

ORIGINAL ARTICLE

Benefits from membership in cancer patient associations: Relations to gender and involvement

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Abstract

Cancer patient associations report a growing number of members and increasing possibilities to influence health care, but knowledge about the members' views on the benefit of involvement is scarce. We therefore investigated how members (n = 1742) of Swedish patient associations for breast cancer and prostate cancer rate the benefit of membership for their physical and psychological well-being and social adjustment to cancer. Using a scoring scale, 2/3 of the members reported that membership had benefit for psychological well-being, whereas half of the members reported benefit for physical well-being and social adjustment. Individuals who had been actively involved in board work and/or contact person activities within the associations reported significantly more benefit for all three parameters. Gender differences were observed with men, represented by individuals affected by prostate cancer, reporting greater benefit for all three parameters, although especially evident for psychological well-being. Individuals who obtained membership within two years of diagnosis reported greater benefit for psychological well-being and social adjustment compared to those who became members later. In conclusion, members in patient associations for cancer report benefit particularly for their psychological well-being and actively involved members and men affected by prostate cancer perceive the greatest benefit from membership.

Being diagnosed with cancer will in most individuals affect both physical and psychological health and social function. Consequently, cancer-related information and support in the adjustment to cancer are commonly requested by the patients and fulfilment of disease-related needs may positively influence treatment adherence, psychological well-being, and quality of life [1,2]. Involvement in a cancer patient association (CPA) represents one means of fulfilling such needs. Currently more than 130 CPAs are registered in Sweden and these associations provide various forms of support e.g. possibilities to meet with other individuals affected by cancer, contact person activities, and cancer-related education [3]. CPA members also refer to information related to the disease, possibilities to participate in physical activities, and a need for psychosocial support when asked to motivate their membership [4,5].

The patient's role within the health care system is changing with greater emphasis on shared decision-

making. The medical knowledge related to cancer also evolves quickly with new treatment options being introduced, standards of care being revised, and a multitude of new cancer drugs evaluated in clinical trials. Hence, patient representatives are anticipated to increasingly take part in cancer-related task forces and the CPAs within this field are likely to have an increasing influence on cancer treatment and care [6–8]. Whereas the north American voluntary associations have strong philanthropic and individual missions, many European associations rather focus on group activities, including physical activities and disease-related information, although individual support e.g. through contact person activities are also offered by the latter [9]. Although patients are increasingly involved, knowledge about their views on involvement is scarce [6,10,11]. We aimed to explore how the benefits from membership are perceived by CPA members representing the two most common cancer types, breast cancer and prostate cancer, with focus

on physical and psychological well-being and social adjustment to cancer [12,13].

Patients and methods

Study sample

All members ($n = 2\,134$) in ten regional, geographically spread CPAs for breast cancer and prostate cancer in Sweden were invited to participate. Whereas the CPAs for breast cancer were established 1981–1990, those for prostate cancer are more recent and were established 1993–2001. Support members, e.g. relatives, friends, and health care personnel were excluded from the study since we aimed at learning how individuals affected by cancer perceived their benefit from membership. Scores were obtained from 1 742 (82%) individuals; 972 members with breast cancer and 770 with prostate cancer (Table I). Except for a lower median age (61 vs. 69 years) among members of CPAs for breast cancer, the two groups were comparable as regards membership characteristics (Table I). The study sample ($n = 1\,742$) corresponds to 13% of the total number of members ($n = 7\,402$) in the Swedish associations for breast cancer and to 55% of the members ($n = 1\,399$) in prostate cancer associations, but represents only a small fraction of the approximately 340 000 cancer survivors currently living in Sweden.

Data collection and analysis

Data were collected during a nine month period in 2002 and for confidentiality reasons the questionnaires were distributed by the CPAs. The forms used consisted of three sections: 1) structured questions on membership characteristics, 2) open-ended questions on motives for becoming and remaining members, and 3) scoring, 1–7, of the value of CPA membership for physical well-being, psychological well-being and social adjustment [14]. The results from section 2 have previously been reported [4]. Members' ratings were grouped into those reporting major benefit (1–2), medium benefit (3–5), and minor benefit (6–7) (Table II, Figure 1). The Mann-Whitney U-test with correction for ties was used to test hypotheses of equal score distributions in the

two groups. The statistical analyses were carried out using Stata 9.0 (StataCorp. 2005, College Station, TX). The study was approved by the Ethics Committee of Lund University (LU 605–01).

Results

In the total sample set major benefit from membership was reported by 28% regarding psychological well-being and 16% regarding physical well-being and social adjustment to cancer (Table II). An additional 34–41% of the members reported median benefit for the three parameters. Consequently, minor benefit was reported by half (48% and 50%) of the members reported for physical well-being and social rehabilitation and by one-third (31%) for psychological well-being (Table II).

Differences were observed in relation to gender, time from diagnosis to membership (early; within two years or late; after two years of diagnosis), and involvement in CPA activities (Table II). Men affected by prostate cancer reported significantly greater benefit than women affected by breast cancer for all three parameters, although the greatest difference applied to psychological well-being (Table II). Members who obtained an early membership also reported greater benefit for their psychological health and social adjustment to cancer (Table II). Finally, individuals actively involved in the associations' activities, i.e. individuals with experience from board work or contact person activities (with no differences between the latter groups) reported a significantly greater benefit from membership for all three parameters (Figure 1). However, gender differences for the perceived benefit were not observed for individuals actively involved in the CPAs (Figure 1).

Discussion

Since physical and psychological well-being and social adjustment to cancer have been identified as key issues among cancer survivors, we asked CPA members representing the two major cancer types in the Western world—breast cancer and prostate cancer—to rate the benefit from their membership. Compared to physical well-being and social adjustment after cancer the greatest benefit from CPA

Table I. Patient characteristics ($n = 1\,742$).

Member in association for	Total number of individuals	Age, Median age (range)	Early* membership (%)	Experience as board member (%)	Experience from contact person activities (%)
Breast cancer	972	61 (23–89)	78	13	30
Prostate cancer	770	69 (45–91)	81	9	29

*within 2 years of diagnosis.

Table II. Members' scores for physical and psychological well-being and social adjustment to cancer.

Benefit (scores)	Major benefit (1–2)	Medium benefit (3–5)	Minor benefit (6–7)	p-value*
Physical well-being				
<i>Total sample set</i>	261 (16)	611 (36)	810 (48)	
<i>Breast cancer</i>	141 (15)	316 (34)	479 (51)	
<i>Prostate cancer</i>	120 (16)	295 (40)	331 (44)	p = 0.02
<i>Board member and/or contact person</i>	155 (27)	246 (43)	167 (29)	
<i>Neither board member nor contact person</i>	106 (10)	365 (33)	643 (58)	p < 0.001
<i>Early membership</i>	215 (16)	473 (36)	628 (48)	
<i>Late membership</i>	41 (12)	127 (37)	172 (51)	p = 0.15
Psychological well-being				
<i>Total sample set</i>	473 (28)	691 (41)	518 (31)	
<i>Breast cancer</i>	293 (26)	356 (38)	340 (36)	
<i>Prostate cancer</i>	234 (31)	335 (45)	178 (24)	p < 0.001
<i>Board member and/or contact person</i>	277 (49)	221 (39)	73 (13)	
<i>Neither board member nor contact person</i>	196 (18)	470 (42)	445 (40)	p < 0.001
<i>Early membership</i>	383 (29)	543 (41)	391 (30)	
<i>Late membership</i>	78 (23)	141 (42)	120 (35)	p = 0.01
Social adjustment				
<i>Total sample set</i>	268 (16)	546 (34)	813 (50)	
<i>Breast cancer</i>	149 (16)	239 (31)	489 (53)	
<i>Prostate cancer</i>	119 (17)	253 (36)	324 (47)	p = 0.04
<i>Board member and/or contact person</i>	170 (31)	232 (42)	150 (27)	
<i>Neither board member nor contact person</i>	98 (9)	314 (29)	663 (62)	p < 0.001
<i>Early membership</i>	221 (17)	450 (35)	605 (47)	
<i>Late membership</i>	39 (12)	90 (28)	197 (60)	p < 0.001

*Mann-Whitney U-test, corrected for ties.

membership was in our study reported for psychological well-being with 28% of the members reporting major benefit and an additional 41% medium benefit. Cancer rehabilitation includes a wide variety of concepts, although psychological rehabilitation predominates [15,16], and our data support the notion that the possibility of meeting individuals in a similar situation represents one of the most important services offered by the CPAs [15].

Physical activity has been reported to correlate with a better quality of life among cancer survivors, but about half of the patients report physical performance limitations that affect activities of daily life several years after diagnosis [17–19]. Decreased health-related quality of life and physical health have been reported in women affected by breast cancer as well as in men affected by prostate cancer [20]. Possibilities for physical activities and rehabilitation are commonly organized by the CPAs, but only 16% of the members in our study reported that membership were of major great benefit for their physical well-being (Table II). The benefit from membership regarding social adjustment to cancer was reported at a similar level with 16% reporting major and an additional 34% medium benefit. Whereas psychological well-being has been demonstrated to improve over time, relationship factors

remain constant [21]. Social networks, satisfaction with social support, and use of supportive care services have been linked to improved quality of life in cancer survivors, but the low fraction of members reporting great benefit from membership with regard to physical well-being and social adjustment to cancer may suggest that other efforts may be needed in these areas [21–23].

Members actively involved in the CPAs reported greater benefit from membership for all three parameters (Table II), which probably reflects that active members obtain updated knowledge about ongoing activities, develop extended social networks, access disease-related information, and thereby achieve a higher degree of personal support and satisfaction [9]. Within this group no differences were observed between men and women for any of the three parameters (Figure 1). Gender differences were, however, observed among the remaining members with men affected by prostate cancer reporting significantly more benefit than women with breast cancer for all three parameters (Figure 1). The timing of membership also seemed to influence the benefit perceived since members who obtained an early membership (within two years of diagnosis) reported greater benefit regarding psychological well-being and social adjustment to cancer. Since the perceived benefit is higher in members who

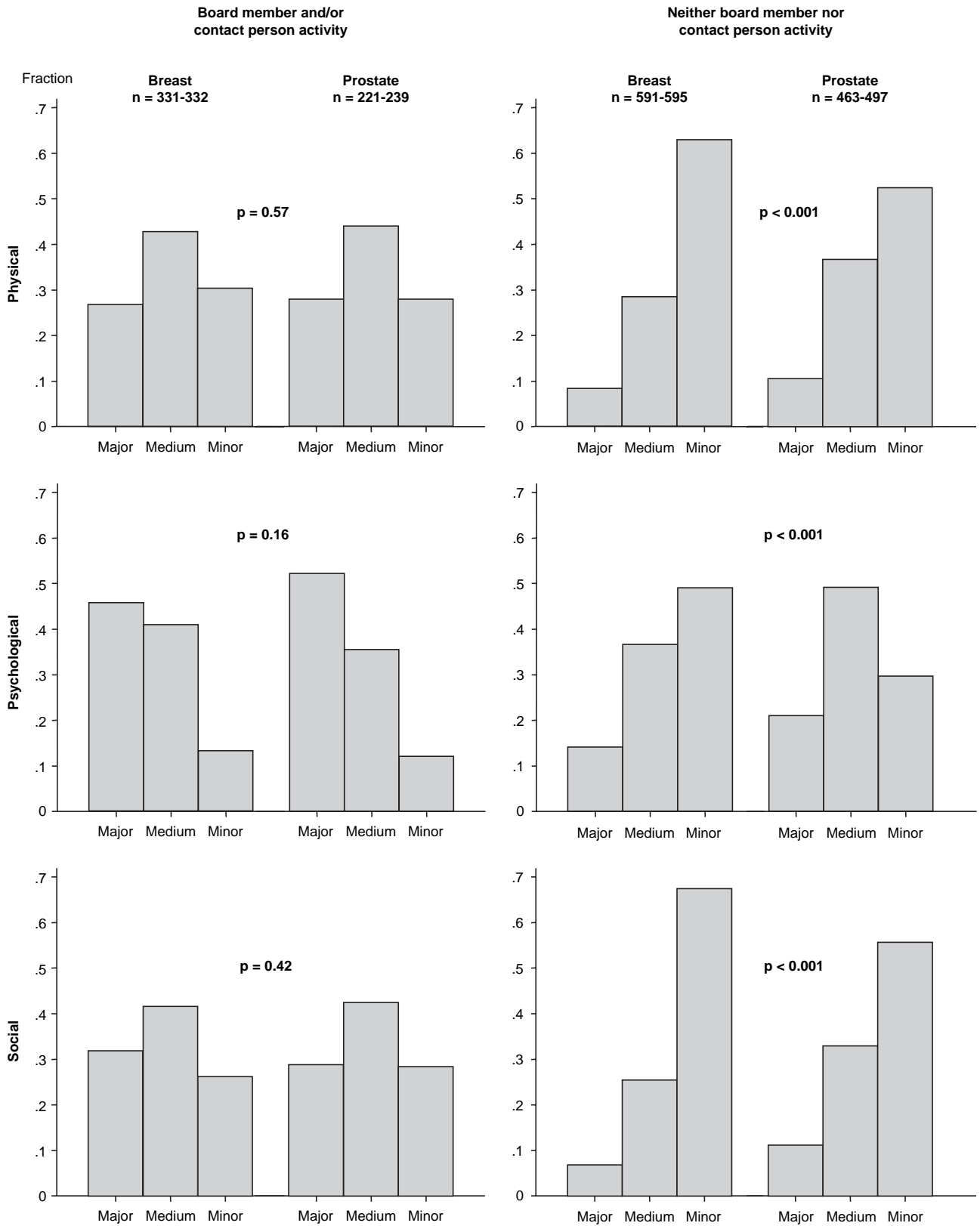


Figure 1. Graphs displaying the distribution of major benefit, medium benefit, and minor benefit scores for the three parameters physical well-being, psychological well-being, and social adjustment to cancer. The data are presented in relation to involvement in CPA activities, and diagnosis. The p-values correspond to Mann-Whitney U-tests corrected for ties.

chose to obtain membership early, this may imply that information about the CPA's existence, mission, and activities should be made available to patients soon after diagnosis. It is, however, not known to what extent the individuals with the greatest need of social support indeed become members and current knowledge may indicate the opposite since patients at highest risk for poor outcome are less likely to utilize formal support networks [5,24].

The number of breast cancer and prostate cancer survivors will substantially increase within the next decade, which is expected to lead to an increased need for support activities. Our study demonstrates that CPA members affected by breast cancer or prostate cancer report that the greatest benefit from membership relates to their psychological well-being. Actively involved members, men affected by prostate cancer, and individuals who obtained membership early after diagnosis perceive the greatest benefit for all parameters investigated, which indicates that getting involved and taking advantage of CPA activities is linked to the perceived benefit from membership.

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