Participation in online patient support groups endorses patients' empowerment

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ABSTRACT

Objective: Although much has been expected of the empowering effect of taking part in online patient support groups, there is no direct evidence thus far for the effects of participation on patient empowerment. Hence our exploring to what extent patients feel empowered by their participation in online support groups, and which processes that occur in these groups are related to the empowering outcomes.
Methods: An online questionnaire was completed by 528 individuals who were active in online groups for patients with breast cancer, fibromyalgia and arthritis.
Results: The respondents felt empowered in several ways by their participation. The empowering outcomes that were experienced to the strongest degree were 'being better informed' and 'enhanced social well-being'. No significant differences in empowering outcomes between diagnostic groups were found. The empowering outcomes could only be predicted in a modest way by the processes that took place in the online support groups.
Conclusion: This study indicates that participation in online support groups can make a valuable contribution to the empowerment of patients.
Practice implications: Health care providers should acquaint their patients with the existence of online support groups and with the benefits that participation in these groups can offer.

1. Introduction

Empowerment reflects the belief in patient autonomy and the right and responsibility of patients to access health information and to make their own health-related decisions [1–3]. Empowered patients are considered to be successful in managing their condition, collaborating with their health providers, maintaining their health functioning and accessing appropriate and high quality care [4].

Much has been expected of the potential empowering effect of taking part in online support groups for patients [5–9]. So far, however, there is no direct evidence for the effects of participation in online support groups on patient empowerment [10,11].

An explanation for the deficiency of studies investigating the effect of participation in online support groups on patient empowerment might be that the concept is inconsistently defined [12–14]. There is a great deal of ambiguity with regard to the precise nature of patient empowerment [15,16].

Within the context of online support groups, only a couple of studies have focused on the concept of patient empowerment. The focus of most of these studies was to identify the processes that take place in online support groups [17–21], while some studies focused on the outcomes experienced by the participants [22–25]. In our opinion, the empowerment concept is operationalized in a limited fashion within these studies. Some studies claim that they study empowerment, but they focus mainly on one aspect of the empowerment concept, such as the doctor–patient relationship. Therefore, we first conducted a qualitative study among participants of online patient support groups to obtain a complete overview of patient empowerment [26]. Results revealed that the following empowering processes occurred in the online support groups: exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others and amusement. The respondents mentioned the following empowering outcomes: being better informed, feeling confident with their physician, their treatment and their social environment, improved acceptance of the illness, increased optimism and control, enhanced self-esteem and social well-being and collective action.

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Despite the fact that this qualitative study revealed relevant information about the empowering processes and outcomes of online support groups, a qualitative study has its limitations. We could not draw any conclusions on the frequency with which the empowering processes and the empowering outcomes of online support groups occurred. Relationships between processes and outcomes could not be determined on the basis of the interviews. Finally, the results of the qualitative study revealed indications for possible differences in empowering processes and outcomes between the patients groups studied. However, because of the small sample size, no clear or consistent differences could be confirmed.

The primary purpose of this quantitative study was to explore, by means of a questionnaire, to what extent patients feel empowered by their participation in online support groups and with which frequency empowering processes occur. In addition, two more research questions guided this study. First, which processes that occur in online support groups are related to these outcomes? Second, are there any differences between patient groups with regard to empowering processes and outcomes?

2. Methods

2.1. Sample and procedure

We focused our study on online support groups for patients with breast cancer, fibromyalgia and arthritis. We chose to explore these three groups because of the contrast between the illnesses (life-threatening, unexplained and chronic disabling). We searched the Internet with the search engine Google to identify all Dutch online support groups for patients with breast cancer, fibromyalgia and arthritis that were active (receiving > 30 postings a month). In total, we found 20 groups. We asked the web owners of these groups for permission to approach the participants for the study. The web owners of 19 groups (7 breast cancer, 6 fibromyalgia and 6 arthritis) supported our study. We sent postings to these groups to ask participants to complete our online questionnaire. Criteria for inclusion were listed in the postings. The participants had to state that they had been diagnosed with either breast cancer, fibromyalgia or arthritis and had engaged passively or actively in online support groups. The medical diagnoses of the respondents were not verified with their physicians. In total, 593 participants responded to our request. Obviously, a response percentage is not available due to the fact that it is not known how many patients participated in the online support groups under study. Of these participants, 65 only filled in the questions concerning their background and were thus not included in the data analysis, leaving a group of 528 respondents.

2.2. Instrument

(1) *Demographic and health characteristics.* The respondents were asked to provide information about demographic character-istics such as age, sex, education and diagnosis. Health-related quality of life was assessed with the SF 12, version 2. Standardized scores were calculated for the physical and mental well-being varying from 0 (poor well-being) to 100 (excellent well-being), with a mean of 50 and a standard deviation of 10 in the general population of the United States [27].

(2) *Use of the support group.* Respondents were asked to indicate since when they had visited the online support group, how frequently they visited it, how long a visit lasted, whether or not they contributed postings and if so, how many postings they had contributed during the last 4 weeks.

(3) *Empowering processes.* On the basis of the results of the qualitative study among participants of online support groups [26], 29 items were formulated that described the processes that took place in the online support groups. In all items we asked for the frequency with which certain events happened in the online support group. Respondents could answer on a 4-point scale, ranging from 'seldom or never' (1) to 'often' (4). For each process the internal consistency (Cronbach's alpha) was determined. 'Exchanging information' was measured with 9 items (α = .88). 'Encountering emotional support' was measured with 12 items (α = .95), which was based on the "Social Support List—Interaction" [28].'Finding recognition' was measured with 4 items (α = .70). 'Helping others' was measured with 2 items (α = .82) and finally 'Sharing experiences' was measured with 2 items (α = .87).

(4) *Empowering outcomes.* On the basis of the results of the qualitative study [26], 38 items were formulated that described empowering outcomes from participation in online support groups. All items had the format of a statement that began with 'Through my participation in online support groups...'. Respondents could answer on a 5-point scale, ranging from 'completely disagree' (1) to 'completely agree' (5). 'Being better informed' was measured with 4 items (α = .85). 'Feeling more confident in the relationship with their physician' was measured with 11 items (α = .91). 'Improved acceptance of the illness'[1] was measured with 5 items (α = .90). 'Feeling more confident about the treatment' was measured with 5 items (α = .89). 'Increased optimism and control over the future' was measured with 8 items (α = .76), partially based on the revised illness perception questionnaire [29] and on the Dutch version of the Mastery Scale [30]. 'Enhanced self-esteem' was measured with 3 items (α = .93), partially based on the Dutch version of the Rosenberg self-esteem scale [31]. Finally, 'Enhanced social well-being' was measured with 2 items (α = .70).

For an overview of the items belonging to all the above-mentioned constructs, see the Appendices A and B. For each construct a mean total score was calculated.

2.3. Data analysis

The data were analyzed with the statistical software package SPSS 12.0. Differences in continuous variables between the three patient groups were tested by means of one-way analysis of variance (ANOVA) followed by a Bonferroni post hoc test and differences in categorical variables by Chi-square. To correct for multiple testing we made use of Bonferroni adjustment. The significance level was set on $P < .002$ (0.5/25).

We also compared the three illness groups by means of non-parametric statistics. The non-parametric statistics rendered the same results as the parametric statistics.

Relationships between the processes that took place within the online support groups and the outcomes experienced by the participants were determined by a Pearson correlation analysis. Since the correlation analysis was carried out only as a guide to the choice of variables to be included in regression analyses, and no conclusions were based on its results, we did not correct for multiple comparisons. A hierarchical multiple regression analysis

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[1] The original constructs "Increased confidence in dealing with the social environment" and "Improved acceptance of the disease" were combined in one scale because of the great similarity between the constructs.

was used to determine to what extent the empowering outcomes could be predicted by the processes that took place in the online support groups. In the first block of the regression analysis, the background variables that correlated significantly with the empowering outcomes were entered. In the second block of the regression analysis, the processes that correlated significantly with the empowering outcomes were entered.

All analyses were repeated for women only, because of the small number of participating men.

3. Results

3.1. Demographic and health characteristics

Of the respondents 41% had the diagnosis breast cancer, 22% had the diagnosis fibromyalgia and 23% of the respondents indicated to have arthritis. The other respondents (14%) indicated to have more than one of these three diagnoses.

Most of the respondents were women (94%) (Table 1). The average age of the respondents was 44 years. The majority of the respondents were married or living with a partner (79%). In total 33% of the participants had a low level of education, while 41% had a medium level of education and 26% had a higher level of education. Most participants were not employed (56%). However, breast cancer patients were more often employed compared to the other patient groups.

The mean duration of the participants' illness was 5 years, with a range of 0–51 years. Breast cancer patients were more recently diagnosed.

The respondents of our questionnaire had an average score of 36.5 on the physical component of the SF12 and an average score of 40.1 on the mental component of the SF12. This indicates that the respondents' physical and mental well-being was worse than the average of the general population. Breast cancer patients had a

higher score compared to the other patient groups concerning the physical component.

3.2. Use of online support groups

On average the respondents had been active for a period of 2.2 years in an online support group (Table 2). Breast cancer patients had joined the online support group more recently. Over half of the respondents (58%) visited the online support group daily. For most respondents the visits to the online support group lasted between 10 and 30 min. The majority of the respondents (79%) indicated that they had at some time contributed a posting to an online support group. During the last 4 weeks, about half of the respondents had posted at least once a week.

3.3. Empowering processes

The processes that took place the most frequently in the online support groups are 'exchanging information' and 'finding recognition' (Table 3). The scores on the separate items (data not shown) revealed that the information exchanged in the online groups was regularly to often considered understandable (94%) and valuable (83%) by the respondents (data not in table). It appeared that the information was not always new: the majority of the respondents (61%) even indicated that they only sometimes or even seldom read new information in the online support group. In total, 83% of the respondents indicated to recognize themselves regularly to often in the stories of the other participants (data not in table).

To a lesser degree, the respondents also 'encountered emotional support', 'helped others' and 'shared experiences' in the online support groups. For example, 42% of the respondents indicated that they regularly to often provided advice and support to other participants (data not in table). The majority of the respondents (53%) regularly to often received good advice of other participants,

Table 1
Demographic and health characteristics

	Breast cancer (170 ≤ n ≤ 214)	Fibromyalgia (96 ≤ n ≤ 117)	Arthritis (82 ≤ n ≤ 121)	More diagnoses (59 ≤ n ≤ 76)	Total (407 ≤ N ≤ 528)	χ^2 (d.f.)	F (d.f.)	P value
Sex[a] (n, %)						59.6 (3)		.000
Female	211 (99%)	115 (98%)	95 (79%)	73 (96%)	494 (94%)			
Male	3 (1%)	2 (2%)	26 (22%)	3 (4%)	34 (6%)			
Age in years[a]						11.9 (3)		.000
Mean (S.D.)	46 (8.9)	40 (9.2)	43 (12.5)	48 (10.3)	44 (10.4)			
Minimum	25	17	18	28	17			
Maximum	72	58	75	73	75			
Marital status (n, %)						1.9 (3)		.589
Single	46 (22%)	21 (18%)	26 (22%)	20 (26%)	113 (21%)			
Together	168 (79%)	96 (82%)	95 (79%)	56 (74%)	415 (79%)			
Education[a] (n, %)						31.7 (6)		.000
Low	52 (25%)	46 (41%)	34 (29%)	39 (51%)	171 (33%)			
Middle	88 (42%)	49 (43%)	48 (40%)	28 (37%)	213 (41%)			
High	71 (34%)	18 (16%)	37 (31%)	9 (12%)	135 (26%)			
Labour[a] (n, %)						44.4 (6)		.000
Paid job (>20 h)	99 (47%)	22 (19%)	32 (26%)	14 (18%)	167 (32%)			
Paid job (<20 uur)	26 (12%)	19 (17%)	15 (12%)	5 (7%)	65 (12%)			
Unemployed	88 (41%)	74 (64%)	74 (61%)	57 (75%)	293 (56%)			
Time passed since diagnosis[a] (in years)						19.3 (3)		.000
Mean (S.D.)	2.9 (3.0)	5.0 (5.6)	7.6 (7.0)	6.8 (7.7)	5.0 (5.9)			
Minimum	0	0	0	0	0			
Maximum	15	38	31	51	51			
Well-being (SF 12) (mean, S.D.)								
Physical well-being[a]	43.0 (10.9)	32.1 (8.8)	33.2 (9.8)	29.5 (8.7)	36.5 (11.4)		43.4 (3)	.000
Mental well-being	40.4 (6.5)	39.3 (6.1)	41.7 (6.0)	38.3 (6.9)	40.1 (6.4)		3.8 (3)	.009

[a] Test values for Chi-square tests or one-way analysis of variance (ANOVA) comparing the three illness groups were considered significant if P < .002.

Table 2
Use of the online support group

	Breast cancer (167 ≤ n ≤ 214)	Fibromyalgia (95 ≤ n ≤ 117)	Arthritis (97 ≤ n ≤ 121)	More diagnoses (61 ≤ n ≤ 76)	Total (420 ≤ N ≤ 528)	χ^2 (d.f.)	F (d.f.)	P value
Number of years active in an online support group[a]							7.2 (3)	.000
Mean (S.D.)	1.7 (1.8)	2.4 (2.1)	2.4 (2.3)	2.9 (2.4)	2.2 (2.1)			
Minimum	0	0	0	0	0			
Maximum	8	9	9	9	9			
Frequency visit online support group (n, %)						19.6 (15)		.187
More times a day	68 (34%)	31 (29%)	24 (21%)	23 (34%)	146 (30%)			
About once a day	58 (29%)	29 (27%)	36 (32%)	16 (24%)	139 (28%)			
More times a week	52 (26%)	25 (24%)	31 (27%)	16 (24%)	124 (25%)			
About once a week	17 (8%)	14 (13%)	9 (8%)	10 (15%)	50 (10%)			
More times a month	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)			
About once a month	3 (2%)	3 (3%)	5 (4%)	2 (3%)	13 (3%)			
Less than once a month	4 (2%)	4 (4%)	9 (8%)	1 (2%)	18 (4%)			
Duration visit online support group (n, %)						8.9 (9)		.443
Less than 10 min	54 (26%)	22 (20%)	34 (29%)	14 (19%)	124 (24%)			
10–30 min	120 (57%)	67 (60%)	60 (50%)	40 (56%)	287 (56%)			
30 min to 1 h	28 (13%)	16 (14%)	16 (13%)	15 (21%)	75 (15%)			
More than 1 h	7 (3%)	6 (5%)	9 (8%)	3 (4%)	25 (5%)			
Contributing postings (n, %)						.75 (3)		.863
Yes	166 (78%)	95 (81%)	97 (80%)	61 (80%)	419 (79%)			
No, I never contributed a posting	48 (22%)	22 (19%)	24 (20%)	15 (20%)	109 (21%)			
Number of postings during the past 4 weeks (n, %)						13.0 (15)		.605
None	26 (16%)	11 (12%)	18 (19%)	11 (18%)	66 (16%)			
Some postings, but less than one a week	55 (33%)	38 (40%)	41 (42%)	20 (33%)	154 (37%)			
One during a week	19 (11%)	11 (12%)	12 (12%)	4 (7%)	46 (11%)			
More during a week, but not everyday	38 (23%)	24 (25%)	19 (20%)	17 (28%)	98 (23%)			
Everyday one posting	5 (3%)	3 (3%)	0 (0%)	2 (3%)	10 (2%)			
Everyday more postings	24 (14%)	8 (8%)	7 (7%)	7 (12%)	46 (11%)			

[a] Test values for Chi-square tests or one-way analysis of variance (ANOVA) comparing the three illness groups were considered significant if $P < .002$.

and many felt regularly to often comforted (44%) or reassured (35%) (data not in table).

The arthritis patients indicated that the processes 'exchanging information' and 'finding recognition' occurred significantly less often in the online support groups in which they participated, compared to the other patient groups.

The analyses for women only gave similar results, only the difference in 'finding recognition' between the arthritis and fibromyalgia patients was not significant anymore.

3.4. Empowering outcomes

The empowering outcomes that were experienced to the strongest degree were 'being better informed', followed by 'enhanced social well-being' (Table 4). Frequency distributions on separate items (data not in table) revealed that 74% of the patients had the feeling that they now had the right knowledge to manage their illness. Almost half of the participants felt less lonely (47%) as a result of participation in an online support group. Many

participants (58%) indicated that their social contacts increased by participating in an online support group (data not in table).

The empowering outcomes 'feeling more confident in the relationship with their physician', 'improved acceptance of the illness', 'feeling more confident about the treatment' and 'increased optimism and control' were experienced to a similar degree by the participants. For example, over half of the respondents (61%) indicated that they knew better which questions to ask their doctor. Also the majority of the respondents (53%) felt better prepared for a doctor's appointment and some of the respondents (56%) had the feeling that they could clarify their needs better to their doctor. In total 55% of the respondents indicated that they dared to be more open about their illness as a result of their participation in an online support group. The majority of the respondents (53%) had the feeling that they took the right decisions regarding their illness by participating in an online support group (data not in table).

Enhanced self-esteem was experienced to a slightly less degree. Some of the patients (43%) indicated that participation in online

Table 3
Mean scores for empowering processes by diagnostic group

	Mean, S.D.					F (d.f.)	P value
	Breast cancer (190 ≤ n ≤ 205)	Fibromyalgia (105 ≤ n ≤ 114)	Arthritis (99 ≤ n ≤ 116)	More diagnoses (66 ≤ n ≤ 75)	Total (460 ≤ N ≤ 510)		
Exchanging information[a] (1–4) (1, 2)	3.1 (.53)	3.0 (.54)	2.8 (.53)	2.9 (.58)	3.0 (.56)	12.5 (3)	.000
Finding recognition[a] (1–4) (3, 4)	2.9 (.60)	2.9 (.55)	2.6 (.50)	2.7 (.54)	2.8 (.58)	9.3 (3)	.000
Sharing experiences (1–4)	2.7 (1.0)	2.8 (.86)	2.5 (.83)	2.6 (.90)	2.7 (.94)	2.7 (3)	.043
Encountering emotional support (1–4)	2.2 (.87)	2.3 (.73)	2.0 (.68)	2.1 (.75)	2.2 (.79)	2.7 (3)	.046
Helping others (1–4)	2.2 (.83)	2.2 (.66)	2.2 (.69)	2.2 (.72)	2.2 (.75)	.18 (3)	.913

1, patients with more than one diagnosis and breast cancer patients differed significantly; 2, patients with arthritis differed significantly from patients with breast cancer and patients with fibromyalgia; 3, patients with arthritis differed significantly from patients with breast cancer and patients with fibromyalgia; 4, patients with more than one diagnosis and breast cancer patients differed significantly.

[a] Test values for one-way analysis of variance (ANOVA) comparing the three illness groups were considered significant if $P < .002$.

Table 4
Mean score for empowering outcomes by diagnostic group

	Mean, S.D.					F (d.f.)	P value
	Breast cancer ($171 \leq n \leq 182$)	Fibromyalgia ($96 \leq n \leq 98$)	Arthritis ($85 \leq n \leq 90$)	More diagnoses ($59 \leq n \leq 64$)	Total ($411 \leq N \leq 434$)		
Being better informed (1–5)	3.8 (.78)	3.8 (.71)	3.5 (.69)	3.8 (.76)	3.7 (.75)	2.4 (3)	.071
Enhanced social well-being (1–5)	3.4 (.99)	3.4 (.94)	3.2 (.82)	3.4 (1.02)	3.4 (.95)	.69 (3)	.557
Feeling more confident in the relationship with their physician (1–5)	3.4 (.73)	3.4 (.65)	3.2 (.62)	3.4 (.80)	3.3 (.70)	1.0 (3)	.373
Improved acceptance of the illness (1–5)	3.1 (.99)	3.4 (.82)	3.2 (.74)	3.3 (1.03)	3.2 (.92)	2.1 (3)	.106
Feeling more confident about the treatment (1–5)	3.2 (.83)	3.4 (.66)	3.1 (.76)	3.2 (.91)	3.2 (.79)	1.8 (3)	.142
Increased optimism and control (1–5)	3.2 (.59)	3.3 (.69)	3.0 (.46)	3.1 (.57)	3.2 (.60)	2.8 (3)	.041
Enhanced self-esteem (1–5)	3.2 (.95)	3.3 (.93)	2.9 (.85)	3.2 (.94)	3.1 (.93)	2.6 (3)	.054

support groups led to a more satisfied feeling about themselves (data not in table).

With regard to the empowering outcomes no significant differences between the patient groups were found. The analyses for women only gave similar results.

3.5. Relationships between processes and outcomes

All processes that took place in the online support groups were significantly correlated, although weak ($<.30$) to moderate ($>.30 < .60$), with the outcomes of participation experienced (Table 5).

It can be concluded that the empowering outcomes could only be predicted partially on the basis of the processes that took place in the online support groups (Table 6). R^2 varied from .13 to .31. The outcomes that could be predicted best are 'being better informed' and 'enhanced social well-being'.

The most important predictors of the outcome 'being better informed' appeared to be 'exchanging information' and 'finding recognition'. In total, 31% of the variance could be explained.

The most important predictors of the outcome 'enhanced social well-being' appeared to be 'encountering emotional support' and 'sharing'. In total, 30% of the variance could be explained.

When focusing on the background variables, education and time passed since diagnosis appeared to be predictors of the empowering outcomes.

The analyses for women only gave similar results.

4. Discussion and conclusion

4.1. Discussion

To the best of our knowledge, this study is the first quantitative study that illustrates how participants in online support groups feel 'empowered' by their participation. Earlier research was mainly qualitative, as a result of which the extent to which participants felt empowered, and the frequency with which the empowering processes occurred in the online support groups could not be determined.

Results of the present study were in line with the results of our earlier qualitative study, by confirming the potential of online support groups in providing the participants with a feeling of 'being empowered' in several areas [26]. However, this study adds some interesting information concerning the extent to which the participants of online support groups feel empowered. Results indicate that participation did not have a similar profound effect on feelings of 'being empowered' in all areas studied.

The empowering outcome that was experienced to the strongest degree was 'being better informed'. This outcome is mentioned as a benefit of participation in online support groups in several other studies (e.g. [21,32,33]). Campbell et al. [34] mentioned in their review of cancer peer support programs that several studies incorporated in their review found that participants had a better understanding of their illness and were better informed as a result of receiving peer support.

'Enhanced social well-being' was also experienced to a strong degree. Respondents indicated that participating in an online support group led to a rise in their number of social contacts and to a decrease in loneliness. These findings are comparable to the study results of other qualitative studies [21,24,33]. Unwanted loneliness is one of the most significant psychosocial stressors that people face following a diagnosis of a chronic illness [24]. Our results show that participation in online support groups can help to reduce this stressor.

The empowering process that took place the most frequently in the online support groups was 'exchanging information'. Despite the fact that 'exchanging information' is the most important process demonstrated, online support groups should not solely be seen as a source of information. Earlier research showed that when information is exchanged in online support groups, it is rarely medical factual information but sooner personal experience [35]. Doctors are there to provide the factual information, but other

Table 5
Pearson correlation coefficients for the relationships between the processes that took place within the online support groups and the outcomes experienced by the participants

	Being better informed ($n = 427$)	Feeling more confident in the relationship with their physician ($n = 427$)	Feeling more confident about the treatment ($n = 422$)	Improved acceptance of the illness ($n = 421$)	Increased optimism and control ($n = 413$)	Enhanced self-esteem ($n = 411$)	Enhanced social well-being ($n = 411$)
Exchanging information	.43[*]	.35[*]	.31[*]	.21[*]	.30[*]	.30[*]	.28[*]
Encountering emotional support	.35[*]	.32[*]	.34[*]	.27[*]	.35[*]	.38[*]	.51[*]
Finding recognition	.42[*]	.39[*]	.34[*]	.26[*]	.34[*]	.28[*]	.31[*]
Helping others	.25[*]	.25[*]	.28[*]	.24[*]	.30[*]	.31[*]	.37[*]
Sharing experiences	.26[*]	.27[*]	.25[*]	.28[*]	.30[*]	.33[*]	.48[*]

[*] $P < .01$.

Table 6
The extent to which empowering outcomes can be predicted by the processes that take place in the online support groups

	Being better informed (n = 394)	Feeling more confident in the relationship with their physician (n = 387)	Improved acceptance of the illness (n = 381)	Feeling more confident about the treatment (n = 382)	Increased optimism and control (n = 373)	Enhanced self-esteem (n = 371)	Enhanced social well-being (n = 371)
	β	B	β	β	β	β	B
Step 1							
Sex	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Age	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Marital status	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Education	−.13*	−.19	n.s.	−.20**	n.s.	n.s.	n.s.
Time passed since diagnosis	−.15*	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Step 2							
Exchanging information	.25**	.16*	n.s.	n.s.	n.s.	n.s.	n.s.
Encountering emotional support	.22*	n.s.	n.s.	.19*	n.s.	.21*	.30**
Finding recognition	.23**	.24**	n.s.	.20*	.18*	n.s.	n.s.
Helping others	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Sharing experiences	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	.19*
	$R^2 = .31$	$R^2 = .25$	$R^2 = .13$	$R^2 = .23$	$R^2 = .20$	$R^2 = .19$	$R^2 = .30$
	$F (10, 384) = 16.9$	$F (10, 377) = 12.3^{**}$	$F (10, 371) = 5.4^{**}$	$F (10, 372) = 10.8^{**}$	$F (10, 363) = 8.8^{**}$	$F (10, 361) = 8.6^{**}$	$F (10, 361) = 15.6^{**}$
	R^2 change $= .23^{**}$	R^2 change $= .18^{**}$	R^2 change $= .11^{**}$	R^2 change $= .16^{**}$	R^2 change $= .17^{**}$	R^2 change $= .18^{**}$	R^2 change $= .27^{**}$

*$P < .01$; **$P < .001$, n.s. = non-significant.

patients can tell you how it feels and what the patient can expect in the future [36]. Support groups should thus not be seen as the sole provider of information for participants, but more as an additional resource [26,37].

According to our study results, 'helping others' is the process that occurred to the least degree. These results are not surprising, because 'helping others' is a process that can only be executed by those who actively contribute postings to an online support group. Those who do not post, so called lurkers, are unable to help other participants in the online support group. In addition, we found that high-frequency posters indicate helping other participants more often ($r = .38$, $P < .01$). These study results are in line with the results of Winefield [38], who found that high-frequency posters referred less often to seeking and more often to providing support in their messages than the less frequent posters did.

In general, it has to be concluded that the empowering outcomes could only be predicted in a modest way by the processes that took place in the online support groups. The outcomes that could be predicted best are 'being better informed' and 'enhanced social well-being'. As could be logically predicted, the process 'exchanging information' played an important part in the prediction of 'feeling better informed', and 'encountering emotional support' was especially important when predicting the outcome 'enhanced social well-being'.

'Finding recognition' appeared to play a significant role when predicting the empowering outcomes 'being better informed', 'feeling more confident in the relationship with their physician', 'feeling more confident about the treatment' and 'increased optimism and control'. The important role of finding recognition also appeared from our qualitative study. Almost all participants mentioned that 'recognition' was the main reason for them to participate in an online support group [26]. In addition, the importance of recognition is frequently raised in the literature on online support groups. For example, Buchanan and Coulson [32] found in their study on a dental anxiety online support group that by accessing the messages posted by others facing similar challenges, members appeared empowered to conquer their fears and to move forward. On the basis of these results, it can again be concluded that online support groups are an ideal platform for finding recognition. There are several reasons as to why finding

recognition has an impact on the empowering outcomes experienced by the participants. First, it is argued that people may accept information provided by peers, people who they can identify with, as more acceptable compared to other sources of information [39]. In addition, peers can act as positive role models [26,39,40,41]. The participants of our qualitative study mentioned that they became more optimistic about their own future by reading the disease stories of other participants who served as positive role models. Also, learning from the personal experiences of peers, e.g. about their experiences with a specific type of treatment, was considered as a positive encouragement for other participants [26].

'Time passed since the diagnosis' appeared to play a significant role when predicting the empowering outcome 'being better informed'. The participants who were diagnosed more recently felt better informed. These results are in line with the results of earlier qualitative studies [22,26]. Interview results revealed that patients who started to participate in the online support group a considerable time after being diagnosed, in some cases received the information too late. At the moment they became active, decisions about the treatment had already been taken [26]. Broom [22] thus advises that patients should be referred to these groups by their physician soon after being diagnosed.

Results of this study showed that those with a lower educational level score higher on the empowering outcomes 'being better informed', 'feeling more confident with the physician' and 'feeling more confident about the treatment'. These results are in contrast to statements made concerning the digital divide. According to this theory, minorities, such as the lower educated, the elderly, the unemployed and immigrants, are expected to profit less from using the Internet because of a lack of digital skills [42]. A specific concern is that in order to be able to comprehend health-related information on the Internet high reading levels are required [43,44]. De Nooijer et al. [45] thus suggest that different groups have to be approached in different ways concerning health promotion interventions on the Internet. Specific skills and usability possibilities of minorities should be taken into account. Our results indicate that online support groups might be a specific appropriate option for those with a lower educational level.

This study is unique due to the fact that we involved several patients' groups. A notable finding of our study was that we did not

find any differences between the diagnostic groups concerning the empowering outcomes. However, we did find differences between the patient groups concerning the frequency with which the processes took place in the online support groups. The processes 'exchanging information' and 'finding recognition' occurred significantly less often in the online support groups for arthritis patients. Perhaps there is coherence with the lesser degree of activity in the online support groups for arthritis patients in comparison to other patient groups. In earlier research [35] it was detected that online support groups for patients with arthritis are the least active. During a period of 3 months there were 932 postings exchanged by the members of online support groups for arthritis patients, while in the same period 15,171 postings were exchanged in the online support groups for breast cancer patients. According to Davison and Pennebaker [46], the explanation for these differences must be sought in the characteristics of the illnesses such as cause and consequences. The high participation rate of the participants of the breast cancer groups might be due to the fact that breast cancer is a life-threatening disease, whereas the high participation rate of the participants of the fibromyalgia groups might be due to the ambiguity of this illness [35]. On the other hand these differences might also be caused by the fact that the arthritis group contains by far the most male participants. Since it is suggested that gender can be an important factor in motives and use of support networks [47], we also conducted the difference analyses concerning the empowering processes between the patient groups without the male participants. The differences did not differ with the exception of the difference between patients with rheumatoid arthritis and fibromyalgia concerning the empowering process "finding recognition": this difference was not significant anymore.

The following limitations of the present study should be considered. Those who chose to complete our online questionnaire are not necessarily representative for all participants in online support groups for patients with breast cancer, fibromyalgia and arthritis. The respondents are probably the most active participants of the online support groups.

In addition, it should be considered that we made use of self-perceived measures. Participants themselves estimated to what extent they felt empowered by participation in online support groups. This does not prove that the patients are truly empowered as a result of participation. It should also be taken into account that we conducted a retrospective study. Because patients used the online support group over a long period of time, the outcomes they reported retrospectively may be either underestimated because the impact was gradual and therefore not sharply detected or they overestimated in order to justify their extended use. Although this study provided us with relevant insights in the empowering outcomes as experienced by the participants, a randomised controlled trial or a longitudinal study is required to evaluate whether the participants are truly empowered.

4.2. Conclusion

This study indicates that patients feel empowered by their participation in online support groups. The findings from this study not only demonstrate the types of empowering outcomes experienced by the participants but also indicate the extent to which patients feel empowered in several areas. The empowering outcome that was experienced to the strongest degree was 'being better informed'. In addition, this study provides insight into the processes that take place in the online support groups and the extent to which these processes could predict the empowering outcomes. The empowering process that took place the most frequent in the online support groups is 'exchanging information'.

'Helping others' is the process that occurred to the least degree according to our study results. In general it has to be concluded that the empowering outcomes could only be predicted in a modest way by the processes that took place in the online support groups.

Strikingly, we did not find any significant differences in this study between the diagnostic groups with regard to empowering outcomes. Therefore, we can conclude that empowerment is a generic mechanism.

4.3. Practice implications

Participation in online patient support groups can make a valuable contribution to empowerment of patients. Our study suggests that these groups are a useful resource for patients and a good alternative to face-to-face support groups. Health care providers should thus acquaint their patients with the existence of online support groups and with the benefits that participation in these groups can provide.

Acknowledgements

Appendix A. 'Constructs empowering processes'

Answer categories: 'seldom to never'; 'sometimes'; 'regularly'; 'often'.

Exchanging information (α = .88):

The information and tips exchanged in this online support group are...

- ... understandable
- ... valuable
- ... usable
- ... new
- ... applicable to my present situation
- ... reliable
- ... correct
- ... of added value to the information I receive from my care providers
- ... in line with the information I receive from my care providers

Encountering emotional support (α = .95):

Does it ever happen in this online support group...

- ... that someone in this online support group invites you to have (personal) contact outside this online support group?
- ... that someone in this online support group starts a private conversation with you?
- ... that someone in this online support group is empathic?
- ... that someone in this online support group consoles you?
- ... that someone in this online support group pays you a compliment?
- ... that someone in this online support group is interested in you?
- ... that someone in this online support group pays particular attention to you in special cases, such as during illness or moving house?
- ... that someone in this online support group reassures you?

- . . . that someone in this online support group offers you sound advice?
- . . . that someone in this online support group points out your strengths?
- . . . that someone in this online support group confides in you?
- . . . that someone in this online support group asks you for your help or advice?

Finding recognition (α = .70):
Does it ever happen in this online support group that. . .

- . . . you recognize yourself in the stories of other online support group members?
- . . . you experience the sense of 'not being the only one'?
- . . . others are an example to you?
- . . . you realize that you are not so bad off after all?

Helping others (α = .82):
Does it ever happen in this online support group that. . .

- . . . you can be an example to other participants?
- . . . you can offer advice and support to others?

Sharing experiences (α = .87):
Does it ever happen in this online support group that you can share . . .

- . . . your experiences with your illness with others?
- . . . your everyday experiences with others?

Appendix B. 'Constructs empowering outcomes'

Answer categories: 'completely disagree'; 'disagree'; 'neither agree nor disagree'; 'agree'; 'completely agree'.
Being better informed (α = .85):
Through my participation in online support groups. . .

- . . . I feel better informed as a patient.
- . . . I understand my illness better.
- . . . I have a clearer picture about my illness.
- . . . I feel like I have more (correct) knowledge at my disposal to deal better with my illness.
Feeling more confident in the relationship with their physician (α = .91):
  Through my participation in online support groups. . .

- . . . I feel better prepared for a doctor's appointment.
- . . . I am more knowledgeable about which questions to ask my physician.
- . . . I can explain my needs to my physician better.
- . . . I have more courage to raise matters with my physician.
- . . . I am more able to oppose my physician.
- . . . I understand the information provided by my physician better.
- . . . the relationship with my physician has improved.
- . . . the relationship with my physician has deteriorated.
- . . . I am more able to judge when I really need the help of my physician.
- . . . I feel less dependent on my physician.
- . . . I am more able to think along with my physician about my treatment.

Improved acceptance of the illness (α = .90):
Through my participation in online support groups. . .

- . . . I am able to be more open about my own illness.
- . . . I can tell others more easily when I am no longer able to do something.
- . . . I can ask others for help more quickly.
- . . . I can give in to my illness better.
- . . . I can accept my illness better.

Feeling more confident about the treatment (α = .89):
Through my participation in online support groups. . .

- . . . I can stick to my treatment regime better.
- . . . I am more able to follow the medical guidelines and advice of my physician.
- . . . I know where to go with questions about my illness.
- . . . I feel I am more skilled at dealing well with my illness.
- . . . I feel able to make the right decisions with regard to my illness.

Increased optimism and control over the future (α = .76):
Through my participation in online support groups. . .

- . . . I feel more in charge of the course of my illness.
- . . . I feel I can influence my illness myself.
- . . . I feel more in control over what is happening to me.
- . . . I feel less in control over what is happening to me.
- . . . I feel that what happens to me in the future is to a large degree dependent on myself.
- . . . I have learned to be more positive.
- . . . I have more faith in the future.
- . . . I have less faith in the future.

Enhanced self-esteem (α = .93):
Through my participation in online support groups. . .

- . . . I have a greater sense of worth.
- . . . I have a more positive attitude towards myself.
- . . . I am in general more content with myself.

Enhanced social well-being (α = .70):
Through my participation in online support groups. . .

- . . . I feel less lonely.
- . . . I have made new social contacts.

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