

Breaking Bad News in Cancer: An Assessment of Maltese Patients' Preferences

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Abstract

Purpose: It is unclear whether Maltese cancer patients wish to know their diagnosis or to what extent they want to be informed.

The aim was to assess patients' preferences for receiving a cancer diagnosis and being involved in the decision-making process, and then compare these with results from similar international studies.

Methods: Two hundred fifty-two Maltese adult cancer patients were invited to complete two standardised tools: the Measure of Patients' Perspective (MPP), assessing patients' preferences for receiving news about their cancer, and the Control Preferences Scale (CPS), examining involvement in decision-making.

Results: Maltese patients rated the 'content' subscale (information given; mean 4.17, SD 0.59) as significantly more important ($p < 0.001$) than 'support' (offering comfort/support; mean 3.73, SD 0.68) and 'facilitation' (how information is given; mean 3.86, SD 0.68). Patients with higher levels of education had significantly higher scores for 'content' ($p = 0.018$) and 'facilitation' ($p < 0.001$) on the MPP, while lower education levels preferred a passive role ($p = 0.01$) on the CPS. Although there is a trend towards a collaborative and even an active role in treatment decisions, patients still exhibit a paternalistic attitude towards their physician. Age, gender and medical variables had no significant influence on response.

Conclusions: Maltese cancer patients want to be informed of their cancer diagnosis, its treatment and prognosis, similar to other international studies. However, 60% of Maltese patients prefer a

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more paternalistic approach towards their physician when compared to other studies.

Keywords

patient preference, patient rights, health literacy, decision making, neoplasms

Introduction

Cancer is a significant disease in Malta, with 1200 Maltese residents presenting with new cancers each year (Malta National Cancer Registry 2002). A diagnosis of cancer goes hand in hand with breaking bad news, which is usually delivered by hospital doctors as the majority of investigations are hospital-based. To break bad news effectively, physicians must devote time to the patient, giving information accordingly, answering any questions that may arise, and dealing with the aftermath of such disclosure. Truth-telling is becoming increasingly advocated and offers far-reaching benefits to all involved.¹

Background

From a medical point of view, bad news has been defined as:

“any information which adversely and seriously affects an individual's view of his or her future”.²

This can be viewed on two levels: a level at which life is temporarily interrupted, such as replacing a hip joint, and a deeper level which threatens the continuity of life, as is the case with malignant disease.³ Unfortunately, the field of oncology is riddled with bad news, ranging from disclosure of a diagnosis, through treatment failure, to recurrence of disease and end of life issues. The way bad news is broken can have a profound effect on improving patients' compliance with treatment, may

lead to a clearer understanding of instructions or symptoms, may help reduce stress and anxiety, and improve overall patient satisfaction.⁴⁻⁵ On the other hand, delivered inappropriately or insensitively, bad news may exert a lasting impact on the ability to adapt and adjust, whilst also inviting the risk of litigation.⁶ Inappropriate delivery of unfavourable news includes usage of unfamiliar medical jargon or giving scanty information. Recipients of such messages may feel confused, anxious or angry.³

In recent decades there has been a dramatic shift towards disclosure of cancer diagnosis in Western Countries, especially in North America, Australia and most of Europe.⁵ The previous paternalistic attitude favouring concealment in order to protect the patient has become overshadowed by the growing importance of safeguarding patient autonomy.⁷ Patients are considered to have a moral and legal right to receive accurate and reliable information, and it remains the doctor's responsibility to deliver the diagnosis accurately and explain treatment options clearly.³ The content of discussions needs to be honest so that patients can provide informed consent about their treatment.⁶ This has undoubtedly been a step in the right direction – patients are now better informed and more respected.⁷

There is no data regarding the standard practice about truth telling to patients in Malta. Only recently, a Patient Charter document was brought into effect locally. Principle 4 of the Charter deals with Shared Decision-Making and Informed Consent, specifying that “one has the right to participate in the collaborative process of decision-making related to one's particular health-care needs and to make an informed consent about one's treatment and care”.⁸ Our research therefore fits in with the

climate in which changes are being made locally in the field of shared decision-making.

Patients and methods

Participants and Procedures

The intention of this cross-sectional survey was to investigate preferences for truth-telling about cancer and involvement in treatment decisions among Maltese cancer patients aged eighteen and over. With a total Maltese population of a little over 400,000 people, Malta has one oncology centre, and the out-patient follow-up clinics were therefore considered an ideal location for recruiting patients for the study.

A consecutive sample of oncology patients were approached in the waiting area by the researcher who was not a member of the oncology team, and were invited to voluntarily complete an anonymous questionnaire in Maltese which would take around twelve minutes. The self-completed questionnaire was presented as a seven-page booklet consisting of an information sheet for patients, demographic and medical data to be filled by the patients and caring physician, and the questionnaires themselves. Field work was carried out every day for two consecutive weeks. The researcher was available at all times to answer any queries and respondents were also furnished with a leaflet about the nature of the study, and contact details of the researcher. Data was collected by quantitative methods.

Inclusion criteria were: diagnosis of any type of solid tumour cancer at least a month prior to interview, having received at least one type of treatment (chemotherapy, radiotherapy, hormonal or other therapy), awareness of a cancer diagnosis and Maltese literacy. Exclusion criteria were: aged

younger than eighteen, non-natives, non-cancer diagnosis, and diagnosis less than one month prior to fieldwork. Prior to commencement of research, permission was sought from the Data Protection Board and University Research Ethics Committee (UREC) of the University of Malta.

Two hundred sixty-nine patients were approached to participate in the study, of which seventeen met the exclusion criteria. All the returned questionnaires were valid, in that most responses had been filled in and could therefore be used for analysis. The questionnaire delivered to patients was bipartite, consisting of the Measure of Patient Preferences (MPP) Questionnaire and the Control Preferences Scale (CPS). The thirty-two-item MPP, scored on a five-point scale (1-5) and initially developed in the United States by Parker *et al.*, was used to assess preferences for characteristics of the bad news encounter. Preferences relate to three aspects: 'facilitation' - the setting in which the news is delivered; the 'content' of the message; and the 'support' offered.⁴ To understand to what degree patients are being involved in the decision-making process, the two-item Control Preferences Scale (CPS), developed in Canada by Degner *et al.* was used.⁹ This five-point (A-E) self-reported scale assesses patients' preferences for control in medical decision-making, ranging from a wholly active role (A) through to a wholly passive role (E). The tool allows respondents to portray how they were involved in treatment decisions (CPS-1), and then to express how they would have liked to have been involved (CPS-2).

Outcome Measures

Permission was obtained from the authors of the MPP and CPS to utilise their questionnaire, who are also authors of this research. The questionnaires were translated

from English into Maltese by a senior lecturer of the Maltese language, followed by conceptual translation to ascertain that concepts were understood in the same way, and to ensure cultural acceptability of the questionnaire. The corrected questionnaire then underwent cognitive debriefing whereby it was actively tested among representatives of the target population to assess whether the questionnaire was being understood in the same way as the original would have. Following the amendments made, the product tool was considered to be reliable for usage in the Maltese sample population. Validity testing was not necessary since this had already been done by Parker *et al.*, and Degner *et al.* in their respective studies which produced the MPP and CPS. The questionnaire was then piloted prior to actual usage.

Demographics and Medical Data

Demographic information, including gender, age, marital status and educational level was collected. Participants supplied information on stage of disease and recurrence status, while their physicians gave additional information on cancer type, date of diagnosis, stage of disease and recurrence, and treatment given (Table 1).

Statistical Analysis

Descriptive statistics were presented for demographic and medical characteristics of the sample, while univariate analysis was conducted to examine independent associations between respondents' demographic and clinical characteristics, and the MPP and CPS data. Since the MPP is assessed through scores, tests for differences between means were used. T-Tests and one-way ANOVA were used as applicable. For the CPS categorical data, odds ratios (OR) were used to assess

independent associations between the demographic variables and CPS category. These associations were then assessed using multinomial regression analysis while adjusting for any possible confounding factors.

For all tests, a $p < 0.05$ was used to assess statistical significance, and confidence intervals (CI) of 95% were presented as applicable.

Results

Two hundred fifty-two patients were eligible to participate in the study, of which forty-two were physically, cognitively or psychologically unable to complete the questionnaire, and 11 refused to participate. Thus, the participation rate was 79%, similar to that obtained in other studies which registered similar eligibility criteria.¹⁶ Patients who refused to participate did not differ by age ($p = 0.758$) or gender ($p = 0.993$) when compared to respondents.

The mean time from diagnosis to completion of the questionnaire was 52.3 months (4.4 years), somewhat more than that in Parker *et al.*'s study (3.3 years),⁴ the long duration resulting from the prolonged follow-up necessary before a patient can be declared disease-free. There was no statistical significance between those with a recent or distant diagnosis. Some had received bad news twice, once on diagnosis and again on recurrence.

Females accounted for 67.3%, and the age range of participants was 27 to 86 years (mean 62.2 years; SD 12.6 years), similar to that observed in the Canadian population study (mean 62.4 years, SD 8.4, range 46-85),¹⁴ and the Japanese population study (62 years, SD 11, range 26-97).¹⁶ Of note, less than a fifth had completed tertiary education, which was similar to a British study where 20.0% had attended college or received a graduate degree.¹³

Table 1: Demographic and medical characteristics of the population sampled

Characteristics	% (n)
Mean time from diagnosis	4.4 years (SD 4.48)
Gender (n=199)	
Male	32.7 (65)
Female	67.3 (134)
Mean Age (n=199)	62.2 years (SD 12.6 years)
Marital Status (n=199)	
Married/Living with Partner	68.3 (136)
Widowed	12.6 (25)
Single	12.6 (25)
Separated/Divorced	6.5 (13)
Level of education reached (n=197)	
Primary	41.6 (82)
Secondary or Post-Secondary	41.1 (81)
Tertiary or Post-Graduate	17.2 (34)
Employment Status (n=198)	
Domestic Tasks	40.9 (81)
Retired	31.3 (62)
Employed	24.3 (48)
Unemployed	3.5 (7)
Cancer Type (n=196)	
Breast	37.8 (74)
Gastrointestinal Tract	13.8 (27)
Prostate	9.2 (18)
Gynaecologic	7.1 (14)
Urological	7.1 (14)
Haematological	6.6 (13)
Lung	5.6 (11)
Thyroid	5.6 (11)
Other cancers	7.1 (14)
Cancer Recurrence (n=196)	
Yes	21.9 (43)
No	78.1 (153)
Mean time	2.49 years (SD 2.68)

Several types of cancers were represented in the population sampled, including rare cancers, reflecting the distribution of cancer types in the Maltese Islands, being similar to those found in the Italian population study¹⁵ (Table 1). The large majority of respondents (91%) accurately reported their diagnosis, and 36.7% were able to stage their disease. More males (72.3%) tended not to know their stage compared to females (60.4%), but this

was not significant ($p=0.101$). Younger patients were more likely to know their disease stage than older ones ($p=0.017$). Of the 71 patients who documented a stage, 16 had no physician-listed stage to compare to. 60% of the remaining reported the correct stage, while 59% of incorrect answers quoted a less advanced stage of disease. Most of the patients received at least two types of treatments/interventions, with surgery being the most common (Table 2).

Table 2: Percentage distribution of surgical and anti-cancer treatments which patients received (patients could have had more than one treatment/intervention)

Surgical and anti-cancer treatments	% (n)
Surgery	70.9 (141)
Radiotherapy	57.1 (114)
Hormonal Therapy	44.9 (89)
Chemotherapy	41.3 (82)
Palliative	2.6 (5)
Other	9.2 (18)

‘Recurrence’ in this study refers to the re-appearance of a previously quiescent disease, or advancement of disease which was previously stable. Just over a fifth (21.9%) had had a recurrence by the time of the survey, which is less than those observed in an American (31%)⁴ and British population (52.7%)¹³. The mean number of months from diagnosis to recurrence was 29.9 months (SD 32.2 months).

MPP

The highest scoring item was ranked at 4.35 (SD 0.81), which comes close to results from the American (4.72, SD 0.49)⁴ and British (4.62, SD 0.67)¹³ studies. Table 3 represents the ten highest and lowest scoring items on the MPP, with seven out of the highest and six out of the lowest scorings being common between the Maltese, American⁴, and British¹³ studies. The lowest scores in this study nonetheless ranked greater than 3.0, indicating that all items in the questionnaire were considered important by respondents.

The same three categories as those identified by Parker *et al.*⁴ were used in this study: ‘Content’, ‘Support’ and ‘Facilitation’. The mean score for ‘Content’ was 4.17 (SD 0.59), for ‘Support’ 3.73 (SD

0.68) and for ‘Facilitation’ 3.86 (SD 0.68). These results were mirrored by those obtained in American⁴, British¹³, and Canadian¹⁴ studies. The mean score for ‘Content’ was significantly higher compared to ‘Support’ ($p<0.001$) and ‘Facilitation’ ($p<0.001$).

When considering demographic and medical characteristics of the population *vis-a-vis* the MPP category scores, education proved to be the only significant predictor, significantly associated with the ‘Content’ ($p=0.018$) and ‘Facilitation’ ($p<0.001$) subscales. Those with primary education reported a lower average ‘Content’ score than those with tertiary education ($p=0.021$), and likewise for ‘Facilitation’ in both the primary ($p<0.001$) and secondary education ($p=0.002$) sub-groups, hence suggesting that those with tertiary education place more importance on the ‘Content’ of the physician-patient dialogue and on how and where bad news is broken (‘Facilitation’). These results are in-keeping with those obtained from the American study, where education significantly predicted scores on the ‘content’ and ‘facilitation’ subscales.⁴

CPS

Two-thirds of respondents (68.2%) experienced a passive role, with a quarter (25.9%) having a collaborative role, and only 5.8% an active role (CPS 1). In CPS-2, although the passive role remains the most popular, this drops from 68.3% to 59.7% indicating a shift to the collaborative and active role (Figure 1). None of the patients’ demographic or medical characteristics increased the likelihood of having either role compared to a passive role (reference group) in CPS-1.

Table 3: Highest and lowest MPP ratings

Highest ratings MPP	Mean (SD)
My doctor describing all of my treatment options in detail	4.35 (0.81)
My doctor telling me the best treatment option	4.35 (0.75)
My doctor being up to date on research on my type of cancer	4.34 (0.69)
Having my doctor take the time to answer all of my questions completely	4.32 (0.77)
Having my doctor give me his/her full attention	4.25 (0.83)
Being given enough time to ask all of my questions about my cancer and the available treatments	4.24 (0.74)
My doctor letting me know all of the different treatment options	4.21 (0.77)
Having the doctor be honest with me about the severity of my condition	4.19 (0.92)
Waiting until all test results are in and he/she is certain about the news before telling me	4.17 (0.85)
Being given detailed information about the results of medical tests	4.14 (0.80)
Lowest ratings MPP	
My doctor telling me about support services that are available to me	3.82 (0.88)
Being told in person rather than over the phone	3.71 (1.11)
Being told in a private, quiet setting	3.69 (1.07)
Telling me it's ok if I become upset	3.66 (0.95)
Having the doctor tell me about resources in the community	3.57 (0.96)
Having the doctor inform my family members about my prognosis	3.52 (1.14)
Having another health care provider present to offer support and information	3.51 (1.08)
Having the doctor inform my family members about my diagnosis	3.49 (1.17)
Having my doctor maintain eye contact during the meeting	3.39 (1.12)
My doctor helps me to figure out how to tell my family and friends about the cancer	3.38 (1.17)

However, in CPS 2, there was a significant difference between primary and tertiary education ($p=0.028$); those in primary education were 81% times less likely (95% CI 0.04 – 0.84) to desire an active role than a passive role compared to the tertiary education group. These results mirror the preferences of British patients,¹³ yet contrast with Canadian patients, where education had no significant effect on the

preferred role.¹⁴ This demonstrates a desire for an increasingly active role with increasing levels of education. None of the other univariate analyses of independent associations were significant.

Since age and gender probably influence education level, a multivariate analysis adjusting for these two variables was conducted, revealing a more significant p -value ($p=0.01$), an OR of 0.12 and a narrower CI (0.26-0.60) (Table 4).

Figure 1: Distribution of responses for each of the items CPS 1 (n=187) and CPS 2 (n=191). Error bars indicate 95% confidence intervals around the proportions.

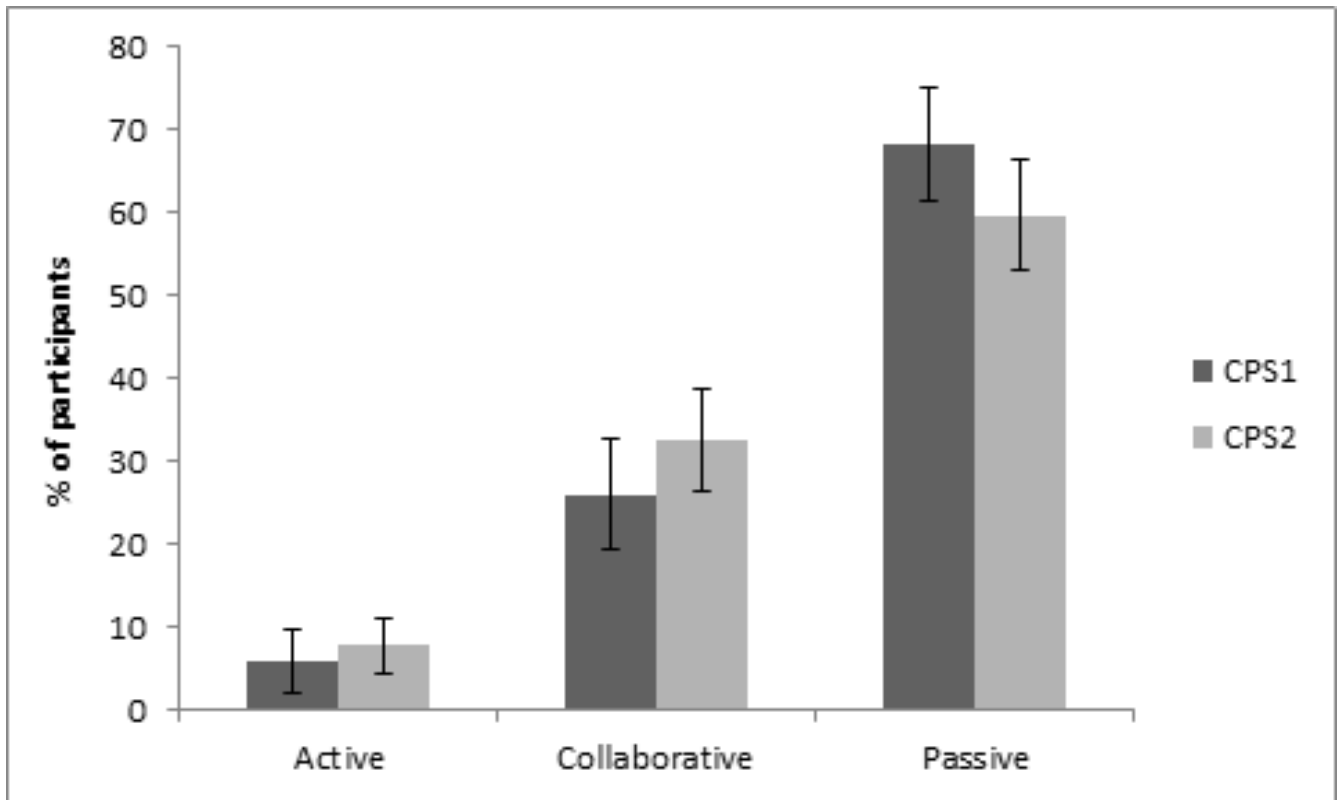


Table 4: Final multivariate model for predictors and CPS2 as outcome. Passive is the reference group

	Active		Collaborative	
	OR (95% CI)	p-value	OR (95% CI)	p-value
Gender				
Male	0.78 (0.23 - 2.60)	0.685	0.97 (0.50 - 1.89)	0.928
Female	Ref	-	Ref	-
Age	1.04 (0.99 - 1.10)	0.1	0.99 (0.97 - 1.02)	0.661
Education				
Primary	0.12 (0.26 - 0.60)	0.01*	1.32 (0.48 - 3.63)	0.585
Secondary/Post-Secondary	0.43 (0.12 - 1.54)	0.193	1.59 (0.61 - 4.12)	0.344
Tertiary/Post-Graduate	Ref	-	Ref	-

Discussion

This study covered a representative sample of patients from the only oncology hospital in Malta, ensuring that patients with a range of disease characteristics and from different educational backgrounds were eligible for recruitment. Results can thus be regarded as reflective of the experience of Maltese oncology patients.

Malta stands out in that, at present, there is no robust framework in place to help patients. In fact, the 2014 European Union Health Literacy (HL) Survey 16 (EU-HLS 16) revealed that 42.5% of Maltese considered themselves to have a 'problematic' level of HL, compared with 35.2% in the EU. Likewise, only 9.2% of the Maltese sample graded themselves as having 'excellent' HL, as opposed to 16.5% in the EU.¹¹ The EU-HLS 16 for Malta echoes the main finding in our study – that level of education plays a vital role in choices patients make regarding their treatment, with statistical significance for the degree of HL at all education levels.

The CPS tool revealed that Maltese patients prefer a passive role in their treatment. This may change once legislation regarding patients' rights is implemented. Creating a climate of increased awareness and availability of information may tip the balance towards Maltese patients becoming more emancipated in their health choices. The nation's focus should change towards what can be done to improve health literacy. Since 7.6% of the Maltese population is illiterate,¹² providing information to the population by audio and visual means will ensure equity for all.

There were a number of limitations to this study. The MPP subscales were developed for an American population,⁴ therefore extrapolating them to a Maltese population may not wholly reflect the

cultural and treatment protocol differences within countries. However, the tool was successfully applied in a number of countries including in Europe, reflecting flexibility of the tool.¹³⁻¹⁸

Excluding some subjects from the study may have overlooked additional needs that these may have had, and possibly a different experience when compared to participants.

Diagnosis was occasionally made several years prior to the study whereby respondents' memories may have faded, introducing recall bias. Furthermore, having re-experienced breaking bad news allowed some subjects increased ability to give feedback, which may also have introduced an element of bias, as subjects were not asked to specify which experience they were referring to. In retrospect, those with a recurrence could have been excluded, and more patients recruited so as not to lose the power of the study.

Studies amongst Maltese cancer patients tend to be small due to our limited population size. This makes sub-group analysis difficult to power. To mitigate this, categorical dummy variables were created to ensure meaningful comparisons, while allowing for statistical power. The study applied a cross-sectional design yet informational needs may change over time.¹⁹ Future research may investigate how these may vary throughout the patient experience.

Conclusion

For Maltese patients, education level is a key factor influencing their preference for the type and amount of information they receive. Considering that the EU-HLS 16 has shown a percentage of the Maltese population with a problematic level of HL, our MPP results are of relevance as they demonstrate that education plays a crucial role in treatment choices patients make.

Similarly, utilising the CPS revealed that Maltese patients overtly prefer a passive role in their treatment. As local legislation is implemented, this study can bolster support for initiatives to improve HL and increase awareness of patients' rights, empowering patients to take an active or collaborative role in treatment decisions. This should lead to better patient satisfaction and hence improve supportive care to cancer patients.

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