RESEARCH ARTICLE

Iranian Cancer Patient Perceptions of Prognosis and the Relationship to Hope

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Abstract

Background: The aim of this study was to investigate Iranian cancer patient perceptions of their prognosis, factors that influence perceptions of prognosis and the effect this has on patient level of hope. Materials and Methods: Iranian cancer patients (n=200) completed self-report measures of their perceptions of their prognosis and level of hope, in order to assess the relationship between the two and identify factors predictive of perceptions by multiple linear regression analysis. Results: Cancer patients perceived of their prognosis positively (mean 11.4 out of 15), believed their disease to be curable, and reported high levels of hope (mean 40.4 out of 48.0). Multiple linear regression analyses demonstrated that participants who were younger, perceived they had greater family support, and had higher levels of hope reported more positive perceptions of their cancer prognosis. Conclusions: Positive perceptions of prognosis and its positive correlation with hope in Iranian cancer patients highlights the importance of cultural issues in the disclosure of cancer related information.

Keywords: Neoplasm - prognosis - hope - disclosure - perception of prognosis

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Introduction

The diagnosis of cancer causes significant emotional distress for patients and their families (Banning et al., 2010; Carlson et al., 2004; Mystakidou et al., 2004) and some studies showed that cancer patients are at risk of suicide (Lee et al., 2014) and experiencing anxiety and depression (Tuncer et al., 2014) and they had impaired function in many aspects of their life (Nazik et al., 2014). So, the disclosure of cancer-related information to patients can be particularly challenging for health care professionals (Mystakidou et al., 2004; Clayton et al., 2005; Franssen et al., 2009; Kazdaglis et al., 2010). Disclosure of the cancer diagnosis and prognosis to the patient is the norm in Western countries (Wood et al., 2009), although there are reports of significant numbers of Western cancer patients who are unaware of their prognosis (Sinclair, 2006). In contrast, cancer patients in non-Western countries are often not told their diagnosis (Hamadeh and Adib, 1998; Numico et al., 2009; Jawaid et al, 2010), and even less so their prognosis (Zamanzadeh et al., 2013). Even though the practice of non-disclosure has changed in non-Western countries in the last decade (Zamanzadeh et al., 2013; Horikawa et al., 1999; Surbone, 2006), the majority of patients in Middle Eastern countries (Oksüzoğlu et al, 2006 Jawaid et al, 2010) including Iran (Larizadeh, 2007), still do not know the prognosis of their disease (Zamanzadeh et al., 2013). In addition, the results of one study showed that most of Iranian breast cancer patients did not prefer to disclose their diagnosis to their friends and co-workers (Mirzaii et al., 2014).

In the Middle Eastern and Iranian context, where the disclosure of prognosis is not common practice (Zamanzadeh et al., 2013), it is unknown how patients make sense of and perceive of their future and their disease prognosis. One qualitative Iranian study found that cancer patients commonly overestimated a positive prognosis and had unrealistic expectations of cure (Rahmani, 2012). Despite this one small study, there is no evidence describing how cancer patients in Iran or other Middle Eastern countries perceive of their prognosis.

There is also limited and mixed evidence regarding the effects of cancer prognosis disclosure on those who do become aware of this information (Hagerty, 2005). While some research suggests that there are few associated negative effects (Barnett, 2006; Last & van, Veldhuizen, 1996; Leung et al., 2006; Yun et al., 2010), there is some evidence that this information negatively effects survival (Yun et al 2011; Kim et al., 2013), physical (Papadopoulos et al., 2011) and mental health (Chochinov et al., 2000;

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Mack et al., 2006; Burridge et al., 2009; Chan, 2011; Papadopoulos et al., 2011) and quality of life (Tang et al., 2008) of cancer patients. The disclosure of cancer-related information very likely has a significant impact on a patient's degree of hope. Hope is a situational and goal directed expectation aimed at obtaining positive and possible outcomes in the future (Kylmä & Vehviläinen, 1997 ; Benzein et al., 1998; Benzein et al., 2000; Duggleby et al., 2010; Eliott & Oliver, 2002). Hope is a central concept in the provision of care (Lohne & Severinsson, 2006) and is a primary mechanism through which cancer patients cope with future uncertainties (Benzein et al., 1998). The few studies that investigated the impact of the disclosure of cancer-related information on a patient's hope have produced mixed results. Lin et al found that among Taiwanese patients, awareness of their cancer diagnosis did not negatively impact cancer patient's hope (Lin & Tsay, 2005). In the study by Helft et al cancer patient's awareness of their prognosis resulted in declines in hope (Helft et al., 2003). In contrast, discussions about prognosis with parents of a child with cancer have been demonstrated to have little effects on parents' levels of hope (Mack et al., 2007). Clearly, much remains unknown about the effects of cancer prognosis disclosure on mental health, including hope, of cancer patients.

Those who are told their diagnosis but not their prognosis, such as the majority in Iran, still contemplate their future and the toll cancer will take. Cancer patients' perceptions of their prognosis and the effect this has on their hope for the future are not understood, particularly in the Middle Eastern cultural context. The aim of the present study was to investigate Iranian cancer patients' perceptions of their prognosis, factors that influence perceptions of prognosis and the effect this has on patient's level of hope for the future. Understanding how patients perceive their cancer prognosis has critically important implications for the subsequent provision of health information and care. This knowledge is essential for designing culturally appropriate guidelines for the disclosure of cancer-related information, especially related to disease prognosis.

Materials and Methods

Design and setting

This descriptive - correlational study was conducted between April and September, 2012, in East Azerbaijan Province, Iran. This is a north-western province of Iran with an approximate population of 3.6 million (Statistical Center of Iran, 2007). Study participants were recruited from in-patient wards and out-patient clinic of Ghazi Tabatabay hospital, as well as the private oncology clinics. The Ghazi Tabatabay hospital is the main cancer centre in East Azerbaijan Province, and is affiliated with the Tabriz University of Medical Sciences. The Tabriz University of Medical Sciences Regional Ethics Committee approved this study.

Participants

All cancer patients who received curative or palliative treatments in Ghazi hospital or the three private oncology clinics were invited to participate. Patients were eligible to participate who were: older than 18 years of age, aware of their cancer diagnosis, mentally and physically able to participate. Using convenience sampling methods, 105 of 112 (94%) cancer patients in Ghazi hospital and 95 of 115 (83%) cancer patients in private oncology clinics agreed to participate.

Measures

The instrument used to collect data consisted of three parts including:The first part was a checklist to ascertain study participants demographic and disease-related characteristics.The second part consisted of three items that assessed participants' perceptions of their prognosis. Each item was based on a 5-point Likert scale from very low (score 1) to very high (score 5), with a total possible score ranging from 3 to 15 and a higher score indicating a more positive perception of prognosis. The research team developed this questionnaire in consultation with the Regional Ethics committee.

The third part assessed participant's level of hope using the Herth Hope Index (HHI) (Herth 1991). HHI is a 12-item questionnaire based on a 4-point Likert scale from

Table 1. Some Demographic and Disease-Related Characteristics, Level of Hope and Perceptions of Prognosis among Cancer Patients Partcipated in The Study

Variables	n (%)	Perceptions of prognosis (mean ± SD)	p-value
Age in years, mean (SD)	44.69 (15.11)	r = -0.21	0.003
Sex*			
Male	93 (47.4)	11.4±2.1	0.557
Female	103 (52.6)	11.6±2.0	
Marital status*			
Single	26 (13.1)	11.3±2.3	0.635
Married	173 (86.9)	11.5±2.0	
Education level			
Illiterate	36 (18)	10.9±2.0	0.016
Primary	83 (41.5)	11.1±2.1	
Diploma	46 (23)	11.9±2.1	
University degree	35 (17.5)	12.1±2.0	
Perceived family support			
Weak	15 (7.9)	9.6±2.2	<0.001
Moderate	12 (6.3)	10.2±2.5	
Good	27 (14.1)	11.1±1.9	
Excellent	137 (71.7)	11.8±1.9	
Type of cancer			
Hematologic	32 (16)	11.4±2.1	0.449
Gastro-intestinal	38 (19)	11.2±2.5	
Lung	36 (18)	11.2±2.0	
Breast	28 (14)	11.8±1.9	
Prostate	11 (5.5)	10.7±1.3	
Skin	16 (8)	11.7±2.1	
Uterus	12 (6)	12.6±1.3	
Others	27 (13.5)	11.4±2.2	
Months aware of diagnosis, mean (SD)	28.01 (36.29)	r=0.07	0.346
Level of hope mean (SD)	40.4 (6.1)	r = 0.41	<0.001

** Not all participants responded to these items
SD = standard deviation

Table 2. Responses of Cancer Patients for each Item of Perceptions of Prognosis Questionnire

Items	Very low, n (%)	Low, n (%)	Average, n (%)	High, n (%)	Very high, n (%)	Mean (SD)
Likelihood the treatments will cure me of cancer	2 (1.0)	9 (4.5)	54 (27.1)	75 (37.7)	59 (29.6)	3.90 (0.91)
Likelihood of living normal lifespan	0 (0)	9 (4.5)	100 (50)	61 (30.7)	29 (14.6)	3.55 (0.79)
Curability of the disease	1 (0.5)	9 (4.5)	42 (21.1)	86 (43.2)	61 (30.7)	3.99 (0.86)
Total score, mean (SD)			11.44 (2.06)			

strongly disagree (score 1) to strongly agree (score 4), with a total possible score ranging from 12 to 48; a higher score indicates a higher level of hope. The HHI demonstrated good internal consistency in pervious Iranian studies (Abdullah-Zadeh et al., 2001; Pourghaznein et al., 2003).

For use in the present study, 14 academic staff from TUOMS assessed the validity of the entire instrument, and minor revisions were made accordingly. The instrument was found to be reliable using pilot data of 29 cancer patients, with a Cronbach α coefficient of 0.88 for perception of prognosis and 0.90 for HHI.

Procedure

The potential study participants were identified by four research assistants at the Ghazi hospital and private oncology clinics. These assistants described the study aims and procedures and invited potential participants to take part in the study. All study participants provided written informed consent. Since it is common in Iran that cancer patients are not told their diagnosis, one important challenge in this study was determining whether potential participants knew their diagnosis because only patients who knew their diagnosis were to be invited to participate. To overcome this challenge, research assistants first questioned the potential participant's family member or health care professional to assess whether the diagnosis had been disclosed to the patient. This information was then validated with the potential participant themselves, during a private interview when they were invited to participate. This procedure was approved by the Regional Ethics Committee.

All literate participants completed the study questionnaires independently following short instruction from the research assistants. The questionnaires of illiterate participants, or those with a low level of education, were completed by research assistants during a short and private interview. All data was collected in private rooms in the Ghazi hospital and private oncology clinics.

Statistical analysis

Descriptive statistics were calculated for demographic and disease-related characteristics, perception of prognosis, and level of hope. The associations between demographic characteristics, disease-related characteristics hope and perceived prognosis were assessed through independent samples t-test, one-way analysis of variance and Pearson correlation coefficient. Multiple linear regression (backwards elimination) was conducted to identify predictors of perceived prognosis. The data analyses were performed with SPSS software (version 16, SPSS Inc., Chicago, IL).

Results

Participants characteristic

The mean age of participants was 44.7±15.1 years (range 18 to 80). Other demographic and disease-related characteristics of participants are presented in Table 1. The majority of participants were female, married, educated at a primary level, had a gastro-intestinal cancer and perceived their family support as excellent.

Perception of prognosis and level of hope

Study participants' total perceptions of prognosis score ranged from 6 to 15, with a mean of 11.4 out of a possible maximum score of 15, as evident in Table 2. A mean score of 11.4 is indicative of a positive perception of cancer prognosis. The study participant's mean level of hope using the HHI was 40.40 (SD=6.1), with levels of hope ranging from 16 to 48. These scores indicated that Iranian cancer patients in this study had high levels of hope.

Factors related to perceptions of prognosis

The mean score of study participants' perceptions of prognosis is reported as per the participant characteristics in Table 1. Educational level, perceived family support, current age and hope were significantly related to perception of prognosis.

Predictors of perceptions of prognosis

For the multiple linear regression analysis, age, sex, marital status, education level, perceived support from family, time since awareness of diagnosis and level of hope were entered into the model. As shown in Table 3, participants who were younger, perceived they had greater family support, and had a higher level of hope had more positive perceptions of their cancer prognosis.

Table 3. The Results of Multiple Linear Regression about Predictors of Perception of Prognosis among Cancer Patients Partcipated in The Study

Variables	β	CI 95% β	p-value
Hope	0.093	0.043-0.143	<0.001
Age	-0.021	-0.035	0.019
Perceived family support	0.544	0.216-0.871	0.001

Discussion

To our knowledge, this study is the first to investigate the relationship between perceptions of prognosis and hope among Middle Eastern cancer patients. The results demonstrate that Iranian cancer patients positively perceive of their prognosis, possibly indicating that most had not received accurate information detailing their prognosis or had received positive information in this regard. This finding is in line with previous studies wherein 93% of Iranian cancer patients did not know their exact prognosis and the majority thought their disease had a good prognosis (Valizadeh et al., 2012; Larizadeh et al., 2007). Another Iranian study found that the prognosis is only disclosed when it is positive and the worse the prognosis the less likely it is disclosed or truthfully communicated (Zamanzadeh et al., 2013; Rahmani, 2012). The cancer patients in another study reported that the most frequent unmet needs were in the health system and information domain (Abdollahzade et al., 2014). While it might be tempting to conclude that positive perceptions of prognosis in the context of a cancer diagnosis are incompatible, advanced cancer patients and their relatives in both Western countries (Duggleby & Wright, 2004; Eliott & Olver, 2009; Robinson, 2012; Sanatani et al., 2008) and non-Western countries (Banning & Gumley, 2012; de Graaff et al., 2010) have reported believing their cancer is curable. It remains unknown whether this is the result of the non-disclosure of the cancer prognosis, as documented in Western (Hagerty et al., 2005) and non-Western countries (Brokalaki et al., 2005; Cavanna et al., 2007; Phungrassami et al., 2003), or, rather, a patients' belief in the power of thinking positively, religion or a miracle cure (Guerrero et al., 2011; Marian, 1990; Widera et al., 2011). It is also possible that the communication of diagnostic and prognositc information is problematic such that even when health care professional provide this emotionally loaded information at a stressful time, patients might misinterpret or fail to remember important details (Brown et al., 2011; Olver, 2012). It should be noted that in this study we conducted no any analysis between curative and palliative cancer patients. In Iranian health care system because of lack of many advanced laboratory technologies physicians do not differentiate between curative and palliative patients or do not inform patients or even their families about it.

The results of the present study indicate that participants had relatively high levels of hope and are consistent with previous Iranian studies (Abdullah-Zadeh et al., 2011; Pourghaznein et al., 2003; Aghahosseini et al., 2012; Jafari et al., 2010) and studies in other countries wherein cancer patients had moderate to high levels of hope (Reynolds, 2008; Utne et al., 2008). Iranian cancer patients have contributed this high degree of hope to the non-disclosure of cancer-related information, health care providers and relatives' indications that their cancer was potentially curable, belief in a miracle cure, religious resources, and the lessening of cancer symptoms following initial treatment (Rahmani, 2012).

In the present study, younger patients perceived of their prognosis more positively, a finding possibly attributable to their higher level of education. But, patients with higher levels of education reported greater negative perception of their disease, a finding that might be the result of these patients having access to more cancer-related information. However, this information might not be accurate, and might be obtained from relatives and unreliable internet sites (Valizadeh et al., 2012). Health care providers and relatives of cancer patients in Iran commonly inspire hope by relaying stories of cured cancer patients and advancements in cancer treatment (Rahmani, 2012). Perhaps, more highly educated patients have greater access to hope inspiring information and so, also have better perception of their prognosis. It is also possible that younger patients were less likely to also have co-morbid conditions and actually have a better prognosis and their positive perceptions of their prognosis were a reflection of better medical odds of overcoming cancer. Clearly, further research is needed.

The participants in this study who reported having greater family support were also more likely to have more positive perceptions of their prognosis. Previous Iranian research suggests that family members frequently discourage the disclosure of any cancer-related information to the patient, and instead reassure the patient that their condition is insignificant and curable (Rahmani, 2012). A positive relationship between hope and social and family support has also been documented (Crothers et al., 2005; Denewer et al., 2011; Zhang et al., 2010), and although this relationship was not testing in the present study, both greater hope and greater family support were related to positive perceptions of disease.

The positive relationship between level of hope and perceptions of prognosis among Iranian cancer patients in the present study is in line with the limited previous research (Helft et al., 2003). One qualitative Iranian study reported that cancer patient's awareness of their prognosis negatively affected their level of hope (Rahmani, 2012). Another study also suggested that communication about prognosis contributes to lower levels of hope among cancer patients (Helft et al., 2003). The evidence thus far indicates that informing Iranian cancer patients about their prognosis may inadvertently undermine their level of hope.

The study results have potential clinical implications. Health care providers need to be aware that most cancer patients positively perceive of their prognosis and in situations where the patient's prognosis is poor, communication ought to be handled with great care as this bad news will be unexpected by most. It is also possible that communicating a poor prognosis to a cancer patient might rob them of hope for their future. While hiding the truth from patients is considered paternalistic in Western countries, in Iran this is not necessarily the case. Careful consideration of the cultural context is paramount when judging the right clinical course of action regarding the disclosure of cancer-related information.

The findings of the present study ought to be interpreted in light of its limitations. Cancer patients' perceptions of their prognosis were measured, yet this information was not compared to their actual prognosis. This is because accurate medical investigations, such as

genetic or laboratory tests, are not always conducted and therefore are unavailable even to health care professionals. Therefore, it is impossible to know the degree to which participants' perceptions corresponded to their medical outlook. Although the disclosure of cancer-related information is uncommon in many Middle Eastern countries, there is variability in the communication of information among the different countries, and even throughout Iran. The findings of this research, therefore, are not necessarily generalizable to other contexts, but do suggest that there is a need for similar research elsewhere. Although there was a good response rate in this study (94% in Ghazi hospital and 83% in private oncology clinics), it is possible that patients who declined participation had predominantly negative perceptions of their prognosis.

Iranian cancer patients have positive perceptions about the prognosis of their disease. Also, participants had relatively high levels of hope and family support. Cancer patients who were younger, perceived they had greater family support, and had a higher level of hope had more positive perceptions of their cancer prognosis. The positive relationship between level of hope and perceptions of prognosis among Iranian cancer patients highlights the importance of cultural issues in the disclosure cancer related information.

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