

VU Research Portal

Being On-line Together

Batenburg, A.E.

2015

document version

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

citation for published version (APA)

Batenburg, A. E. (2015). *Being On-line Together: The Effects of Peer-led Online Support Community Participation on Breast Cancer Patients' Psychological Well-being*. Vrije Universiteit.

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

E-mail address:

vuresearchportal.ub@vu.nl

CHAPTER 7

General Discussion

General Discussion

The main goal of the research covered in the current dissertation was to extend knowledge on the effects of participating in online peer-led support communities on patients' psychological well-being. An increasing amount of patients gather online, and form groups to share information and experiences with peers. However, studies testing the psychological effects of participating in such online communities are lacking. With the current research project I aimed to fill this gap. Since the amount of breast cancer patients is expected to grow in the coming years¹, and breast cancer patients are more motivated to search for information and support online compared to other patient groups^{2,3}, we decided to focus on breast cancer patients visiting an online support community.

The current approach complements previous research in three ways: (1) we conducted a longitudinal study design to assess effects on psychological well-being over time as a function of patients' intensity of online participation; (2) assessed moderating factors (i.e., individual differences; responses from others) that affect the relationship between online participation and psychological well-being; and (3) studied if the online environment contributes to psychological well-being beyond patients' offline situation (for example, we took into account the offline support patients receive from family and friends).

This final chapter covers a summary and the theoretical implications of the empirical findings presented in this dissertation. Subsequently, I reflect on implications for multidisciplinary research, the practical implications of the current findings, limitations of the presented studies and directions for future research. I end with the main conclusion of the current thesis.

Main findings

Part One: The Personal Perspective – Coping with Illness

Part one of this dissertation focused on how patients differ in their way of dealing with thoughts and emotions, and how this personal characteristic influences psychological effects of online support group participation. Prior research has indicated that actively coping with emotions positively affects patients' well-being over time¹¹. Amongst other things, patients use online communities to share (i.e., write about) their experiences and related thoughts and emotions. As a result, variations in patients' emotional coping style might influence the relationship between online support group participation and patients' psychological well-being. For instance, patients' emotional coping style could affect personal online writing behavior, and might impact how one deals with reading emotional stories from peers.

Chapter 2 describes a cross-sectional survey study amongst breast cancer patients visiting an online peer-led support community. The intention of this study was to find out if patient's emotional coping style influences the relationship between online support group participation and psychological well-being. Participants filled out an online survey in which we assessed their intensity of online participation, several 'coping with illness-related emotions' measures such as emotional processing, emotional expression, and cognitive avoidance, and measures for psychological well-being. Findings revealed that individual coping differences indeed affected the relationship between intensity of online participation and psychological well-being. Specifically, we found a difference in depression, emotional well-being and breast cancer-related concerns due to coping style among patients who were highly active online. Patients, who participated rather actively online, reported a better psychological well-being when they scored high on emotional expression and low on cognitive avoidance, than equally active patients with lower scores on these coping measures. For patients who were less active online, we found no coping-related differences in well-being. These findings suggest that online support group participation especially makes a difference for participants who make active use of the support group. Although the cross-sectional design prevented us from drawing conclusions regarding cause and effect, we learned from these findings that individual differences in coping with emotions were worthwhile to investigate further.

Chapter 3 covers a study that was a follow-up to Chapter 2. A longitudinal approach was required to assess causal relations between online support group participation, coping style, and well-being. With two points of measurement, we assessed emotional approach coping, intensity of online participation and change in psychological well-being over time among breast cancer patients who were part of an online support community. Results showed that emotional well-being increased over time for patients with a low score on emotional approach coping, provided that they were highly active online. Patients who were highly active online with a high score on emotional approach coping reported no change in sense of well-being, but showed the highest level of well-being overall. For patients who were not very active online, coping style seems to have outweighed intensity of online participation. To be more specific, patients with a high score on emotional approach coping showed an increase in well-being, while patients with a low score on emotional approach coping experienced no significant change in well-being over time. As a result, findings suggest that intense support group participation does no harm, and may be especially beneficial for the well-being of patients who approach emotions less actively. Future research should reveal what exactly occurs online that corrects for negative outcomes of coping styles generally defined as maladaptive. On the one hand it could be that online peers teach one another to process and express emotions (hence, coping style might be less stable than expected). On the other hand, there might be other online therapeutic processes present that offset detrimental effects of avoiding emotions.

Another interesting finding of chapters 2 and 3 was the important role of offline factors. Previous studies often did not take into account patients' offline world, which implicitly assumes that only the online environment affects patients' well-being. However, the studies presented in this dissertation showed that receiving psychological help from a professional, the support patients receive from friends and family, disease status, education level and if patients perform a job were also related to patients' psychological well-being. For that reason, such 'offline' factors are highly relevant to measure when we aim to reconcile the added value of online peer support.

Part Two: The Social Perspective –Social Comparison and Support Messages

When patients turn to an online support community they 'meet' peers, notably in two ways; 1) patients read about the experiences of others, and 2) peers respond to the messages of patients in need. To unravel the psychological effects of online participation, I proposed that psychological mechanisms associated with these two online processes need more empirical attention.

In **Chapter 4** we looked at the relevance of social comparisons. When patients read about the experiences of other patients, they automatically compare their own situation with the situation of the other⁴. How one generally interprets such comparisons has an influence on psychological well-being⁵. For example, when another patient seems to be in a better situation, one could feel frustrated about doing worse (i.e., *upward contrast*) or gain hope out of this story (i.e., *upward identification*). On the other hand, when a peer is doing worse, one could feel lucky to be in a better position (i.e., *downward contrast*) or getting anxious to be in that position one day (i.e., *downward identification*). Hence, patients can gain something positive or negative out of upward and downward comparisons. The study described in Chapter 4 showed that especially pessimistic comparisons (i.e., mainly upward contrast, and in some cases downward identification) were related to lower levels of emotional well-being and higher levels of depression and breast cancer-related concerns. The negative relationship between downward identification and breast cancer related-concerns seems particularly prominent among patients who showed high levels of activity within the online support community. Again, offline factors such as education level, offline social support, and receiving psychological help from a professional were also related to patients' level of psychological well-being. Although the cross-sectional design prevents us from drawing conclusions regarding causal effects, these findings suggest that patients should be careful not to become 'entrapped' by pessimistic social comparison processes online.

Chapter 5 covers an experimental study that showed the effects of support messages on the recipient's level of emotional well-being (i.e., emotional distress). In online support communities, peers share experiences and difficulties regarding the illness, and provide each other with support. The aim of Chapter 5 was to answer the question: What kinds of support messages produce positive

psychological effects on the person disclosing a stressful experience? To our knowledge, this is one of the first studies that combines literature on support communication⁶ with literature from psychology on processing and disclosing trauma^{7,8}. Previous research from psychology showed that the psychological impact of an event not only depends on characteristics of the event itself but also on individuals' personal appraisal of the experience, something that is often neglected in the field of support communication (see Chapter 5). Depending on the phase of processing, individuals disclose details about the negative experience in different ways; more emotionally during a crisis situation, or with a focus on cognitive reappraisal (i.e., re-creation of meaning) during moments of transition^{7,9}. For that reason, we hypothesized that the psychological effects of different support messages depend on one's disclosure style (i.e., the fit between disclosure style and support message). Findings showed that a cognitive reappraisal support message (which focused on reinterpreting the negative life experience) decreased levels of emotional distress particularly for individuals who had just expressed their deepest emotions. Cognitive reappraisal responses had no effect on participants who cognitively reappraised the negative life event during disclosure. Although socio-affective responses were positively evaluated, cognitive reappraisal responses may be more effective during emotional upheaval because they provide a positive way out of negative emotions.

Part Three: Causal Relationships and Added Value

The goal of the last study (*Chapter 6*) was twofold: to reveal the direction of the relationship between intensity of online participation and psychological well-being, and to assess if online peer support adds to psychological well-being on top of other well-being modifiers from the "offline world". One could state that participating in an online community affects patients' well-being, for example due to emotional expression and the support one receives from peers. However, a patient's state of well-being might also influence the intensity of participation. For instance, when patients go through difficult emotional times, one might also become more active online because the need for support from similar others increases. This 3-wave study revealed that especially disease status functioned as a catalyst for more intensive online participation, and intensity of online participation, in turn, caused lower levels of depression over time. Hence, intensity of online participation positively affected psychological well-being, rather than the other way around. Furthermore, beneficial effects on well-being were significant on top of the influence of other factors outside the online environment 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, cause it seems to be of added value for patients' psychological well-being.

Theoretical implications

This dissertation extends previous knowledge on the psychological effects of online peer-led support community participation in three ways. The first main contribution is that the present findings indicate no detrimental psychological effects of intensity of online participation; in both longitudinal studies we found positive effects over time. Second, effects seem to depend on moderating factors, such as patients' level of emotional approach coping, social comparison mechanisms, and the support messages one receives. And third, online peer support appears to contribute to well-being on top of one's 'offline' situation, i.e., factors outside the online environment affecting psychological well-being.

The overall positive long-term effects on top of offline modifiers are in line with the general concept of social capital, i.e., the value of social networks¹⁰. Basically, social capital means the presence of value creation because individuals are connected. These connections are of value due to for example shared information, cooperation, trust and reciprocity. Also, different social connections provide people with different recourses¹⁰. Consequently, the online community connects a patient with a group of similar others who provide each other with support, which is one of our fundamental human needs¹¹.

Furthermore, the concept of social capital might also explain part of the second contribution of this dissertation. The presence of moderating factors showed that online peer support is not equally helpful to all patients. In the context of emotional approach coping, this social capital concept could clarify why we found that active online community participation was especially beneficial for patients who approach emotions less actively. The illness-related experiences patients share in online communities might provide the resources (i.e., recognition and trust) that are needed to express private issues and related emotions. As a result, the online environment might complement 'offline' support resources, and prove especially beneficial for patients who talk less about emotional issues in their daily 'offline' life. Hence, the online environment might provide them with a safe setting to vent what is on their mind.

The Internet supplements our offline world with new possibilities for human connection and interactions. Our findings underscore the importance of their added value to our 'offline' lives. In previous studies the offline world is often neglected. However, there exists no online world without an offline world. To understand the impact of online communities on individuals' well-being we should not neglect one's offline situation¹³. To illustrate, the present findings showed that other important 'offline' well-being modifiers, i.e., factors outside the online environment, also play a key role in determining patients' well-being. Thus, in future research on the psychological impact of online communities, it is recommended to address relevant 'offline' factors as well.

It is however important to stress that we might have to change our "on- and offline" labels into "before the Internet" and "after the Internet", because the

online world is not separated from our offline world (anymore). The impact of the Internet has been increased over the last years; it has burrowed itself into our lives. Because the online world is almost completely integrated in our daily lives, it changes our concept of community and relationships in general. Hence, researchers have to retest -and possibly redefine- theories and concepts that touch upon social interactions, community, and group dynamics to adjust them to today's society.

Results of the current dissertation also stress the importance of individual differences when we study psychological effects of online communities. Next to coping differences, other moderating factors (i.e., online social comparisons, and the kind of support one receives) seem to co-determine the relationship between online participation and psychological well-being. In online communities individuals interact with each other, and these individuals have their own personalities, preferences and behaviors¹² that might influence one's own well-being, but also influence others inside a network. Such moderating factors are often overlooked in previous studies. The current project showed that different personal- and interpersonal dynamics indeed determine the effectiveness of online peer support. Consequently, when we aim to reveal the impact of various online communities on individuals within our society, it is essential to uncover such dynamics.

Implications for multidisciplinary research

Because of its' multidisciplinary character, the current research also extends other fields of research. By integrating literature on processing distressing life events and support communication, we showed that effects of support messages probably depend on the disclosure style of the person in need. This means that researchers in the field of support communication testing the effects of support messages need to go beyond their own interpretation of the impact of the event, and include the appraisal of the individual. Second, in the field of support communication effectiveness of support messages is mostly assessed with self-report measures of perceived helpfulness, instead of actual emotional distress measures (from psychology). Involving such outcome measures appears informative, since we found that these measures showed different results than the self-reported evaluations of helpfulness. Hence, integrating theories and methods from communication science and psychology is of great value when we aim to understand how individuals should support each other in difficult times.

Second, the present studies on emotional approach coping (a concept from psychology) showed that online communities have the potential to influence the assumed psychological effects of this coping style. Our findings indicated that especially patients who cope less actively with their emotions experienced an increase in well-being over time, on the condition that they participated frequently online. However, the coping literature has shown that patients who cope actively with emotions generally report a better well-being than patients

who cope with emotions less actively¹⁴⁻¹⁶, and presumed that coping style is a rather stable personality characteristic (and therefore often measured once in longitudinal studies, e.g.,¹⁵). Interestingly, our findings show that the online environment probably affects this relationship; particularly patients with a low score on emotional approach coping benefit from support group participation over time. Hence, online conversations seem to correct for one's initial, maladaptive coping style. Consequently, it might be worthwhile to test psychological effects of coping in different on- and offline communication environments, since different environment might produce different results.

Finally, this thesis contributes to the social comparison literature. Effects of social comparisons are mostly studied in offline settings, showing that optimistic comparisons (i.e., upward identification and downward contrast) are generally positively related to well-being, and that pessimistic comparisons (i.e., upward contrast and downward identification) are negatively related to measures of well-being¹⁷⁻¹⁹. The same pattern was found in the online environment. However, our findings showed that the relationship between pessimistic comparisons and well-being overruled the relation between optimistic comparisons and well-being, and that intensity of online participation might intensify the effects of pessimistic social comparisons. One explanation might be that the online environment strengthens the effects of pessimistic comparisons because of the lack of face-to-face interaction. An online a-synchronous system gives the possibility to react and ask each other questions, though on a slower pace than in real life interactions and not everyone responds online; there is great amount of lurkers²⁰. In face-to-face interactions (like in an offline support group) it might be easier for patients to make meaning out of a story together, i.e., constructing a story together while talking. As a result, face-to-face interactions might put negative stories in better perspective. Again, this finding indicates that social comparison mechanisms should be tested in both on- and offline settings, because social comparisons might affect individuals' differently due to the communication environment.

Although it takes more effort to get acquainted with different research paradigms, methodological approaches, and it may sometimes be harder to find an appropriate publication outlet for interdisciplinary studies, I believe this should not prevent us from connecting knowledge from different fields to get a little closer to the truth. Applying psychological mechanisms to different settings (i.e., different environments in which we communicate with each other) explains on the one hand how the communication environment affects the individual, but -on the other hand- also contributes to the psychology literature, by testing if theories hold in different (on- and offline) contexts.

Practical implications

The Internet has undeniably become part of our daily lives, and patients apparently feel the need to connect with each other online. The Internet is an open environment; we can neither prevent people from participating nor oblige them

to participate on a frequent basis. Nevertheless, research can reveal the potential benefits and risks of online peer-to-peer interactions, and we can provide health professionals and patients with this information.

From the current findings we can conclude that especially breast cancer patients who have difficulties coping with their illness-related emotions can benefit from regular online participation. Particularly for these patients sharing experiences and feelings with online peers is likely to increase their psychological well-being. Furthermore, when patients support each other online during moments of stress, it seems more beneficial to focus on re-creating meaning to overcome mental perseveration and to temper emotional distress than solely affirming one's negative feelings. Although one should always acknowledge another one's feelings and perspective⁶, carefully helping someone to move from a crisis situation (eliciting emotional arousal) to a transitional state (i.e., reinterpretation of the experience), seems to be more helpful.

Additionally, when patients read stories from others online, one should be careful not to get caught in pessimistic comparisons. To be more specific, when someone visits an online community to read stories from others, one will encounter stories from patients who are in a better or worse situation than the reader's condition. One could get anxious of stories from others who do worse, and one might get frustrated from stories of patients who are doing better. It seems however more constructive to appreciate one's own situation when another is doing worse, or to gain hope out of positive stories. This is however easier said than done. If patients notice that they feel down or become anxious due to the stories of others, it might be better to distance oneself from these personal anecdotes and find another solution to find the required information. For example, if one is only looking for illness- or treatment-related information, one could visit websites that provide solely factual information, or ask a doctor for advice. If one is, for instance, looking for patient experiences with a certain treatment, one could also ask a family member or friend to investigate anecdotal experiences online.

To reconcile, descriptive studies showed the presence of therapeutic processes within online communities that might benefit psychological well-being²¹⁻²³. However, our studies showed that these therapeutic aspects might not be applicable to all patients due to individual differences. Nevertheless, although for some patients these therapeutic aspects (e.g., emotional expression) seem to be of less value, communities also entail other aspects that might be helpful for other purposes (i.e., aspects not directly promoting psychological well-being). For example, one might be better informed, and therefore, feel more confident in the relationship with the physician, or more confident about a treatment²⁴. Hence, although online communities might not foster psychological well-being in every case (as has been shown in the current dissertation), online platforms as such might still be helpful in other ways.

The present results are also relevant for health professionals setting up online interventions to guide patients. First of all, the findings indicate that mainly

disease status incites intensity of online participation; patients who were more recently diagnosed are more active online than others whose cancer cells are not present in the body anymore. This is in line with previous research showing that a female breast cancer patient especially turned online when she was experiencing illness-related difficulties²⁵. A breast cancer diagnosis is a life changing moment. The abrupt change from being a healthy person to a patient is distressing and can trigger many questions.

Many patients have a clear need for information about the disease and upcoming treatment, to gain as much (feeling of) control over the situation as possible^{26,27}. Some professionals have issued the concern that patients and other laymen sometimes share wrong information within online communities. However, studies also showed that posts predominantly do not contain potentially dangerous information²⁸, and members mention that discussion boards are often “self-cleansing”, i.e., someone mediates when flawed or unproven claims are posted²⁹. Nevertheless, health professionals remain the most appropriate stakeholder in providing correct and updated information, and in creating decision-making tools for treatment options, on the one hand.

On the other hand, patients need to adjust to the new, yet unfamiliar, situation. At this moment of insecurity, role models showing how one should think and feel can be helpful to maintain a sense of normalcy⁵. In such cases, emotional support from healthy others (family, friends, and health professionals) could be perceived as patronizing, since healthy others may not always be able to relate to how it feels to be ill and to possibly face death. For that reason, peers who understand one’s situation, thoughts and feelings might be the most suitable to fulfill this role. Hence, online peer-to-peer communities may be the proper platform to provide patients with this kind of support.

This raises the question if online peer support should be arranged within new health interventions in the first place. In the field of e-health and clinical psychology, health professionals design online interventions to guide patients through a period of illness, and these interventions often include peer support. An example of such an intervention is Bossom Buddies, which is structured by health professionals. Specifically, it is a 12-week program, introducing a new breast cancer-related topic every week, and a health professional moderates the online conversations. Another example is CHESS³⁰, where patients are able to receive expert advice on breast cancer, learn where to obtain help, and read relevant articles, in addition to talking with their peers online.

Due to the recognition of potential improvement of care and the overall health of the population, the number of (online) interventions is increasing. To recruit sufficient patients to participate in these interventions, researchers mainly depend on the involvement of general practitioners. Though, getting general practitioners involved seems to be difficult sometimes³¹⁻³³. Hence, a considerable amount of money is spent on the creation of new support platforms and recruitment of participants, while patients already gather innately online. Perhaps, if patients establish online support communities by themselves, it might

be a better solution to collaborate with patient unions (who often set-up these peer-led communities). Hence, re-inventing the wheel might be less efficient if patients already group online and provide each other with peer-support that appears psychologically beneficial. It might be more cost-effective to provide these communities with correct information, and additional tools to enhance decision-making or improve coping skills.

Limitations and future research

A first limitation is that we might have encountered self-selection bias because we studied patients who chose to be part of an online support community. Since our aim was to study patients in their natural environment, -and patients decide for themselves if they want to be part of an online community- our findings are only generalizable to this group of patients. This immediately results in an interesting question for follow-up research; Who are the patients that do not visit an online community? Are they patients who are less familiar with the Internet and its possibilities, or are they patients who consciously decide that they do not want to be part of such an online community? What is the level of psychological well-being of these patients? There is some evidence that certain patients choose to withdraw from an online support platform^{34,35}, for example because they have difficulties in dealing with the negative stories from other patients. Perhaps these patients have different needs and a different approach to help them psychologically is required.

Second, and related, the present study design also resulted in the absence of a control group. Consequently, we cannot compare study outcomes with patients who do not visit an online support community. It might be interesting to compare the level of psychological well-being of participants with non-users to uncover whether online community members initially show higher or lower levels of well-being than non-members. However, since we studied patients who chose to be part of an online community, it might be an insurmountable challenge to compose a comparable control group. Randomization is impossible, and patients who deliberately choose not to participate might differ in personality and coping style. To partially overcome this issue, we included a measure of intensity of online participation to reveal if high or low levels of participation made a difference in psychological well-being.

The current dissertation focused on female breast cancer patients. As a result, we cannot generalize our findings to male breast cancer patients and to other patients groups. Nevertheless, a few previous studies in which different online patients groups were compared (i.e., breast cancer, rheumatoid arthritis and fibromyalgia patients) showed some differences in online behavior (i.e., frequency of online contribution and the topics of posts), but these differences did not translate into differences in perceived empowering outcomes³⁶. Furthermore, descriptive studies on different online patient groups show the presence of comparable therapeutic and empowering processes across groups^{21,23,29,37-40}. Moreover, several of the psychological and social mechanisms we assessed in

our research, such as how individuals cope with emotions, how individuals compare themselves to others, and how others provide support, play a role in many life-changing events, including illness. In this sense, our findings may extend to several other research domains by showing that the relationship between sharing experiences online and psychological well-being may co-depend on coping styles, social comparisons, and social support. Hence, with caution, we could expect similar results for different online patient groups, but this assumption needs further testing.

During the current project, I aimed for larger study samples but it was a challenge to find enough study participants. Currently, the Internet provides researchers with the opportunity to find cancer patients that are willing to be study participants. However, many patients are overburdened with requests to participate in online studies, and some breast cancer patients participate in more than fifteen academic studies inside the hospitals setting alone. Of course, as researchers we aim to help patients with our findings, but this raises the question if we ask too much of them. To amplify the study samples of this dissertation, also platforms from other English speaking countries were contacted. However, these foreign platforms were much more upfront in protecting their members, and refused to put research requests online. One solution to expand study samples is to include patients with different diseases. Although this procedure would result in less homogeneous patient groups, previous studies showed little differences in perceived empowering processes and outcomes among different patient groups³⁶.

The present dissertation showed an overall positive effect of intensity of online support group participation on psychological well-being over time; revealed moderating factors that affect the relationship between online participation and psychological well-being; and indicated that online peer support seems to contribute to well-being on top of one's 'offline' situation. The next important step would be to connect online behavior with survey data. In Chapter 6 we made a start by comparing actual online posting behavior with our self-report measurement for online activity within the support community (see Chapter 6, Appendix 1). For future research, it would be very informative to connect individual coping styles with online behavior (e.g., the topics patients write about, and their writing-style) and examine relations with psychological well-being over time. Important follow-up research questions are, for example; What aspects within the online community help patients who approach emotions less actively to improve their well-being over time? Does interacting with peers teach patients to process and express their own thoughts and feelings? Or are there other therapeutic processes at work that benefit this group of patients?

Another interesting direction for future research would be to examine the effects of helping behavior. Patients seem to gain satisfaction from helping others^{29,41}. Several questions regarding helping behavior in online communities are still unanswered, for example; Who are the ones that provide others with support? Do they differ on certain personality characteristics? How does this

behavior affect the support-provider over time, i.e., is providing support to others beneficial for all patients? What about the proportion of receiving and providing support, i.e., is there a certain amount of reciprocity needed to elicit positive effects on one's well-being? These questions remain to be answered by future studies.

Final conclusions

The findings presented in this dissertation show that online support communities set-up by patients seem helpful under certain circumstances, and are of value beyond important (offline) factors related to well-being, such as physical well-being, and offline social support. Taking part in an online community on a regular basis positively affects patients who do not actively cope with their emotions. Furthermore, being highly active online did not show any harm in our longitudinal studies, we only found positive long-term effects on breast cancer patients' well-being. However, cross-sectional findings revealed the presence of pessimistic social comparisons, which showed a predominant negative relationship with psychological well-being. Additionally, an experimental study showed that some support messages are more effective in reducing emotional distress than others; cognitively reappraising a stressful situation appears more beneficial than providing socio-affective support. Future research is needed to test long-term effects of social comparisons and the support messages patients receive online.

Although the current longitudinal outcomes were all positive, our finding also showed that psychological outcomes are caused by a complex interplay of different underlying processes. Online support communities are not a one-size-fits-all 'magic box' that solves the complex and changing issues that different patients have to deal with on a daily basis. In the current dissertation I unraveled several of these complexities; we showed that coping with emotions, social comparisons, and the kind of support one receives all co-determine the relationship between online participation and well-being. Furthermore, we showed that online communities do not exist in a vacuum, and that other important 'offline' well-being modifiers, i.e., factors outside the online environment, also play a key role in determining patients' well-being. The findings in the current dissertation showed that *being on-line together* can make a difference, even on top of patients' offline world.

References

1. IKNL: Integraal Kankercentrum Nederland. Cijfers over kanker - prevalentie. 2013.
2. Davison KP, Pennebaker JW, Dickerson SS. Who talks? The social psychology of illness support groups. *Am Psychol.* 2000;55(2):205-17.

3. Nagler RH, Gray SW, Romantan A, et al. Differences in information seeking among breast, prostate, and colorectal cancer patients: results from a population-based survey. *Patient Educ Couns*. 2010;81 Suppl:S54-62. doi:10.1016/j.pec.2010.09.010.
4. Festinger L. A theory of social comparison processes. *Hum Relations*. 1954;7:117-140.
5. Buunk BP, Ybema JF. Social comparison and occupational stress: the identification-contrast model. In: Buunk BP, Gibbons FX, eds. *Health, coping and well-being: perspectives from social comparison theory*. Hillsdale, NJ: Lawrence Erlbaum; 1997:359-388.
6. Burleson BR, Goldsmith DJ. How the comforting process works: Alleviating emotional distress through conversationally induced reappraisals. In: Andersen PA, Guerrero LK, eds. *Handbook of communication and emotion: Research, theory, applications, and contexts*. San Diego, CA: Academic Press; 1998:245-280.
7. Rimé B. Interpersonal emotion regulation. In: Gross JJ, ed. *Handbook of emotion regulation*. New York: The Guilford Press; 2007:466-485.
8. Pennebaker JW. Putting stress into words: Health, linguistic, and therapeutic implications. *Behav Res Ther*. 1993;31(6):539-548. doi:10.1016/0005-7967(93)90105-4.
9. Jacobson DE. Types and timing of social support. *J Health Soc Behav*. 1986;27(3):250-64.
10. Wellman B, Wortley S. Different Strokes from Different Folks: Community Ties and Social Support. *Am J Sociol*. 1990;96(3):558. doi:10.1086/229572.
11. Baumeister RF, Leary MR. The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychol Bull*. 1995;117(3):497-529. doi:10.1037/0033-2909.117.3.497.
12. Ajzen I. *Attitudes, Personality and Behavior*. New York: Open University Press; 2005.
13. Wellman B, Gulia M. Virtual Communities as Communities: Net Surfers Don't Ride Alone. In: Smith MA, Kollock P, eds. *Communities in Cyberspace*. London: Routledge; 1999:167-94.

14. Classen C, Koopman C, Angell K, Spiegel D. Coping styles associated with psychological adjustment to advanced breast cancer. *Health Psychol.* 1996;15(6):434-7. doi=10.1037/0278-6133.15.6.434.
15. Stanton AL, Danoff-Burg S, Cameron CL, et al. Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *J Consult Clin Psychol.* 2000;68(5):875-82. doi:10.1037//0022-006X.68.5.875.
16. Stanton AL, Danoff-Burg S, Huggins ME. The first year after breast cancer diagnosis: hope and coping strategies as predictors of adjustment. *Psychooncology.* 2002;11(2):93-102. doi:10.1002/pon.574.
17. Morris BA, Campbell M, Dwyer M, Dunn J, Chambers SK. Survivor identity and post-traumatic growth after participating in challenge-based peer-support programmes. *Br J Health Psychol.* 2011;16:660-674. doi:10.1348/2044-8287.002004.
18. Legg M, Occhipinti S, Ferguson M, Dunn J, Chambers SK. When peer support may be most beneficial: the relationship between upward comparison and perceived threat. *Psychooncology.* 2011;20:1358-62. doi:10.1002/pon.1862.
19. Dibb B, Yardley L. How does social comparison within a self-help group influence adjustment to chronic illness? A longitudinal study. *Soc Sci Med.* 2006;63(6):1602-13. doi:10.1016/j.socscimed.2006.03.031.
20. Setoyama Y, Yamazaki Y, Namayama K. Benefits of peer support in online Japanese breast cancer communities: differences between lurkers and posters. *J Med Internet Res.* 2011;13(4):e122. doi:10.2196/jmir.1696.
21. Vilhauer RP. Perceived benefits of online support groups for women with metastatic breast cancer. *Women Health.* 2009;49(5):381-404. doi:10.1080/03630240903238719.
22. Klemm P, Nolan MT. Internet cancer support groups: legal and ethical issues for nurse researchers. In: *Oncology nursing forum.* Vol 25.; 1998:673.
23. Setoyama Y, Nakayama K, Yamazaki Y. Peer support from online community on the internet among patients with breast cancer in Japan. *Stud Health Technol Inform.* 2009;146:886.

24. Van Uden-Kraan CF, Drossaert CHC, Taal E, Seydel ER, van de Laar MAFJ. Participation in online patient support groups endorses patients' empowerment. *Patient Educ Couns*. 2009;74(1):61-9. doi:10.1016/j.pec.2008.07.044.
25. Wen KY, McTavish F, Kreps G, Wise M, Gustafson D. From diagnosis to death: a case study of coping with breast cancer as seen through on-line discussion group messages. *J Comput Commun*. 2011;16(2):331-361. doi:10.1111/j.1083-6101.2011.01542.x.
26. Miller SM. Monitoring and blunting of threatening information: cognitive interference and facilitation in the coping process. In: Sarason IG, Pierce GR, Sarason BR, eds. *Cognitive Interference: Theories, Methods and Findings*. Routledge; 1999:175-190.
27. Ong LM, Visser MR, van Zuuren FJ, Rietbroek RC, Lammes FB, de Haes JC. Cancer patients' coping styles and doctor-patient communication. *Psychooncology*. 1999;8(2):155-66. doi:10.1002/(SICI)1099-1611(199903/04)8:2<155::AID-PON350>3.0.CO;2-A.
28. Van Uden-Kraan CF, Drossaert CHC, Taal E, et al. Coping with somatic illnesses in online support groups: Do the feared disadvantages actually occur? *Comput Human Behav*. 2008;24(2):309-324. doi:10.1016/j.chb.2007.01.014.
29. Van Uden-Kraan CF, Drossaert CHC, Taal E, Shaw BR, Seydel ER, van de Laar MAFJ. Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qual Health Res*. 2008;18(3):405-17. doi:10.1177/1049732307313429.
30. Gustafson D, Wise M, McTavish F, et al. Development and pilot evaluation of a computer-based support system for women with breast cancer. *J Psychosoc Oncol*. 1994;11(4):69-93. doi:10.1300/J077V11N04_05.
31. Silagy CA, Carson NE. Factors affecting the level of interest and activity in primary care research among general practitioners. *Fam Pract*. 1989;6(3):173-6. doi:10.1093/fampra/6.3.173
32. Askew DA, Clavarino AM, Glasziou PP, Del Mar CB. General practice research: attitudes and involvement of Queensland general practitioners. *Med J Aust*. 2002;177(2):74-7.

33. Murphy E, Spiegel N, Kinmonth AL. "Will you help me with my research?" Gaining access to primary care settings and subjects. *Br J Gen Pract.* 1992;42(357):162-5.
34. Sandaunet A. The challenge of fitting in: non-participation and withdrawal from an online self-help group for breast cancer patients. *Sociol Health Illn.* 2008;30(1):131-44. doi:10.1111/j.1467-9566.2007.01041.x.
35. Sandaunet A. A space for suffering? Communicating breast cancer in an online self-help context. *Qual Health Res.* 2008;18(12):1631-41. doi:10.1177/1049732308327076.
36. Van Uden-Kraan CF. *Online Peer Support for Patients with Somatic Diseases.* 2008. ISBN: 978-90-713-8265-9. Available at: <http://doc.utwente.nl/60136/>. Accessed August 24, 2012.
37. Klemm P, Reppert K, Visich L. A nontraditional cancer support group. The Internet. *Comput Nurs.* 1998;16(1):31-6. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/9454992>. Accessed March 21, 2011.
38. Coulson NS, Buchanan H, Aubeeluck A. Social support in cyberspace: a content analysis of communication within a Huntington's disease online support group. *Patient Educ Couns.* 2007;68(2):173-178. doi:10.1016/j.pec.2007.06.002
39. Mo PKH, Coulson NS. Online support group use and psychological health for individuals living with HIV/AIDS. *Patient Educ Couns.* 2013. doi:10.1016/j.pec.2013.04.004.
40. Coulson NS. Receiving social support online: an analysis of a computer-mediated support group for individuals living with irritable bowel syndrome. *Cyberpsychol Behav.* 2005;8(6):580-4. doi:10.1089/cpb.2005.8.580.
41. Shaw BR, McTavish F, Hawkins R, Gustafson DH, Pingree S. Experiences of women with breast cancer: exchanging social support over the CHESS computer network. *J Health Commun.* 2000;5(2):135. doi:10.1080/108107300406866

