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Batenburg, A.E.

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PART THREE

Causal Relationships and Added Value

CHAPTER 6

The Bigger Picture: Do Peer-led Online Support Communities Really Contribute to Breast Cancer Patients' Psychological Well-being?

A shorter version of this chapter is under review at *Psycho-Oncology* as: Batenburg, A. & Das, E. The bigger picture: Do peer-led online support communities really contribute to breast cancer patients' psychological well-being? [A 3-wave study]

Abstract

There is a lack of studies testing the direction of the relationship between participating within online peer-led support communities and psychological well-being. Moreover, the contribution of online peer support on top of other relevant 'offline' factors is unknown. The current study addresses these two issues in a three-wave study among breast cancer patients participating in a peer-led online support community. Seventy support group members filled out three surveys in a period of ten months, assessing intensity of participation, psychological well-being and potential covariates. Causal relationships between intensity of online participation and well-being were tested with multiple regression models. Results showed an effect of intensity of online participation (wave 2) on depression (wave 3). Physical well-being affected breast cancer-related concerns (from wave 1 to 2, and from wave 2 to 3). Intensity of online participation was mainly caused by disease status. Hence, intensity of online participation positively affected psychological well-being, rather than the other way around. Furthermore, findings were significant on top of the influence of other factors such as physical well-being and support from friends and family. With caution, patients could be encouraged to look for support from their peers online.

Introduction

Online peer-led cancer support communities, mostly designed as online bulletin boards (i.e., online forums), are increasingly available on the Internet. These communities are set up by patients or ex-patients to share experiences and information with peers. An advantage of peer-led online communities compared to traditional offline support groups is its free accessibility, 24-hour availability, anonymity and the provided information has no geographical boundaries^{1,2}. Patients also have freedom in choosing how they want to participate; some individuals only read posts from others (lurkers), while others disclose their experiences and respond to messages from others³.

Although research has shown that members appreciate participating in peer-led online communities⁴, the question to what extent online forums factually contribute to patients' psychological well-being has not been answered. There are two issues that hindered the answer to this question. First, there is a lack of studies testing causal relationship between online participation and psychological well-being. Second, the contribution of online peer support on top of other relevant factors, such as offline support from family and medical professionals, is unknown. The aim of the present study was therefore to assess causal effects of online health forum participation on psychological well-being (and vice versa), and to test to what extent online forum participation adds to effects of offline factors. We addressed this question in a three-wave study among breast cancer patients participating in a peer-led online support community.

The issue of causality and covariates

One of the reasons for the lack of outcome studies on peer-led support communities might be its 'uncontrolled' setting. Although anonymity and freedom in participation are highly valued by its members, it causes difficulties for researchers who aim to study the effects of online participation. Perhaps for that reason, most studies on peer-led support communities are descriptive in nature; researchers conducted interviews or surveys among members or studied the online content. These studies showed the presence of empowering- and therapeutic processes, such as informational-, and emotional support^{5,6}, finding recognition⁷, emotional expression, and insight⁸. Though less often mentioned by its participants, some disempowering processes are present as well. For example, some patients stated they have difficulties with the negative

stories from others, or with others complaining^{7,9-11}. Evidence suggesting positive effects mostly comes from randomized control trials, where online social support is part of an intervention designed to benefit patients. These studies showed for example decreased depression, reactions to pain¹², cancer-related trauma, and perceived stress¹³ (review papers¹⁴⁻¹⁶). Though these interventions have the advantage of a controlled setting, there are also aspects that prevent these interventions from being a point-to-point replacement of peer-led communities. First, the “natural setting” gets lost, i.e. in peer-led communities patients only participate if they want to. Second, these online interventions often include other aspects besides peer support such as decision-making tools, skill training or online conversations are monitored by health professionals¹⁴. Consequently, it is ambiguous if improvements in patients’ well-being are caused by sheer peer support or by other features of the intervention.

A few empirical studies examined peer-led bulletin boards; one study showed positive changes in psychological well-being among its’ participants over time¹. Two other studies showed that positive change was related to particular online word-use (i.e., words indicating anger, sadness, anxiety¹⁷; and insightful disclosure)¹⁸. However, for the first study it is unclear if participants’ well-being just changed for the better as time passed, or due to online participation. Likewise for the other studies, it is uncertain if word-use caused changes in well-being, or was a reflection of patients’ improved well-being. Consequently, there is a need for studies testing the direction of the relationship between online participation and psychological well-being; does online participation predict well-being, or does well-being predict online participation? In the current study we aim to solve this causality issue by employing (1) a robust measure for the intensity of online support group (OSG) participation and (2) a longitudinal study design.

Another issue is that even though factors outside the online environment might improve or decline psychological well-being, such factors are often neglected in empirical studies. For example, research has shown that social support from relatives and friends is highly important when it comes to patients’ adjustment to cancer^{19,20}. Furthermore, cross-sectional studies on online peer-led support community participation showed significant correlations between patients’ psychological well-being and disease status, physical well-being, working status (i.e., if patients (still) perform a job), support from friends and family, and psychological help from a professional^{21,22}. Hence, the question remains if online peer support can contribute significantly to well-being in addition to these factors. The second goal of the current study was to examine the added value of online peer support on top of other correlates of patients’ psychological well-being.

Methods

Participants and procedure

Since we intended to follow online support community participants for several months, we approached a well-established Dutch peer-led online breast cancer community designed as 24-hour available message board that was most stable in terms of activity and continuity. Upon approval of the website owners we posted a request to participate in an online study that would consist of 3 surveys, conducted in a period of 9 months (with three months in between, see Table 1). The introduction page of the survey included the length and goal of the survey (i.e., the helpfulness of online peer support) and contact information of the investigator, and ensured anonymity. 117 participants filled out the first survey in January and February 2013, whereof 83 participants provided their e-mail address to receive an invitation for the two follow-up studies. In the first follow-up in May and June 2013, 73 patients participated, and 78 participants filled out the third survey in September and October 2013. Five patients participated in survey 1 and 3 but missed survey 2, and three patients filled out survey 1 and 2 but quit participating at survey 3.

Table 1. Time Schedule of Data Collection

Survey T1					Survey T2					Survey T3
→	time	→	time	→	time	→	time	→		
1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth		

After merging the three waves of data, a sample of 70 Dutch breast cancer survivors covered all three waves of study (47 drop-outs in total). The group of study dropouts did not differ significantly from our study sample regarding all variables included in the current study (i.e., demographics, illness characteristics, psychological well-being, offline social support, and intensity of OSG participation T1). All procedures adhered to all the APA ethical guidelines²³, complied with EU legislation²⁴ and the Dutch legislation²⁵ on data protection, and were approved by the Department of Communication Science of the VU University Amsterdam.

Measurements

Demographics and health status. The first survey included questions on patients' age, gender (all participants were female), education level, and working status (i.e., if patients were currently working). See Table 2. Furthermore, since ex-patients also participated within the community, but are never officially declared as cured, we asked if cancer cells were currently detected in ones' body. Approximately half of the participants (still) had cancer cells at T1. Additionally, we asked if participants were currently under treatment. See Table 2 for the answer categories. Since this categorical variable has no incremental scale, we decided to transform this measure into two categories for multiple regression analysis purposes: not under treatment (anymore) (0) *vs.* currently/very soon under treatment (1). Furthermore, we measured patients' physical well-being with 7 items from the FACT-B²⁶ on a 5-point scale (e.g., "I have pain"). The index was internally consistent at all three measurements (T1 Cronbach's $\alpha = .865$; T2 Cronbach's $\alpha = .832$; T3 Cronbach's $\alpha = .874$). These measures were used to assess if intensity of OSG participation had an influence on patients' psychological well-being on top of demographics and disease characteristics.

Psychological well-beingⁱⁱⁱ. Depression was measured with the CES-D10²⁷ at three time points. The scale consisted of 10 items (e.g., 'I felt that everything I did took me quite some effort'). Participants rated on a 4-point scale if the statements applied to them the last week, from 'less than one day' to '5 to 7 days'. The index was internally consistent in all three questionnaires (T1 Cronbach's $\alpha = .859$; T2 Cronbach's $\alpha = .852$; T3 Cronbach's $\alpha = .849$) but was positively skewed at T1. A log-transformation was performed for depression to meet the assumptions of multiple regression analysis²⁸.

Breast cancer-related concerns (Profile of Concerns about Breast cancer²⁹) were measured with an index of 26 items assessed on a 5-point scale (e.g., "As you think about your illness, how much are you concerned that chemotherapy or radiation therapy will damage your body in some way?"). By request of the website owners, two items were deleted because these items were too intense for patients in phase IV of the disease ("As you think about your illness, how much are you concerned that you may die soon" and "...that the cancer will come back"). The index showed consistency (T1 Cronbach's $\alpha = .954$; T2 Cronbach's $\alpha = .967$; T3 Cronbach's $\alpha = .898$).

Intensity of online support group (OSG) participation. Patients' intensity of OSG participation was assessed by four different questions regarding *frequency of visits*, *average length of visits*, *contribution* (i.e., reading, responding, starting new topics or questions), and *frequency of posts* in the last four weeks [cf.^{21,22,30}]. *Frequency of visits* was assessed on a 7-pointscale; the other items were assessed

iii We also measured 'happiness' with a single item scale³². We decided to exclude this measurement, because it failed to meet the assumptions of multiple regression analysis due to skewness at all three time points. Despite of performing log-, square root and reciprocal transformations, the skewness of the distributions did not improve.

on a 4-point scale. To merge these different scales into one index, all items were transformed into z-scores. Factor analyses was used to examine the structure of the current items (Varimax Rotation). *Length of visits* was removed from the index because factor loadings were below 0.30 at all three points of measurements. The three remaining items showed internal reliability at T1 (Cronbach's $\alpha = .798$), T2 (Cronbach's $\alpha = .826$), and T3 (Cronbach's $\alpha = .832$). For the exact items, see Table 3. To validate this index we also tested if this measurement was related to the actual amount of messages posted online. Findings showed high correlations between the self-report measurement of online activity and the actual amount of messages that one posted online (see Appendix 1 for the procedure and outcomes).

Support outside the online environment. Because social support from resources others than online peers may affect psychological well-being, we asked if patients received any psychological help from a professional regarding the cancer, and assessed the social support they received from their friends and family (based on the six Social Well-being items from the FACT-B²⁶). Items referring to support from friends were adjusted into items that clearly referred to offline friends. Respondents rated on a 5-point scale if the statements applied to them, ranging from 'Not at all' to 'Totally' (T1 Cronbach's $\alpha = .864$; T2 Cronbach's $\alpha = .839$; T3 Cronbach's $\alpha = .858$).

Statistical analyses

We conducted a pairwise correlation matrix in SPSS to reveal which variables were related to intensity of OSG participation and psychological well-being (i.e., depression and breast cancer-related concerns). We then performed multiple regression analyses to test the effect of intensity of OSG participation at T1 on psychological well-being at T2, including psychological well-being at T1 as independent variable in our model. To draw conclusions regarding causality, we also examined the reversed effects by testing the effects of psychological well-being T1 on intensity of OSG participation at T2, adding intensity of OSG participation T1 as control variable. Furthermore, we included other factors that correlated significantly with intensity of OSG participation and psychological well-being as potential covariates. This procedure was conducted for significant effects of T1 on T2 variables, and for significant effects of T2 on T3 variables. We assessed relationships between the three points of measurement separately -instead of testing the effects of T1 measurements on T2 and T3 outcome variables- because the process of illness might fluctuate significantly over a period of ten months.

Table 2. Demographics and Health Characteristics at T1, n=70

		n	%
Age			
Mean (SD)		44.96 (8.46)	
Minimu		28	
Maximum		63	
Education^a			
Elementary school		0	0
Secondary education	Low	6	8.6
	Middle	5	7.1
	High	0	0
Tertiary education	Low ^b	4	5.7
	Middle	15	21.4
	High	30	42.9
	Scientific Degree	9	12.9
	Unknown	1	1.4
Working status			
Not working		29	41.4
Working		41	58.6
Disease status			
No visible cancer cells (incl. being monitored by physician or adjuvant hormone therapy to prevent recurrence)		34	48.6
Cancer cells, tumor, and/or metastases		32	45.7
Unknown		4	5.7
Treatment status			
No treatment (e.g., finished)		22	31.4
Waiting for treatment or surgery		3	4.3
Hormone therapy		29	41.4
Chemotherapy and/or radiation		16	22.9
Psychological help during period of illness			
Yes		39	55.7
No		31	44.3

Notes. ^alevels within the Dutch education system: education is divided over three schools for different age groups, which are divided in streams for different educational levels. ^bLBO/LTS existed until 1992

Results

Sample characteristics

Table 2 represents characteristics of the current study participants. All participants were female with a mean age of 45 years. Most participants were highly educated, and almost 60% were (still) performing a job. Nearly half of the patients were not actively under treatment (anymore), whereas the others were in de midst of treatment at T1. Approximately 55% of the patients received professional psychological guidance during the period of illness. Table 3 shows patients' online activity within the support group.

Table 3. Use of the Online Support Community, n=70

	T1		T2		T3	
	n	%	n	%	n	%
Frequency of visits						
Less than once a month	6	8.6	17	24.3	16	22.9
Approximately once a month	5	7.1	5	7.1	11	15.7
Multiple times per month	10	14.3	8	11.4	5	7.1
Approximately once a week	11	15.7	8	11.4	6	8.6
Multiple times per week	16	22.9	10	14.3	15	21.4
Approximately once a day	7	10	11	15.7	10	14.3
Multiple times per day	15	21.4	11	15.7	7	10
Frequency of posts the last 4 weeks						
None	26	37.1	38	54.3	40	57.1
One per week or less	23	32.9	20	28.6	16	22.9
Multiple posts per week, but not every day	16	22.9	8	11.4	12	17.1
Every day one post or more	5	7.1	4	5.7	2	2.9
Forum contribution						
I only read posts from others	19	27.1	26	37.1	30	42.9
I reacted on (a) post(s) of someone else	20	28.6	21	30	17	24.3
I started a new topic or asked a question	6	8.6	5	7.1	5	7.1
I both started a new topic or asked a question AND I reacted on (a) post(s) of another	25	35.7	18	25.7	18	25.7

Correlations

We ran a correlation matrix to explore pairwise associations between intensity of OSG participation, psychological well-being, and the other variables included in the current study (see Table 4). All variables that correlated significantly with psychological well-being or intensity of OSG participation were included as covariates in our models.

Effects of forum participation on psychological well-being

Table 5 shows the causal effect testing of intensity of OSG participation at on depression and breast cancer-related concerns. From T1 to T2, only the level of depression at T1 predicted the level of depression at T2. Breast cancer-related concerns at T2 was caused by concerns at T1 and by patients' physical well-being at T1. The worse patients felt physically at T1 the more concerns they had at T2 and the more concerns patients' had at T1 the more concerns they had at T2. Intensity of OSG participation did not predict changes in depression and breast cancer-related concerns. Intensity of OSG participation at T2 did predict depression at T3, as did depression at T2. The more active patients were within the online support community at T2, the less depressed they felt at T3. The more depressed participants were at T2, the more depressive feelings they had at T3. Breast cancer-related concerns at T3 were predicted by physical well-being T2 and breast cancer-related concerns at T2. The more concerns patients reported at T2, the more concerns they had at T3. Patients physically worse at T2 showed more concerns at T3. Intensity of OSG participation at T2 did not predict breast cancer-related concerns at T3.

Effects of psychological well-being on intensity of OSG participation

Table 6 presents the effects of psychological well-being on intensity of OSG participation. Psychological well-being did not predict intensity of OSG participation. Only level of participation at T1 predicted the level of participation at T2. The more active patients were at T1, the more active they were at T2. From T2 to T3, disease status predicted online participation. Patients who had cancer cells at T2 were more active online at T3 than patients who had no cancer cells at T2. Patients who were more active on the support forum at T2 were also more active at T3.

Table 4. Intercorrelations of Intensity of OSG Participation, Psychological Well-being and Covariates^{iv}

	Intensity of OSG participation			Depression (LOG)			BC related concerns		
	T1	T2	T3	T1	T2	T3	T1	T2	T3
Intensity of OSG participation T1 ^a	-	-	-	-.066	-.107	-.172	.112	.039	-.030
Intensity of OSG participation T2 ^a	.810 ^a	-	-	-.119	-.185	-.290 ^f	.000	-.016	-.126
Intensity of OSG participation T3 ^a	.786 ^a	.817 ^a	-	-.127	-.183	-.245 ^f	.035	-.039	-.136
Age	-.148	.066	-.083	-.034	-.053	-.031	-.257 ^f	-.234	-.207
Education level	.152	-.051	-.009	.266 ^f	.262 ^f	.345 ^a	.163	.188	.237 ^f
Working status T1 ^b	-.174	-.025	-.096	-.212	-.020	-.228	.167	-.111	-.219
Working status T2 ^b	-.376 ^f	-.228	-.267 ^f	-.029	.095	-.029	-.215	-.102	-.115
Working status T3 ^b	-.235	-.194	-.232	.053	.102	-.089	-.145	-.006	-.117
Offline soc. support T1	.113	.029	.028	-.142	-.210	-.092	-.054	-.131	-.007
Offline soc. support T2	.100	.073	.056	-.109	-.238 ^f	-.201	-.030	-.230	-.127
Offline soc. support T3	.010	.035	.102	-.198	-.275 ^f	-.174	-.102	-.234	-.172
Psychological help T1 ^b	-.101	-.095	-.082	.175	.187	-.139	.220	.246 ^f	.148
Psychological help T2 ^b	-.025	-.041	-.088	.196	.218	.024	.227	.271 ^f	.282 ^f
Psychological help T3 ^b	-.017	-.033	-.123	.221	.186	-.045	.229	.281 ^f	.308 ^f
Disease status T1 ^c	.308 ^f	.116	.269 ^f	.179	.140	.264 ^f	.262 ^f	.245 ^f	.235
Disease status T2 ^c	.353 ^a	.276 ^f	.409 ^a	.072	.091	-.007	.242 ^f	.273 ^f	.136
Disease status T3 ^c	.327 ^a	.277 ^f	.435 ^a	.097	.049	-.013	.131	.159	.041
Treatment status T1 ^d	.262 ^f	-.039	.119	.092	.081	.130	.313 ^a	.186	.222
Treatment status T2 ^d	.130	-.063	.108	-.030	.002	.186	.190	.163	.251 ^f
Treatment status T3 ^d	.081	-.089	.049	-.010	.026	.133	.206	.163	.200
Physical well-being T1	-.127	.000	-.025	-.535 ^a	-.430 ^a	-.362 ^a	-.501 ^a	-.543 ^a	-.497 ^a
Physical well-being T2	-.096	.057	.008	-.504 ^a	-.600 ^a	-.426 ^a	-.593 ^a	-.623 ^a	-.632 ^a
Physical well-being T3	-.110	.090	.079	-.363 ^a	-.369 ^a	-.574 ^a	-.317 ^a	-.431 ^a	-.555 ^a

Notes. ^aItems are standardized into Z scores. ^bCoded 0=no, 1=yes. ^cCoded 0=currently no tumor or metastases, 1=currently in phase 1,2,3 or 4. ^dCoded 0=no treatment (e.g., finished), 1=currently/very soon under treatment. ^eCorrelations significant at the .01 level (two-tailed). ^fCorrelations significant at the .05 level (two-tailed).

iv We also measured for how long participants were diagnosed with breast cancer in months (min=1, max=165, M=43.5, SD=40.13) and for how long they were visiting the online support community in months (min=1, max=140, M=38.31, SD=35.04). Both variables were not significantly correlated to depression, BC concerns or intensity of OSG participation.

Table 5. Hierarchical Regression Results for the Effects of Intensity of OSG Participation T1 on Depression T2 and Breast Cancer-related Concerns T2, and Effects of Intensity of OSG Participation T2 on Depression T3 and Breast Cancer-related Concerns T3

Independent Variable	Dependent variable LOG Depression T2 (n=69)			Dependent variable BC concerns T2 (n=66)		
	<i>b</i> (SE)	<i>b</i>	<i>P</i>	<i>b</i> (SE)	<i>b</i>	<i>P</i>
Education	.006 (.006)	.076	.367	-	-	-
Disease status T1 ^b	-	-	-	.086 (.127)	.062	.501
Offline support T1	-.023 (.016)	-.119	.165	-	-	-
Psychological help T1 ^a	-	-	-	.155 (.122)	.111	.208
Physical well-being T1	-.015 (.015)	-.104	.309	-.221 (.077)	-.279	.006
LOG Depression T1	.647 (.101)	.657	.000	-	-	-
BC concerns T1	-	-	-	.525 (.097)	.543	<.001
Intensity of OSG participation T1	-.012 (.011)	-.093	.269	-.034 (.061)	-.049	.582
<i>R</i> ²	.601			.575		
ANOVA	<i>F</i> (5,63)=18.963, <i>p</i> <.001			<i>F</i> (5,61)=16.476, <i>p</i> <.001		
Adjusted <i>R</i> ²	.569			.540		
Independent Variable	Dependent variable LOG Depression T3 (n=65)			Dependent variable BC concerns T3 (n=62)		
	<i>b</i> (SE)	<i>b</i>	<i>P</i>	<i>b</i> (SE)	<i>b</i>	<i>P</i>
Education	.014 (.007)	.195	.056	.004 (.029)	.010	.892
Disease status T1 ^b	.042 (.022)	.172	.076	.019 (.098)	.015	.843
Psychological help T2 ^a	-	-	-	.132 (.101)	.102	.183
Physical well-being T2	-.029 (.017)	-.197	.101	-.212 (.073)	-.268	.005
Depression T2	.334 (.120)	.353	.007	-	-	-
BC concerns T2	-	-	-	.542 (.088)	.592	<.001
Intensity of OSG participation T2	-.024 (.011)	-.204	.039	-.056 (.047)	-.087	.240
<i>R</i> ²	.489			.691		
ANOVA	<i>F</i> (5,60)=11.466, <i>p</i> <.001			<i>F</i> (6,59)=21.994, <i>p</i> <.001		
Adjusted <i>R</i> ²	.446			.660		

Notes. ^aCoded 0=no, 1=yes; ^bCoded 0=currently no active disease, 1=currently in phase 1,2,3 or 4

Table 6. Hierarchical Regression Results for the Effects of Depression T1 and Breast Cancer-related Concerns T1 on Intensity of OSG Participation T2, and Depression T2 and Breast Cancer-related Concerns T2 on Intensity of OSG Participation T3

Independent Variable	Dependent variable			Dependent variable		
	Intensity of OSG participation T2 (n=69)			Intensity of OSG participation T3 (n=69)		
	<i>b</i> (SE)	<i>b</i>	<i>P</i>	<i>b</i> (SE)	<i>b</i>	<i>P</i>
Working status T2 ^a	-	-	-	-.048 (.154)	-.023	.754
Disease status T2 ^b	.022 (.164)	.011	.893	.455 (.160)	.217	.006
Intensity of OSG participation T1	.814 (.077)	.814	<.001	-	-	-
Intensity of OSG participation T2	-	-	-	.747 (.072)	.747	<.001
LOG Depression T1	-.188 (.626)	-.025	.764	-	-	-
LOG Depression T2	-	-	-	-.148 (.625)	-.020	.814
BC Concerns T1	-.107 (.114)	-.081	.349	-	-	-
BC Concerns T2	-	-	-	-.108 (.116)	-.078	.357
<i>R</i> ²	.666			.712		
ANOVA	<i>F</i> (4, 65)=32.372, <i>p</i> <.001			<i>F</i> (5, 64)=31.669, <i>p</i> <.001		
Adjusted <i>R</i> ²	.645			.690		

Notes. ^aCoded 0=not performing a job, 1= performing a job; ^bCoded 0= currently no tumor or metastases, 1=current in phase 1,2,3 or 4

Discussion

With the current three-wave study we aimed to extend previous scarce findings on the effects of peer-led support group participation. Specifically, our goal was to reveal if the level of participation within a peer-led online support community predicted changes in psychological well-being, or if psychological well-being incites variations in online participation. In addition, we aimed to uncover the contribution of the online support environment to patients' psychological well-being on top of other 'offline' factors that are often associated with patients' psychological well-being, such as physical well-being and social support from relatives and friends.

Findings showed that psychological well-being (i.e., depression and breast cancer-related concerns) does not predict intensity of OSG participation, but intensity of OSG participation rather predicts changes in psychological well-being. Specifically, intensity of OSG participation at T2 affected changes in depression from T2 to T3. Patients more active within the online community at

T2, show lower levels of depression at T3. We did not find a relation between intensity of OSG participation and depression from T1 to T2, and intensity of OSG participation did not affect changes in breast cancer-related concerns over time.

To our knowledge, this the first study with the aim to unravel the causal relationship between online participation and psychological well-being. Our results contribute to the understanding of results from previous (cross-sectional) studies on online peer-led support group participation^{1,21}. We can conclude that in the current study patients' online behavior is partly, but significantly, responsible for positive changes in psychological well-being. Although keeping in mind that we cannot compare the current results with patients not participating in an online community, results suggest that online interactions with peers may really help breast cancer patients to reduce depression, even on top of other significant well-being modifiers (such as support from family or state of physical well-being). With caution, patients could be encouraged to look for support from their peers online. As found in previous descriptive studies, empowering processes such as support from peers, and recognition found in stories from others might help patients to deal with their own difficulties during illness⁷.

In addition, the current study extends knowledge on peer-led support communities by showing that intensity of OSG participation is particularly caused by disease status. Patients with cancer cells at T2 became more active online at T3 than patients who had no cancer cells detected in their body at T2. This finding is in line with a qualitative case study that showed that a particular breast cancer patient especially turned to the online group when she experienced cancer-related stress-inducing events³¹. Survivors participating in the online community after treatment might need less informational and emotional support, and therefore become less active online.

Furthermore, we included potential covariates, i.e., other offline factors that might influence patients' psychological well-being to put the unique effects of online peer support in perspective. Other predictors of depression –apart from previous depression levels- were education level and disease status, though these relationships were marginally significant and only present from T2 to T3. With caution, we can conclude that higher educated patients have a greater chance to get more depressed than patients with a lower level of education. In addition, patients under treatment seemed to be more depressed than patients who do not get treatment. Notably, in the current study we found less correlates with psychological well-being than were found in previous studies, which e.g., also reported relationships with working status, psychological help from a professional and support from family and friends^{21,22}. We recommend not neglecting such factors in future research on peer-led online communities. By gathering more information on patients' current condition, it becomes easier to explain findings and to put the contribution of online peer support in perspective.

Limitations and future research

The first, and probably most important, limitation of the present research is the lack of a control group. Although we aimed to focus on the intensity of OSG participation in the current study, and results showed that different levels of online activity within the community affects changes in well-being, we cannot compare results with patients not participating within an online peer support group. It is possible that the current data suffer from a selection bias because patients participating in an online community might differ from patients who do not participate within such a community. Furthermore, because of participants' anonymity and freedom in use, there is no information on what patients did before our first measurement and study dropouts. However, we did ask when patients start to participate within the online community and when they were diagnosed with breast cancer. Both factors had no influence on intensity of OSG participation or psychological well-being. Another limitation of the current study is the small sample size. Though we aimed for more study participants, it was rather difficult to find breast cancer patients willing to participate for a period of ten months. In future studies it is important to replicate current findings with larger sample sizes.

In the current study we found no relationship between intensity of OSG participation and breast cancer-related concerns. Although breast cancer-related concerns was related to levels of depression, online peer support might not be sufficient to abate particular concerns. Only patients' physical well-being affected changes in the amount of concerns, which suggests that concerns depend mostly on disease factors.

Although the measurement for online activity showed consistency in previous studies^{21,22}, in the current study the item measuring the approximate length of visits did not fit the other items measuring online intensity of participation. A possible clarification might be the differences between posters and lurkers. Lurkers may take their time to read messages from others, but do not post messages about their own experiences or replying to stories and question from peers. Posters, in contrast, merely turn online to talk about their own situation, but spent less time on reading posts from others. Though complicated to measure due to anonymity, in future research it would be interesting to reveal actual differences in online behavior (i.e., not based on self-reports), and how this affects outcomes of participation.

Conclusion

The present longitudinal study aimed to capture causal effects of online peerled support group participation. Findings suggest that intensity of participation affects psychological well-being -rather than the other way round- and indicate a positive effect on levels of depression. Changes in intensity of participation depended mostly on disease status.

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Appendix 1. Validation of the ‘Intensity of OSG participation’ measurement

We were interested if our (previously used) survey measurement for intensity of online support group participation reflects the actual amount of messages participants posted online.

In the three surveys we asked participants for their average online activity in the last four weeks (i.e., ‘intensity of online support group participation’, see method section). To assess real online posting behavior we asked survey participants for the nickname they use on the online platform. A number of 58 participants were willing to provide this information, and allowed us to analyze their online behavior. We scraped^v the messages from the online platform that belonged to the survey participants who provided their nickname. The amount of messages participants had posted online between every conducted survey (and four months upfront the end date of survey 1; table 1) was calculated per participant.

Table 1. Time Schedule of Data Collection

				Survey T1								Survey T2								Survey T3			
Online messages T1				Online messages T1				Online messages T1				Online messages T1				Online messages T1							
time →		time →		time →		time →		time →		time →		time →		time →		time →		time →		time →			
1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth	1 mth

The actual amount of messages (obtained by scraping the online forum) involved the number of messages one posted in between two surveys. In other words, this measurement reflects a longer period of time than the self-report survey measurement. Findings showed high correlations between the self-report measurement of online activity (i.e., intensity of OSG participation), and the actual amount of messages that one posted online. See Table 2.

^v Computer software technique of extracting information from websites

Table 2. Inter-correlations between self-report measures of intensity of on-line participation and the actual number of posts, n=58

	Intensity of OSG participation T1	Intensity of OSG participation T2	Intensity of OSG participation T3
Number of posts → T1	.415 ^a	.320 ^a	.385 ^a
Number of posts T1-T2	.416 ^a	.532 ^a	.455 ^a
Number of posts T2-T3	.459 ^a	.510 ^a	.580 ^a

Note. ^a correlations significant at the .01 level (2-tailed)

