(116)
Disclosure of terminal illness diagnosis will lead to depression	37.8(308)	48.6(396)	13.5(110)
Disclosure of terminal illness diagnosis will increase my hope	38.7(315)	47.9(390)	13.4(109)
Disclosure of terminal illness diagnosis will increase suicidal ideation	9(73)	31.1(253)	60(488)
Disclosure of terminal illness diagnosis will increase my commitment to the treatment plan	73.3(597)	22.4(182)	4.3(35)
Disclosure of terminal illness diagnosis will increase my lack of commitment to the treatment plan	12.7(103)	33.3(271)	54.1(440)
Disclosure of terminal illness diagnosis will reduce my confusion	60.4(492)	29.6(241)	10(81)

Participants' attitude	Agree, % (n)	Neutral, % (n)	Disagree, % (n)
Disclosure of terminal illness diagnosis will increase the trust relationship between patient and health care providers	76.9(626)	17.3(141)	5.8(47)
Disclosure of terminal illness diagnosis will enhance the communication between patient and health care providers	78.1(636)	18.3(149)	3.6(29)
Disclosure of terminal illness diagnosis will improve my understanding of the disease	82.8(674)	13.9(113)	3.3(27)
Disclosure of terminal illness diagnosis will improve patient cooperation	75.1(611)	21.1(172)	3.8(31)
Disclosure of terminal illness diagnosis will improve the patient quality of life	46.3(377)	43.1(351)	10.6(86)
Male can tolerate disclosure of terminal illness diagnosis rather than female	32.3(263)	39.2(319)	28.5(232)
Female can tolerate disclosure of terminal illness diagnosis rather than male	17.6(143)	48.6(396)	33.8(275)

Reasons for Non-disclosure of terminal illness

Of note, the participants disagreed with the following non-disclosure reason; "health care providers have no enough time" (60.7%), "when the patient has a low level of education" (45%), but participants agreed with the following non-disclosure reason; "when health care providers have no enough courage to inform about the diagnosis" (48.8%). Details of the participants' agreement level with the non-disclosure reasons are presented in Table 3. Differences in participant's disclosure

Table 3. Descriptive statistics of the participant perception of non-disclosure reasons (N=814).

Participant's perception	Agree, % (N)	Neutral, % (N)	Disagree, % (N)
Non-disclosure of terminal illness diagnosis is preferred when the patient has a low level of education	18.2(148)	36.9(300)	45(366)
Non-disclosure of terminal illness diagnosis is preferred when health care providers have no enough time to explain about diagnosis	14.4(117)	24.9(203)	60.7(494)
Non-disclosure of terminal illness diagnosis is preferred when health care providers have no enough courage to inform about diagnosis	48.8(397)	30.3(247)	20.9(170)

preference based on demographic and professional characteristics

A Chi-square ($\chi 2$) test was performed for the categorical variables to assess disclosure preference concerning age, gender, educational level, nationality, marital status, and economic status. The results revealed significant statistical differences in disclosure preference concerning gender, $\chi 2(2) = 18.7$, $p < .01$, with females expressing a more preference for terminal illness diagnosis disclosure than males. It was also found that single participants were more likely to express a preference for terminal illness disclosure than married participants, $\chi 2(4) = 10.91$, $p < .05$. How-

ever, other demographic and professional characteristics revealed no significant differences in disclosure preference (Table 4).

.Table 4. Analysis of terminal illness disclosure preferences by categorical variables

Categorical variable	Disclosure preference			Chi-square test		
	Disagree	Neutral	Agree	χ^2	Df	***P*-value**
Gender						
Male	12	50	218	18.7	2	.000**
Female	10	48	476			
Age						
15-20	2	17	128	13.44	8	.098
21-30	5	39	309			
31-40	8	27	135			
41-50	6	11	84			
51-60	1	4	38			
Nationality						
Saudis	21	93	646	.62	2	.74
Non-Saudis	1	5	48			
Marital status						
Single	5	51	396	10.91	4	.028*
Married	16	45	281			
Others	1	2	17			
Economic status						
Low	1	9	59	5.97	4	.20
Intermediate	19	79	602			
High	2	10	33			

(Notes: * $p < 0.05$; ** $p < 0.01$ (two-tailed

Abbreviations: Df, degree of freedom

Discussion

This study explored the disclosure preference and responses of individuals from the population when diagnosed with terminal diseases. Specifically, it looked into the determinant variables such as the demographic information that can affect an individual's preference and responses. The results revealed that the demographic information of the mainstream population has no influence on their preferences to disclosure the terminal disease. The earlier study confirmed that irrespective of variables like sex, an individual's age, culture, and civil status, and some particular determinants differ from each individual [17]. Other studies show that most patients prefer to be informed and that it might benefit from timely recognition of the terminal phase[2,18]. While, patients, families, and caregivers may differ on disclosure preference, patients themselves still preferred to have a direct disclosure with the palliative care option [19]. It is for the fact that while

the preferences differ from one patient to another, it is important to note how the physician assesses their readiness, which helps to understand their condition. This finding is very important to the physician to strategize how this terminal disease is communicated and be prepared to respond to the individual's reaction. Moreover, this helps in addressing the fear of putting stress on the patient and their family by way of addressing their concerns in a timely and considerate manner.

Married individuals were found to respond differently when being told about their terminal disease. One possible reason could be the fact that married people may understand the impending burden that creates adjustment to their married life because of the diagnosis. Spouses often feel devastated because they have not considered what life together with illness would involve[20]. De-Vleminck and colleagues postulate that married people and even those who share a house are found to prefer disclosure information about their illness and to be provided to their family members [16]. Conversely, other variables like age, sex, nationality, and educational level were not found to have a significant difference in to perceive response of the mainstream population. Although, helping the individual or the family member in their grieving process as a response to knowing their terminal disease is an important consideration. Indeed, helping the family member to be open to the grieving process and providing support and acceptance regardless of the reaction are very important 20. The finding that married individuals respond differently is a clear indication that when diagnosed with terminal illness support and presence of family are highly needed.

One of the preferred approaches of the mainstream population when being told about terminal diagnosis is being with their loved ones or relatives. Current studies showed that patients preferred to be aware of their diagnosis and to involve their families [21], and most patients would always want their relatives to be informed about their disease and prognosis [16]. In Saudi Arabia, the majority of the general population would prefer to have the family be present when being told about their terminal diagnosis [22]. As such, consideration of the responsibilities of the family-like emotional support is very essential. Having preferred to know the diagnosis first before their family is one of the considerations that healthcare professionals have to look into whenever disclosing the diagnosis.

These findings are very important for healthcare personnel to consider when disclosing the disease information. Indeed, it helps them to strategize a way of telling

the truth where prompt decision-making of the patient and families are of the essence in the treatment process. This can prepare the physicians to convey the actual information needed by the patients and their families.

Limitations of the Study

Other variables such as religion and culture are not explored in this study, which may give a clearer picture of how the physician would disclose the information in that context. This can be part of future exploration. Moreover, the self-report of the general population is prone to bias because the situation is hypothetical. An actual sample of the patient can be included to explore their actual perception of the phenomenon.

This study highlights information and understanding on the preference and responses of the general population when being told about their terminal diagnosis. Therefore, this study results recommend tailored fit strategies from the medical health workers when disclosing terminal diseases. As such, this will lessen the psychological burden to the patient and family.

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