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Features of members of a prostate cancer patients' association

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ABSTRACT
Background: The objective of this study was to compare prostate cancer (PC) patients who are and who are not members of the Dutch prostate cancer patients' association (PCPA) with respect to demographic, medical and psychosocial characteristics.
Methods: Using a cross-sectional design, 88 non-members and 150 members of the PCPA were included.
Results: The results show that members are younger, have a higher socio-economic status and experience higher levels of distress. Furthermore, members are less content with the patient education and the psychosocial support available in hospital. Members also have a higher need to talk about problems and a more positive attitude towards participation in support groups.
Conclusion: It can be concluded that members of the patients' association differ from non-members. This has clinical and methodological relevance for further study among PC patients, as well as practical relevance for the policy of patients' associations.

INTRODUCTION
The incidence of cancer in the Netherlands was 69,000 cases in the year 2000. The prevalence of cancer patients in that same year was approximately 366,000 [1]. For many types of cancer, patients' associations have been founded. There are 24 registered patients' associations in the Netherlands, together accommodating 25,000 cancer sufferers. This implies that 7% of the cancer patients are members of a patients' association. In 1997 the prostate cancer patients' association (PCPA) was founded in the Netherlands; nearly 7000 new cases of prostate cancer (PC) are diagnosed each year [2]. In the year 2000, the prevalence of PC was 33,000 patients, while the PCPA had about 400 members (1%), which is a much smaller number of patients than is found in other associations.

There may be several reasons for joining a patients' association. Patients may have needs related to having cancer or may join a patients' association for information, support or activities [3]. Shortcomings in the professional healthcare available can also be a reason for becoming a member of a patients' association [4].

Survival rate also plays a role. Treatment of localised PC by surgery or radiation is effective in producing a good survival rate (51–95% after 5 years) [5], but can also cause serious side effects [6]. Metastatic PC, hormonally treated, has a survival rate of 20% after 5 years [7]. Because of the good survival rate, men and their partners have to learn to live with the side effects of the treatment and/or the fear of recurrence. Patient organisations can help with this. Knowledge regarding the psychosocial problems of men with PC has grown in the last decade. Studies report the presence of anxiety (8–49%), depression (0–48 %), post-traumatic stress disorder (14%) and feelings of isolation (20%) [8,9]. These may also be reasons for finding support in a patient organisation.

There are no studies available that compare the psychosocial problems between members and non-members of a patients' organisation. However, there are some studies comparing socio-demographic and psychosocial factors of those men joining a support group and those who do not. Support groups are often organised by patients' organisations [10]. Katz et al found that men who attend a PC support group had a higher income and a higher socio-economic status [11]. That study also reported better mental health among support group members. Another study found differences in coping style between men who did and who did not attend a support group. Men who attended a support group more often endorsed anxious preoccupation as a coping style [12].Gray et al showed that men attended self-help groups in order to get information about PC [13]. The same held true for a study by Carlsson et al [3], who found that 53% of the members of a patients' association for men with PC wanted to use the patients' association for information and activities. This is consistent with another study that indicated a gap between the informational needs of patients and the actual information provided by health professionals [14]. There are also indications that social support needs are unmet by healthcare professionals [15]. These studies reflect the idea that support groups can facilitate adaptation to the problems related to PC. These studies, however, do not provide any knowledge of how far just membership of a patients' association might facilitate this adaptation. Both the decision to become a member of a patients' organisation and enrolling in a support group represent an attitude of taking a more active role in dealing with the disease.

Since there are no studies on the characteristics of members of a PCPA compared to non-members, it is important to gain knowledge on their possible differences for a number of reasons. There are a growing number of PC patients, making knowledge about this issue increasingly important. It is unknown why only a small number of PC patients are actively involved in their disease, as reflected by membership. Active involvement can be associated with better mental health so it would be interesting to motivate men to join the patients' association. Such a study could also provide information on the features of men who want or need extra support in coping with their disease and which psychosocial support is needed. Finally, from a methodological viewpoint, if there are differences between members and non-members, membership of a patients' association could be a confounder which would have to be taken into account in studies on psychosocial problems and quality of life of men with PC.

In the present study, members and non-members were compared with respect to socio-demographic variables (age, socio-economic and marital status), medical characteristics (treatment, disease stage, time since diagnosis), satisfaction with hospital care, psychosocial characteristics (quality of life, sexuality, joy in life, psychosocial problems/needs, worries about the level of prostate specific antigen (PSA), distress, coping strategies, social support, emotional regulation and spirituality), attitude, subjective norms and perceived possibilities towards participation in support groups.

METHODS

Data collection

This study is part of a larger research project assessing health-related quality of life, psychosocial problems and the need for psychosocial support in PC patients. This research project was approved by the medical ethical board of the Onze Lieve Vrouwe Gasthuis, Amsterdam, The Netherlands. For the recruitment of patients, leaflets providing information about the study and including a response card

were used. Urologists in five hospitals handed out these leaflets. The leaflets were also mailed to all members of the Dutch PCPA. When an affirmative response was received, a questionnaire was mailed to the patient. Inclusion criteria for the study were having PC at any stage and speaking and reading Dutch to a sufficient level to understand the questionnaires. Exclusion criteria were having another type of cancer or a serious disease that impaired health related quality of life. These criteria were obtained from medical files and by patient's self-reports.

Instruments
Since this was the first large study in the Netherlands on health related quality of life and psychosocial problems in men with PC, an exploratory and descriptive approach was chosen. Therefore a wide variety of questionnaires was used to obtain detailed information about background characteristics, medical history, health-related quality of life, emotional well being, social support, psychosocial problems and the need for support in men with PC. An overview of the psychometric characteristics and the background to the measures applied is presented in Table 1.

[TABLE 1]

The Prostate Specific Antigen (PSA) Knowledge and Worries scale is an instrument we constructed for measuring both knowledge and fears about PSA levels. The scale, of the Likert type, was constructed in consultation with an urologist (G.v.A.). Some examples of items are: What is your last measured PSA level (knowledge)? Do you have worries about your PSA level? (worries). Are you nervous when you get the result of your PSA test? (worries). The scale was pre-tested in an urology practice among 15 patients who were then interviewed afterwards regarding their understanding of the meaning of the items, which was adequate in all patients. The reliability of the worries scale is good (α = 0.82).

Complaints about care and information supply by hospitals were highlighted in a brief pilot study [15]. Therefore, questions on satisfaction with hospital care were included to obtain insight into the extent that patients were content with various aspects of the information supplied by physicians and nurses, as well as with the care received in hospital. Both questionnaires had good reliability (α = 0.88 and α = 0.86).

Quality of life was included since it is an important concept in psycho-oncological research. It was measured using the standardised European Organisation for Research and Treatment of Cancer (EORTC) questionnaire; reliabilities ranged between α = 0.67 and 0.90. The module on prostate-specific quality of life issues in the EORTC questionnaire is still under development. It has a low reliability for problems related to hormonal treatment (α = 0.37) and bowel problems (α = 0.52). To construct a measure for sexual problems for this particular population, items from the EORTC prostate cancer module, from studies by Voogt et al [16] and van Andel et al [17] and newly constructed items were used. Together these formed a broad measure of general sexual dysfunction (α = 0.76). In addition, a joy of life scale, part of a questionnaire developed and tested to assess adjustment to cancer, was included [18].

The Psychosocial Problems Inventory was based on a questionnaire developed by Osse et al [19]. It is an inventory of nine problems together with how much the patient feels the urge to talk about these problems and with whom. The items include the following problem areas: physical complaints, social contacts, financial situation, feelings and emotions, communication with medical staff, sexuality, micturation, daily activities and memory and concentration. This questionnaire was pre-tested as described above for the PSA worries scale.

The measurement of Determinants of Group Participation is based on the theory of planned behaviour [20]. The items were developed according to the guidelines for that theory. The concepts measured are attitude towards support group participation (α = 0.75), social norms concerning support group participation (α = 0.68) and self-efficacy, defined as the perceived possibilities for support group participation (α = 0.61). This questionnaire was also pretested as described above for the PSA worries scale.

Distress was measured using the Profile of Mood States (POMS) [21]. Some scales from the EORTC quality of life questionnaire (EORTC QOL C30) overlap with the POMS and with the Social Support List. However, is was decided to include both scales in the study because the POMS measures more

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dimensions of emotional states and the Social Support List includes more information on social support than does the EORTC QOL C30 scales.

Since being diagnosed as having cancer is often seen as a traumatic event, the Impact of Events Scale (IES) section on symptoms of posttraumatic stress disorder was included [22]. The POMS and the IES are often used in clinical research and have good reliabilities ($\alpha = 0.91$ and $\alpha = 0.90$, respectively).

The Life Events scale [23] and the Daily Hassles scale [24] were both reduced to one item. This was done to lessen the questionnaire burden for the patients. Social support was measured using the Social Support Questionnaire [25], coping by the Utrecht Coping List [26] and emotional control and rationality was measured using the Emotional Control and Rationality scale [27]. These last three are original questionnaires with good reliabilities. A measurement instrument for spirituality was included because this concept is becoming increasingly important in research in psycho- oncology [28,29]. The 'transcendence' subscale was omitted from the Spirituality Assessment Scale [30], because of its low reliability in another study [31].

Analyses

Correlation coefficients were calculated to determine the degree of overlap between the emotional functioning scale and the social functioning scale of the EORTC QOL C30 on the one hand and the POMS total score and the Social Support questionnaire on the other.

In order to test statistically for differences between members and non-members, Chi^2-tests, student t-tests and Mann-Whitney U tests were used, depending on the measurement level and the distribution of the variables. The significance level was set at $\alpha = 0.05$. When corrected for multiple testing however, an α value of 0.001 was needed to reach significance. In addition, a logistic regression analysis (which is most suitable in exploratory studies), using the stepwise backward method was carried out to identify the main factors related to membership of the patients' association [32]. In that analysis, correlations between the various applied constructs can be taken into account.

RESULTS

Subjects

From the leaflets handed out, 303 affirmative response cards were returned: 110 from the hospitals and 193 from the patients' association. Questionnaires were sent to all of these men and 103 (94%) of the hospital-recruited men returned their questionnaires compared with 157 (81%) of the patients' association members.

Of the men recruited in hospital, 14 were in fact members of the PCPA and so were added to the group of members in the database. Furthermore, 15 'hospital' men and 7 patients' association men were rejected because they did not meet the inclusion criteria or had too many missing values. In total, 238 questionnaires were eligible for this study, 88 from men recruited in hospitals or at educational meetings and 150 patients' association members.

Background characteristics

The background characteristics of the respondents are presented in Table 2. The average age of non-members is 71.2 years, whereas that of members is 65.9 years. Non-members have a lower score of 7.2 on the socio-economic status scale than members, who score 8.7. The vast majority of all subjects (78% and 84%) are married. Prostate cancer had been diagnosed more than 2 years ago for 60% of non-members and 70% of members. For both groups almost one-third have metastasised PC. The most common treatments in non-members and members are radical prostatectomy (23% and 29%), radiation therapy (21% and 14%) and hormonal therapy (25% and 24%), while combinations of operation or radiation and hormone therapy were given in 19% and 22% of the cases, respectively. Compared to non-members, patients' association members are younger and have a higher socio-economic status. No significant differences were found for marital status, time since diagnosis, stage of the disease, type of treatment, comorbidity and PSA level.

[TABLE 2]

Psychosocial characteristics

Correlations between the emotional functioning subscale of the EORTC QOL C30 and the POMS total scale show a considerable overlap ($r = -0.73$, $p < 0.01$). The Social Support List score has a correlation of $r = -0.25$ with the social functioning scale of the EORTC QOL C30. The high correlation between the EORTC-C30 emotional functioning scale and the POMS total scale indicates that they probably, in part, measure the same construct. In the logistic regression analysis, these correlations will be taken into account. The results of the comparison of psychosocial factors between PCPA members and non-members are displayed in Table 3.

[TABLE 3]

  PCPA members have a greater knowledge of what PSA means and they also worry more about their PSA level. With respect to satisfaction with hospital care, members are less content with the information provided about PC and with their care in general, compared to non-members. Concerning quality of life, members have a lower score on emotional functioning compared to non-members. This is congruent with the higher distress scores found on the POMS for members and the lower joy in life scores found for non-members. Furthermore, a substantially higher score was found on the traumatic stress scale for members and with respect to coping, members have higher scores for problem avoidance. In addition, members show a lower score on emotional control, indicating they have fewer problems in showing their emotions compared to non-members.

  Regarding psycho-social problems and needs, Table 3 shows that the number of problems relating to PC reported by patients is equal for members and non-members. However, the degree to which men want to talk about these problems is significantly higher among members. This is in acccordance with the finding that members have a more positive attitude towards support group participation than non-members. Members also report a higher sense of self-efficacy, which means they see themselves as more capable of attending group meetings. Finally, no significant difference was found between members and non-members in the percentage of men choosing to attend support groups, although there is a trend ($p = 0.09$) for members to choose to attend.

Logistic regression analysis

The factors that differed significantly between members and non-members were used as predictor variables in a logistic regression to identify which factors were the most predictive for membership of the patients' association. Table 4 shows that six factors are associated with membership.

[TABLE 4]

  A higher socio-economic status and a lower age are associated with membership. Lower satisfaction with information about PC is also associated with membership. Clearly there is a constellation of distress factors associated with membership. Higher distress scores influence the odds of being a member in a positive way.

CONCLUSION AND DISCUSSION

To the best of our knowledge, this is the first study to compare members and non-members of a PCPA on a diversity of characteristics. Several interesting and coherent differences were found. Dissatisfaction with the information provided by medical care givers as well as dissatisfaction with the care received in general, is associated with being a member of the patients' association. There is a strong need for information in these patients [33]. A difference can be made between medical information and information about the psycho-social consequences of PC. One study found that the urologist is a satisfactory source of medical information for most men [34]. Concerning information on experiential and psycho-social issues, another study pointed out that two thirds of both patients and physicians considered that the physician was not a good person to offer emotional support [10]. Information, on emotional and experiential support, as well as additional medical information can be very adequately obtained from fellow patients [35]. By attending a patients' association or a support group, men might find out that there is much more to know than the physician has explained, causing

dissatisfaction retrospectively. The relatively younger men with a higher socio-economic status were more active information seekers. This has also been found in other studies outside the Netherlands [11,36]. This can be related to the finding that younger, more highly educated men wish to play a more active role in their treatment and the whole process of managing their disease and therefore need more information [37,38].

The results concerning distress, coping and emotional regulation are also consistent. Members experience higher levels of distress, which is consistent with lower emotional control and poor coping strategies. Interestingly, the logistic regression analysis points out that three measures of emotional distress contribute significantly to the odds of being a member of the PCPA. This is surprising, given the fact that there is an overlap between these measures. Logistic regression takes into account shared variance, but still three different measures were kept in the equation as significant contributors. Studies have indicated that emotional support is less valued than information by PC patients [39]. However, our results show that lower emotional functioning and higher levels of distress are associated with membership of the patients' association. It can, therefore, be concluded that the PCPA governing body should emphasise the importance of sharing emotions in its policy statement and aim to develop programs or support groups that will target distress, especially traumatic stress, in addition to informational programs.

Regarding the methodology of this study, it can, indeed, be concluded that there is a considerable bias in the patients' association sample. Balderson et al found a similar result in their study of support group members, finding higher levels of distress than in other studies [40]. In future studies in PC patients, this is something to be aware of when sample-taking.

To compare our study with previous research, only studies concerning support groups for men with PC are available. Support groups are different because they can be regarded as an intervention more than can membership of a patients' association. Although we do not know why men became members of a patients' association, differences between members and non-members do give information about specific characteristics of members. These differences can not be explained by the decision to participate in support groups. At the time of this study, no groups had been organised, apart from one pilot study [41]. Also the percentage of men choosing a support group was equal in members and nonmembers.

This study has some limitations. Since the study design is cross-sectional, it is unknown whether men become members to alleviate their distress or whether membership causes distress. The latter seems, however, not very plausible, since other studies have highlighted the beneficial effects of attending support groups in men with PC [42]. This indicates that actively being involved in one's own illness process, perhaps also by being a member of a patients' association, can be beneficial in adapting to the experience of PC. Because of the many constructs involved in this study, one might argue that the results are based on multiple testing effects. However, when corrected for multiple testing using the Bonferroni procedure, most of the problem areas that had significant results between members and non-members remained significant. Another point of consideration is the length of the questionnaire. Having to answer many questions may lead to fatigue or loss of motivation, and this possibly influences the responses. The questionnaire included items on this matter and answers indicate that half the sample considered the questionnaire to be too long, while one third found it acceptable. Eighty percent found the questions to be not too difficult and only 7% considered the questions to be irrelevant. Instructions in the questionnaire booklet emphasised the need to take as much time as was necessary to fill out the questions. From this, it can be concluded that it is not likely that the number of questions produced a significant bias. However, only a limited number of concepts were found to be relevant for drawing conclusions from this study; these were satisfaction with the care and information from the hospital, emotional distress measures, psychosocial problems and needs, and attitude towards group participation. For future studies, this is an indication of which concepts can play a role and which do not in comparing different groups of PC patients.

The clinical relevance of this study is that knowledge has been gained on shortcomings in the professional health care for PC patients. The psychosocial areas of concern that need extra attention have been highlighted. One of the bottlenecks is information supply for the patient. The patients' association is one of the sources that can play a role in filling that gap by providing experiential information. One cause for concern is that traumatic stress was found to be higher among members. It

is recommended that urologists and patients' association organisers should be alert to traumatic stress symptoms and, if necessary, refer the patient for specialised psycho-social care.

  The methodological relevance is that samples taken from a patients' association are biased. Concerning future research, it is important to confirmthese results using a prospective design and to elaborate knowledge of the features of men who become members of a PCPA.

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TABLES

Table 1 Background and psychometric characteristics of the questionnaires used in this study

Questionnaires	Number of items	Range	Cronbach's Alpha	Reference
1. Prostate-specific antigen (PSA) worries scale				This study
Knowledge of own PSA level	1	0–997	n.a.	
Knowledge of PSA in general	3	3–8	0.36	
Worries about PSA	2	2–8	0.82	
2. Satisfaction with hospital care				
Satisfaction with information about prostate cancer	4	4–20	0.88	Visser [43]
Satisfaction with medical and emotional support provided	3	3–30	0.86	Visser [43]
3. Quality of life (EORTC-C30)				Aaronson et al. [44]
Physical functioning	5	0–100	0.75	
Role functioning	2	0–100	0.85	
Social functioning	2	0–100	0.75	
Emotional functioning	4	0–100	0.86	
Cognitive functioning	2	0–100	0.67	
General health-related QOL	2	0–100	0.90	

Table 1 (*Continued*)

Questionnaires	Number of items	Range	Cronbach's Alpha	Reference
4. Prostate cancer specific problems (EORTC-PR25)				Aaronson [45]
Urological symptoms	5	0–100	0.77	
Burden of urological symptoms	3	0–100	0.71	
Bowel problems	4	0–100	0.52	
Problems related to hormonal treatment	6	0–100	0.37	
5. Sexuality				
Sexual behaviour questionnaire (SBQ)				based on Derogatis and
Total sexual dysfunction	9	9–39	0.76	Kourlesis [46]
Sexual problems (EORTC-PR 25)	2	0–100	0.81	Aaronson [45]
6. Psychosocial Problems Inventory for prostate cancer	9		n.a.	Osse et al. [19] adjusted
Number of problems		0–9		
Need to talk about problems		1–3		
7. Determinants of Group Participation				Ajzen [20]
Attitude towards talking about prostate cancer	1	−2–2	n.a	
Attitude towards group participation	10	−10–10	0.75	
Perceived social norms	8	−8–8	0.68	
Personal efficacy	3	−2–2	0.61	
8. Distress				
Profile of Mood States (POMS-short form)	32	0–4	0.91	Wald and Mellenbergh [21]
Joy in life scale (Health and Disease inventory)	13	0–100	0.87	Bruin and van Dijk [18]
Impact of Events Scale (IES)	15	15–60	0.90	Horowitz et al. [22]
Life Events Scale	1	1–3	n.a.	Based on Sarason et al. [23]
Daily Hassles scale	1	1–3	n.a.	Based on Vinherhoets et al. [24]
9. Social Support				
Disease specific social support	6	6–17	0.74	De Haes [47]
Social Support Questionnaire Differences (SSL-D)				Von Sonderen [25]
Daily affection	4	4–12	0.83	
Emotional support	8	8–24	0.91	
Approval	6	6–18	0.86	
Instrumental support	7	7–21	0.83	
Companionship	5	5–15	0.80	
Informational support	4	4–12	0.78	
Total social support	34	34–102	0.95	
10. Coping				Schreurs et al. [26]
Utrecht Coping List (UCL, short form)				
Problem focussed coping	5	5–20	0.83	
Avoidance	4	4–16	0.77	
Support seeking	5	5–20	0.72	
11. Emotional Control and Rationality (ECR)				Bleiker et al. [27]
Rationality	6	6–24	0.77	
Anti-emotionality	4	4–16	0.81	
Understanding others	3	3–12	0.74	
Emotional control	6	6–24	0.86	
12. Spirituality Assessment Scale (SAS)				Howden [30]
Total score	22	22–88	0.90	

Table 2 Background characteristics of men who are and are not members of the Dutch prostate cancer patient association

	Non-members *n* = 88	Members *n* = 150	Statistics
1. Background characteristics			
Age			
Mean (SD)	71.2 (6.7)	65.9 (8.3)	$t = 5.46^{**}$
Range	56–86	42–85	
Socio-economic status			
Mean (SD)	7.2 (2.2)	8.7 (2.1)	$t = -5.38^{**}$
Range	4–12	4–12	
Marital status *n* (%)			
Married	69 (78)	126 (84)	$Chi^2 = 1.17$
Single	19 (22)	24 (16)	
2. Medical characteristics			
Time since diagnosis *n* (%)			
<1 year	17 (20)	16 (11)	$Chi^2 = 3.75$
>1 year <2 years	15 (18)	28 (19)	
≥2 years	52 (62)	102 (70)	
Missing	4 (4)	4 (2)	
Metastasis *n* (%)			
No	57 (65)	89 (59)	$Chi^2 = 1.83$
Yes	26 (30)	45 (30)	
Not diagnosed	5 (6)	16 (11)	
Treatment *n* (%)			
Radical prostatectomy (RP)	20 (23)	43 (29)	$Chi^2 = 3.81$
Radiation therapy (RT)	18 (21)	21 (14)	
Hormone therapy (HT)	22 (25)	36 (24)	
RP & RT	4 (5)	10 (7)	
Intentionally curative + HT	17 (19)	33 (22)	
No treatment/wait & see	7 (8)	7 (7)	
Number of other diseases			
Mean (SD)	0.8 (0.8)	0.6 (0.8)	$t = 1.56$
Range	0–3	0–3	
Prostate specific antigen level			
Mean (SD)	13.4 (48.8)	20.1 (91.2)	$t = -0.70$
Range	0–400	0–910	

$^{**}p < 0.01.$

Table 3 Comparison of psychosocial factors in members and non-members of the prostate cancer patients' association

Measure	Non-members $n = 88$ mean (SD)	Members $n = 150$ mean (SD)	Statistics
1. PSA knowledge and worries scale			
Knowledge of PSA	2.6 (1.4)	3.5 (1.4)	$Z = -4.85$[***]
Worries about PSA level	3.8 (1.9)	4.4 (1.7)	$Z = -2.90$[**]
2. Satisfaction with hospital care			
Satisfaction with information about prostate cancer	12.9 (3.7)	11.3 (3.9)	$Z = 3.26$[***]
Satisfaction with medical and emotional care provided	22.6 (4.5)	19.6 (5.5)	$Z = 4.15$[***]
3. Quality of life (EORTC-C30)			
Physical functioning	82.8 (16.1)	82.6 (18.7)	$Z = -0.53$
Role functioning	85.6 (21.6)	82.1 (25.9)	$Z = -0.66$
Social functioning	88.4 (19.6)	85.6 (20.7)	$Z = -1.18$
Emotional functioning	85.1 (19.1)	77.8 (20.7)	$Z = -3.06$[**]
Cognitive functioning	86.2 (17.5)	83.3 (20.2)	$Z = -0.91$
General health-related QOL	78.9 (16.0)	74.8 (17.0)	$Z = -1.71$
4. Prostate cancer specific problems (EORTC-PR 25)			
Urological symptoms	24.4 (17.8)	22.2 (16.4)	$Z = -0.85$
Burden of urological symptoms	9.3 (16.2)	10.9 (16.0)	$Z = -1.93$
Bowel problems	4.8 (9.0)	5.9 (9.8)	$Z = -1.01$
Problems related to hormonal treatment	12.9 (12.2)	13.1 (11.8)	$Z = -0.24$
5. Sexuality			
Sexual Behaviour Questionnaire (SBQ)			
Total sexual dysfunction	26.8 (4.5)	27.1 (4.6)	$Z = -0.06$
Sexual problems (EORTC-PR25)	22.2 (22.6)	25.2 (24.1)	$Z = -0.81$
6. Distress			
Profile of Mood States	−0.5 (2.1)	0.4 (2.9)	$t = -2.71$[**]
Joy in Life scale (HDI-A)	59.8 (10.3)	56.6 (9.9)	$t = 2.42$[*]
Impact of Events scale (IES)	14.4 (14.4)	22.3 (14.6)	$t = -3.96$[***]
Life Events scale	1.7 (0.7)	1.8 (0.8)	$Z = -1.47$
Daily hassles scale	1.7 (0.8)	1.8 (0.9)	$Z = -1.60$
7. Social Support			
Disease specific social support	16.2 (3.7)	16.4 (3.0)	$Z = -0.23$
Social Support Questionnaire Differences (SSL-D) Total social support	47.0 (14.9)	48.5 (13.5)	$Z = -1.38$

Table 3 (*Continued*)

Measure	Non-members n = 88 mean (SD)	Members n = 150 mean (SD)	Statistics
8. Coping			
Utrecht Coping List			
Problem focussed coping	12.2 (3.6)	13.1 (3.0)	$Z = -1.91$
Avoidance	8.1 (2.2)	8.8 (2.2)	$Z = -2.45^*$
Emotional support seeking	9.5 (2.7)	10.0 (2.2)	$Z = -1.69$
9. Emotional Control and Rationality			
Emotional control	17.5 (3.9)	16.5 (3.6)	$Z = 2.04^*$
Rationality	16.7 (3.8)	16.9 (3.0)	$Z = -0.63$
Anti-emotionality	9.4 (2.8)	9.8 (2.7)	$Z = -0.81$
Understanding	7.3 (2.1)	7.5 (1.9)	$Z = -1.09$
10. Spirituality (SAS) total score	62.7 (11.0)	62.1 (9.9)	$Z = -0.85$
11. Psychosocial problems and needs			
Number of problems	4.1 (2.3)	4.7 (3.1)	$t = -1.72$
Need to talk about problems	1.7 (0.6)	2.2 (0.5)	$t = -5.61^{***}$
12. Determinants of group participation			
Attitude towards group participation	0.72 (2.5)	2.5 (2.5)	$t = -5.27^{***}$
Perceived social norms	2.1 (2.6)	2.6 (2.3)	$t = -1.55$
Personal efficacy	0.7 (1.0)	1.0 (0.8)	$t = -2.73^{**}$
13. Participated in groups	n %	n %	
Yes	13 (15)	34 (23)	$Chi^2 = 0.09$
No	75 (85)	116 (77)	

$^*p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$.

Table 4 Logistic regression analysis for factors related to membership of the patients' association

Factor	Odds ratio	95% CI
Socio-economic status	1.28	1.08–1.53**
Distress (POMS)	1.28	1.02–1.60*
Impact of events scale	1.05	1.02–1.09**
Emotional functioning	1.03	1.00–1.07*
Age	0.91	0.86–0.96**
Satisfaction with information about prostate cancer	0.86	0.78–0.94**

$N = 238$; POMS, Profile of Mood States; $^*p < 0.05$; $^{**}p < 0.01$.