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Screening of Distress and Referral Need in Dutch oncology practice

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Distress, problems and referral wish of cancer patients: differences according to relationship status and life phase

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Abstract

Objective The aim of this study is to examine differences in distress, problems and referral wish in cancer patients according to relationship status and life phase.

Methods A cross-sectional group of 1340 patients (response = 51%) completed socio-demographic and illness-related questions, and the Dutch version of the Distress Thermometer and Problem List that also assesses desire for additional care (yes, maybe and no). Relationship status was categorized into six groups (married, cohabiting, LAT (=living-apart-together: have a partner but live alone), di- vorced, widowed or single) and age into young (18–50), middle aged (51–65) and older (65+) cohorts.

Results Relationship status and life phase were independently related to high distress, referral wish and accordance between the latter two. Single and LAT patients were around two times more likely than married patients to be highly distressed, and wanting additional care. The same was found for younger patients as compared to 65+ patients. Whereas high distress is usually not a strong indication for additional care needs, single, LAT and younger patients most often wanted care when they were highly distressed.

Conclusion Health care professionals who implement distress screening in practice can expect a higher need for additional care in single and LAT patients, but only when they are younger or middle aged. The benefit of having a partner around on a daily basis seems less important in dealing with cancer-related problems when patients are older.

Introduction

In the past 30 years research has been done on the overall burden of cancer diagnosis and treatment, referred to as distress [1]. During and after treatment an estimated 30% of cancer patients suffer from overall distress [2–4]. Many studies focus on identifying patients at risk for distress, and one risk factor for elevated distress appears to be relationship status [5–9].

One obstacle in interpreting relationship status as a predictor for distress after cancer is that most studies use dichotomous variables pooling single, divorced and widowed patients together in one group, or comparing married to unmarried patients [10]. However, marriage is not the norm anymore. Cohabiting, serial partnering and also divorce are more common in the last decades, as well as staying single up to older age [11]. Even though marriage has been repeatedly found related to better (mental) health [12,13], there are more subtle differences according to previous relationship status, time since bereavement and life phase [14–16]. Single, divorced and widowed people have been found to experience less well-being than those who are married or cohabiting [17], but divorced people have also been found to report greater life satisfaction than the never-married people [18] or similar functioning as long-term married people after a few years [16].

Besides past relationship status, grouping together for example, older widowed and younger single patients does not do justice to their phase in life [14]. Younger age is the phase where people have children living in their home, combine caretaking tasks with working outside the home, whereas middle age is the phase where older children can also support their parents [19], while older people are faced with a shrinking social network and diminished health [20]. Not taking into account life phase will confound the effect of relationship status with age specific stressors [21,22]. The impact of relationship status on health and well-being differs according to life course stage in general [14,23]. We will therefore include life stage in our study.

How a difference in relationship status is related to the level of distress after a cancer diagnosis remains unclear. One study comparing healthy people, cancer survivors and patients with non/malignant illnesses, showed that distress was highest among the unmarried people. However, the association between being unmarried and feeling distressed was strongest in cancer patients, suggesting

that unmarried cancer patients face unique issues [24]. We do not know what specific problems unpartnered cancer patients encounter that might explain their heightened distress. The present study aims to fill this gap. We will do this using the recommended Dutch screening tool that combines the distress thermometer, problem list and a question on referral wish [25].

It is likely that cancer patients who live without a partner want professional psychosocial help more often because they have less informal daily support [7]. Indeed, shortly after completing treatment, more single and widowed patients (43%) wanted to talk to a care provider as compared to married or cohabiting patients (29%) [26], and young single patients had the highest intent of using psychosocial services [7]. Unmarried cancer patients were more often referred to specialized psychosocial oncology care than were married patients [27]. We already know that around half of patients who report elevated distress do not necessarily want additional care [4,25,26]. It is suggested that these patients can handle problems with the help of their family ties. We will be the first to examine whether relationship status is related to accordance between elevated distress and need for help.

This study was conducted to gain insight into the effect of relationship status (married, cohabiting, LAT (living-alone-together: partners do not share a home), divorced, widowed and single) on distress and referral need in cancer patients, next to and in combination with life phase. The primary goal was to examine differences according to relationship status in:

1. distress,
2. number and nature of problems,
3. desire for additional support and its accordance with elevated distress.

Methods

Sample

The current study reports on the same sample of cancer patients reported by Admiraal, but analyses and reported outcomes do not overlap [28]. This study was conducted in the Netherlands and was part of the process of implementing screening for distress in the participating hospitals between February 2006 and December 2011. Inclusion criteria were that patients had received their cancer diagnosis and provisional treatment plan, were over 18 years of age, had sufficient command of the Dutch language and were physically fit and cognitively able as assessed by the inviting nurse or physician.

Procedures

Study coordination was performed by the Comprehensive Cancer Centre the Netherlands, location Groningen (CCCN). All twenty-three hospitals in the North-Eastern CCCN region were approached, and 19 agreed to participate (83%). Three hospitals situated elsewhere in the Netherlands also requested to participate. The study was performed according to the regulations of the medical ethical committee of the University Medical Centre Groningen and followed the ethical guidelines of the participating hospitals. Between 30 and 300 questionnaires were handed out in each hospital, numbers differed according to hospital size. Patients on nursing wards or visiting the outpatient clinics and who met the inclusion criteria were invited by their physician or nurse to participate and received a package with information about the study, procedures, contact information of the investigators, the questionnaire, an informed consent form and a prepaid return envelope. Questionnaires were sent back to the CCCN for analysis.

Measures

Patients reported on their sociodemographic and illness-related characteristics. Relationship status includes being married, cohabiting, divorced, widowed, living-alone-together (LAT) and single.

Distress was measured using the Dutch Distress Thermometer/Problem List (DT/PL) [25]. The DT consists of a single item that asks patients to indicate the amount of overall distress experienced during the past week on an 11-point scale. Scores range from 0 to 10 (no to extreme distress). The cut-off point for the Netherlands

was 5, with a negative predictive value of 95%. The Dutch PL incorporates 47 items. Patients can indicate whether or not (yes/no) they experienced practical (7 items), family/social (3 items), emotional (10 items), religious/spiritual (2 items) and physical problems (25 items). PL scores were computed by taking the sum of the times answered yes for the complete list and for the 5 subscales. The last question of the questionnaire covered patients' referral wish (yes, maybe or no) to a psychosocial (psychologist, psychiatrist, social or pastoral worker) or allied (physical therapist, dietician) health care professional.

Data analysis

Descriptive analyses were performed for the sociodemographic and illness-related variables, and the DT/PL. Independent-samples *t*-tests and ANOVAs (age and time since diagnosis) and Chi^2 analyses (gender, having children (at home), daily activities) were performed to examine differences between relationship status groups.

We performed ANOVA (general distress) and logistic regression analyses (scoring above the cut-off score, referral wish and accordance between these two), entering gender, relationship status, life phase and the interaction term between relationship status and life phase as predictors. Earlier studies on distress after cancer showed that women report more distress than men; therefore, we entered gender in all analyses [28–30]. We used three age cohorts: young (18–50), middle aged (51–65) and older (65+). These cohorts best fit phases in life according to responsibilities regarding caretaking and professional tasks. Bonferroni post-hoc tests were used to test group differences in distress and in the number of problems answered with yes in the total problem list. Post-hoc Wilk's lambda was used to test group differences in the number of problems for the 5 domains of the PL.

Results

Patient characteristics

A total of 2640 eligible patients were invited to participate in the study, of whom 1352 returned the questionnaire (response = 51%). Two patients were excluded because they were aged <18 years. Ten questionnaires were excluded due to incomplete data. Most patients (43%) had breast cancer, followed by prostate cancer (13%), cancer in the digestive tract (11%), lung cancer (7%) or other (5%). Mean time since diagnosis was 2 years (sd 3.0), range 0.6 – 34 years. More than half (53%) of patients had completed treatment. There were no differences in cancer related variables between the 6 relationship groups, but they did differ in age (F = 29.5, p < .001), gender (Chi^2 = 32.4, p < .001), having children (Chi^2 = 343.6, p < .001), children living at home (Chi^2 = 16.7, p < .01) and employment status (Chi^2 = 35.5, p < .001) (Table 1).

Preliminary analyses

We aimed to divide groups into meaningful age cohorts, reflecting differences in combining responsibilities such as taking care of children and having a job. Indeed, the youngest group (18–50) most often had children living at home (90%) and had work (70%), whereas 27% of the middle aged patients (51–65) had children at home (27%) and had work (44%), and in the older group (65+) almost no patients had children living at home (5%) nor had work (4%).

Does distress differ according to relationship status?

ANOVA (with gender, life phase and relationship status as predictors) showed no differences in overall distress for gender or the six relationship groups (Table 2), but there was an effect of life phase ($F(df2)$ = 10.5, p < .001) (Table 3). Post-hoc Bonferroni test showed that young patients (95% CI .63–1.65, p < .001) and middle-aged patients (95% CI, 42–1.22. P < .001) were more distressed than the older patients.

Table 1 *Demographic variables and relationship status*

	Total N=1340	**Married** n=1004	**Cohabiting** n=85
Age (m, sd)	60.9 (11.6)	61.3 (10.6)	52.2 (14,1)
Range	21-89	28-89	22-83
Women	63%	56%	77%
Children	84%	91%	55%
Children at home	25%	29%	27%
Employed	33%	32%	53%

Table 2 *Distress thermometer, problem list and referral wish*

	Married	**Cohabiting**
Distress		
mean (sd)	3.7 (2.6)	3.8 (2.7)
≥5 (%)	40%	42%
OR*		1.0
Problem List	9.6 (8.1)	11.6 (8.5)
Practical (0-7)	.71 (1.2)	1.0 (1.6)
Social (0-3)	.33 (.75)	.48 (.85)
Emotional (0-10)	2.7 (2.8)	3.4 (2.4)
Spiritual (0-2)	.28 (.61)	.30 (.60)
Physical (0-25)	5.7 (4.7)	6.4 (5.0)
Referral wish		
No	68%	60%
Yes/ Maybe	32%	40%
OR*		1.4
≥5 & referral wish	45%	61%
OR*		1.8

* logistic regression, with married patients and >65 age as reference groups for the Odds Ratios (OR)
** significant OR

LAT n=28	Divorced n=43	Widowed n=96	Single n=81
56.9 (13.9) 26-81	58.9 (8.6) 45-81	70.7 (8.9) 50-89	56.3 (14.4) 21-87
57%	84%	78%	68%
68%	95%	91%	21%
15%	37%	17%	17%
39%	43%	13%	36%

LAT	Divorced	Widowed	Single
4.6 (2.9)	4.0 (2.6)	3.3 (2.7)	4.5 (2.6)
60%	44%	40%	55%
2.4 **	1.1	.95	1.7 **
12.6 (10.5)	11.1 (10.5)	8.6 (7.2)	12.5 (8.8)
1.5 (2.1)	1.5 (1.8)	.64 (.89)	1.2 (1.4)
.38 (.89)	.34 (.66)	.17 (.48)	.32 (.54)
3.3 (2.9)	3.1 (3.2)	2.4 (2.6)	3.4 (3.1)
.27 (.53)	.44 (.74)	.30 (.62)	.30 (.60)
7.0 (5.3)	6.3 (5.9)	5.1 (4.9)	7.0 (5.1)
48%	62%	75%	49%
48%	38%	25%	51%
2.1	1.3	.72	1.9 **
71%	53%	42%	70%
3.4 **	1.3	.82	2.5 **

Table 3 *Distress, elevated distress and referral wish in three age cohorts*

Age	Relationship status	n	%
>18 <50			
	Married/cohabiting	199	84
	LAT, Divorced, single	39	16
	Widowed		0
>50 <65			
	Married/cohabiting	476	83
	LAT, divorced, single	71	12
	Widowed	25	4
65+			
	Married/cohabiting	411	79
	LAT, divorced, single	41	8
	Widowed	71	14

Grey rows: analyses in whole sample; white rows: analyses within each life phase cohort
OR = Odds ratios (married/cohabiting patients and 65+ as reference groups)
* p<.05, ** p<.01 *** p<.001

Does elevated distress differ according to relationship status?
Logistic regression analysis (dependent variable DT cut- off score) (Chi*2* (*df*8) = 29.9, p = .001) showed no significant effect of gender, but did show that LAT patients (Wald = 3.9, p = .042) were 2.4 times, and single patients (Wald = 5.0, p = .02) were 1.9 times more likely than married patients to score above the cut-off (Table 2). Young patients (Wald = 10.1, p = .002) were 1.8 times and middle-aged patients (Wald = 9.4, p = .002) were 1.5 times as likely as older patients to score above the cut-off (Table 3).

Do the number and nature of problems differ according to relationship status?
In the whole sample, patients reported a mean number of 9.9 problems on the PL (sd = 8.3). ANOVA showed no significant effect of gender, but did show that the six relationship status groups differed in the total number of problems (F = 2.9, P = .013, η^2 = .013) (Table 2). MANOVA (the number of problems for each domain as dependent variables and covariate gender) showed that groups differed in the number of problems in the separate domains (Wilks' Lambda = 10.6, p < .001). However, only significant differences were found for the practical (F = 6.1, p <

DT score	DT ≥5	Referral wish	>5 & referral wish
***	OR=1.8 **	OR=2.1 ***	OR=2.6 ***
4.3 (2.5)	49%	40%	26%
4.7 (2.7)	54%	66% OR=2.9 **	46%
0	0		
***	OR=1.5 **	OR=1.5 **	OR=2.1 ***
3.9 (2.7)	42%	36%	23%
4.7 (2.7)	62% OR=2.2**	39%	36% OR=1.9*
4.0 (2.6)	48%	38%	25%
3.2 (2.6)	33%	25%	11%
3.5 (2.2)	34%	41%	22%
3.0 (2.0)	37%	24%	16%

.001) and the emotional domain (F = 2.4, p = .033). Divorced (95% CI 1.5 – .07, p = .005) and single patients (95% CI 1.1 – .10, p = .006) reported significantly more practical problems than married patients. Divorced patients also reported more practical problems than widowed patients (95% CI -1.6 – -.07, p = .02).

Does the desire for additional support differ according to relationship status?
In the whole sample, 67% of patients showed no referral wish, 20% maybe wanted a referral and 13% did express a referral wish. Logistic regression analysis (Chi^2 = 35.7, p < .001, df = 8) indicated that single patients were 1.9 times as likely (Wald = 9.1, p = .006) than married patients to want a referral (Table 2). Young patients (Wald = 15.2, p = .001) were 2.1 times and middle-aged patients (Wald = 9.4, p = .002) 1.5 times as likely than older patients to want a referral (Table 3). Gender was not significant as predictor.

In patients who reported high distress (scored ≥ 5 on the DT), LAT patients (Wald = 8.3, p = .004) were 3.6 times and single patients (Wald = 12.1, p = .001) 2.5 times as likely to want a referral than married patients (Chi^2 = 16.1, p = .013) (Table 2).

Highly distressed young patients (Wald = 15.1, p = .001) were 2.4 times and highly distressed middle aged patients (Wald = 15.8, p = .001) were 2.1 times as likely as highly distressed older patients to want a referral (Table 3).

Does distress, elevated distress and referral wish differ between relationship status groups in three age cohorts?

Some cells in the life phase × relationship status interaction variable turned out empty or very small (no young widowed, < 10 divorced young and older patients). Probably as a result of this, the interaction term was non-significant for all of our outcomes. We therefore decided to explore whether relation- ship status had an effect on the outcomes within each of the three age cohorts separately (Table 3). Due to small groups within the age cohorts, we grouped together LAT, divorced and single patients. No differences in overall distress were found. In the younger age group, LAT/divorced/single patients were 2.9 times more likely (Wald = 7.8, p = .005) to want a referral for additional care than married/cohabiting patients (Chi^2= 8.5, p = .015, df = 2). Within the middle aged group, LAT/divorced/single patients were 2.2 times more likely (Wald = 8.8, p = .003) than married/cohabiting patients to score above the cut-off (Chi^2= 10.4, p = .01 df = 3) and LAT/divorced/single patients were 1.9 times more likely (Wald = 4.8, p = .03) to want a referral when highly distressed than married/cohabiting patients (Chi^2 = 8.0 df = 2, p < .04).

Discussion

The current study was aimed at understanding associations between relationship status and distress after a cancer diagnosis, number of problems experienced and referral wish, while taking life phase into account. Important differences between married, cohabiting, Living-Apart-Together (LAT, having a partner but not sharing a home), divorced, widowed and single patients appeared, next to differences due to life phase. Elevated distress and wanting additional help depend on both the responsibilities and problems patients have due to their phase in life, as well as whether they have a partner at home to support them.

Even though groups did not differ in overall level of distress, single and LAT patients were 1.7 and 2.4 times more likely to be clinically distressed than married patients. The fact that LAT patients were as often highly distressed as

single patients suggests that the mere fact of having a partner is not sufficient in protecting against distress after a cancer diagnosis, even though support from a partner has been found more effective than that from family or friends [31,32]. The crucial aspect may be being with your partner on a daily basis.

Additionally, single patients were 2 times as likely to desire a referral for professional care than married patients. Earlier studies showed that having high distress does not necessarily imply a need for additional care, as around half of distressed patients does not want further help [25]. We found that 70% of single and LAT patients did want help when they were distressed. This made them 2.5 and 3.4 times more likely to want help when highly distressed as compared to married patients. Screening for distress is probably not a one-size-fits-all process, where health care professionals can rely on average scores to refer a patient. As was found, e.g. for different types of cancer, with prostate cancer patients having a lower cut-off point indicating high distress [28], differences in partner status appear related to whether patients want specialized additional care after cancer, and not the thermometer score per se. A high score on the distress thermometer is a better indication to arrange a referral for single and LAT patients than it is for other groups.

The differences according to life phase showed that the younger patients (<65) were most likely to report elevated dis- tress and wanting help, up to 2.1 times more likely than the oldest patients. This corresponds with earlier studies, showing that younger age is related to higher distress after cancer [28,26,33–35]. Also, within the group of older patients, we found that living together with a partner or not was unrelated to their distress and need for help. Widowed patients reported the least distress and need for help, even less than married and cohabiting patients who do have a partner close by. We proposed that the relationship between age and distress is probably not linear, but related to the responsibilities that come with certain life phases. It seems that combining work and taking care of children living at home while also dealing with cancer, as especially young and middle-aged patients did, elevates the need for extra care. Patients over 80 have been found most distressed as compared to patients over 60 or over 70 years old, probably because of co-morbidities and functional decline at a very old age [36]. In our sample, very few older patients were aged over 80, had work or caretaking responsibilities.

The answers on the Problem List give more insight into what type of problems underlie patients' level of distress and can guide the referral that is needed. LAT and single patients experienced the highest number of problems, almost 13 (of the possible 47). Single and divorced patients reported having the most practical and emotional problems as compared to the married and widowed patients. These domains encompass problems such as trouble with housekeeping, finances, and work, fear, emotional control, self-esteem and loneliness. This is in line with a recent study that showed that especially younger single cancer patients reported having more practical problems than those in committed relationships [7].

Some limitations hamper more firm conclusions. The non-married groups were small, which hindered us from adding interactions in the analyses, for example between life phase and relationship status or a between relationship status and gender. Finally, we could not keep track of characteristics of non-responders, nor send invited patients a reminder to fill in the questionnaire, which could have affected our response rate. Our response rate was 51%, which was the lowest estimation, based on questionnaire packages given to hospitals. It might be that not all packages were handed out to patients. Even though the response rate was low, we did have the advantage of broad sampling, because multiple departments of 17 hospitals across the Netherlands were engaged in recruitment, covering most regions. In this way, we know we reached a representative sample of Dutch cancer patients in demographic characteristics.

Health care workers in oncology should pay extra attention to additional care needs in single and LAT patients, and in younger and middle-aged patients. Making use of the Distress Thermometer and Problem List as a communication tool will guide health care workers on what type of referral would be most beneficial.

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