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English Summary

Background

This dissertation presents a collection of studies aimed at understanding the psychological effects of participating in peer-led virtual support communities. Although online support communities exist on many different topics, the current thesis focuses on breast cancer because research has shown that individuals who are concerned or feel stigmatized especially feel the need to connect with similar others. For example, individuals dealing with AIDS, depression, cancer, diabetes and alcoholism are motivated to seek information and support from peers (both on- and offline)¹.

Virtual support communities, often set-up by patients or ex-patients, are mostly designed as bulletin boards (i.e., online forums). Because members participate anonymously, support communities provide a safe communication environment for individuals who have feelings of anxiety, such as fears of humiliation and embarrassment¹. Perhaps for those reasons, an increasing number of patients visit online communities to share illness-related experiences and information². Hence, patients connect online to support each other during their course of illness. But do support communities really help? Currently empirical evidence for the psychological consequences of participating in virtual support communities is lacking. It is important to examine these consequences, as 'being online together' could go both ways, patients could build each other up, but also tear each other down. Furthermore, consequences might also vary due to other factors, such as individual differences between patients.

Current state of research

Research has to date already provided valuable information on virtual support communities. For example, descriptive studies suggest potentially beneficial processes exist within these online communities, such as group cohesiveness, recognition and support, emotional expression, insight, advice, and instillation of hope³⁻⁶. Moreover, members of such communities reported that they felt better informed and their social well-being increased⁷. However, there are also a number of studies exposing certain downsides, such as patients being concerned about being misinformed, experiencing difficulties with negative sides of the disease, or dealing with complainers^{3,6,8,9}. Although these studies indicate that most members appreciate an online support community and seem to benefit from being online together with peers, there are several issues that prevent us from drawing firm conclusions on the actual psychological effects of participation.

First of all, almost no study empirically tested the (long-term) causal psychological effects of participation. In most studies researchers analyzed online content to see what patients write about and how they support each other, or they interviewed individual members about their experiences. However, studies revealing if and when online participation affects the psychological well-being of community members are still lacking.

A second issue is the shortage of studies taking into account potential moderating factors, such as individual differences between patients. As human beings differ significantly in terms of personalities, attitudes, and behavior¹⁰, we can expect that in case of a life threatening disease such as breast cancer, not every patient copes with the illness and the online environment in the same manner. As a result, therapeutic processes that seem to be present in online communities may not apply equally to all their members. Rather, participating online can be assumed to produce different psychological effects for different users.

The third issue is the lack of consideration of members' offline world in existing studies. Researchers examining online environments often neglect offline aspects of a person's life¹¹. However, online and offline worlds are inseparable. There are various factors besides online peer support that benefit or harm patients' psychological well-being. For example, patients vary in illness characteristics such as disease status and treatment, but also in the support they receive offline, for example from family, friends, social workers, or a therapist. These factors should be considered when assessing the psychological contribution of online support communities to well-being.

Research approach

To overcome these three issues, this research project (1) contained a longitudinal study design to assess effects on psychological well-being over time as a function of patients' intensity of online participation, for example, by measuring how often one visits the community, for how long, and how many messages one posts online; (2) included factors that might influence (i.e., moderate) the relationship between online participation and psychological well-being, for example, by studying how a patient deals with emotions, how one compares their own situation to the situation of peers, and the varying support messages patients receive from others; and (3) addressed psychological well-being modifiers outside the online community to assess if the online environment contributes to psychological well-being beyond patients' offline situation.

Main findings

This dissertation extends current knowledge on the relationship between online support community participation and members' psychological well-being in three important ways. This research (1) clarified the causality issue through a longitudinal study design, (2) revealed important moderating factors, and (3) demonstrated the added value of online support communities for patients' wellbeing on top of their 'offline' world.

Psychological effects. The first main conclusion of this dissertation regards the causality issue. To date, empirical studies testing psychological effects of online community participation are scarce, and as a result, the direction of the relationship between the intensity of online participation and psychological well-being remained unclear. On the one hand, one could argue that participating in an online community affects users' well-being, for example due to the expression of felt emotions and the support from peers. Conversely, a patient's state of well-being might influence the intensity of participation. For instance, when patients go through difficult emotional times, they might also become more active online because the need for support from others, who undergo similar struggles, increases. Results from the 3-wave longitudinal study described in Chapter 6 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. This finding clarifies causalities; the intensity of online participation affects levels of psychological well-being over time, rather than the other way around.

Moderating factors. Second, several moderating factors have been identified that influence the relationship between online participation and psychological wellbeing. The studies from Chapter 2 and 3 found that members' personal coping style (i.e., level of **emotional approach coping**¹²) determined the psychological effects of how intense a patient participates online. Previous research showed that actively processing and expressing emotions often produces beneficial effects when dealing with a stressful life-event¹³⁻¹⁵. Since online support communities are a suitable place to share illness-related emotions with peers, we expected that members' ability to approach their emotions would affect the psychological effects of their online participation. The longitudinal study described in Chapter 3 showed that especially community members who generally pay less attention to their emotions benefit from active online participation; they report an increase in psychological well-being over time. Members who were highly active within the community and approached their emotions effectively did not experience a change in psychological well-being over time, but showed the highest level of well-being overall. Hence, these findings suggest that intense online participation does no harm, and may be especially beneficial for the psychological well-being of patients who pay less attention to their emotions. An explanation for this finding may be that online peers teach one another to process and express emotions. However, it could also be that other online therapeutic processes offset detrimental effects of avoiding emotions. Future research is needed to identify possible explanations for this finding.

Furthermore, Chapter 4 focused on members' **social comparison strategies**. This study showed that the way users interpret the stories of peers also affects the relationship between online participation and psychological well-being. When patients read about the experiences of others online they automatically compare their own situation with the situation of the other person, which can result in optimistic and pessimistic conclusions^{16,17}. For example, when another

patient seems to be in a better situation, one could feel frustrated about doing worse (*upward contrast*) or gain hope from this story (*upward identification*). On the other hand, when a peer is doing worse, one could feel lucky to be in a better position (*downward contrast*) or become anxious to be in that position one day (*downward identification*). This study revealed that members holding online pessimistic comparisons display lower levels of psychological well-being and this relationship outweighed the potentially positive psychological effects of optimistic comparisons; no positive relationships between optimistic comparisons and well-being were found. Furthermore, active online participation intensified the negative relationship between downward identification (i.e., being afraid to be in the same situation one day as someone doing worse) and psychological well-being. Although the cross-sectional design of this study prevents us from drawing definite conclusions regarding causality, these findings suggest that online members should be careful not to become 'entrapped' by pessimistic social comparisons.

Chapter 5 covers an experiment on the underlying psychological mechanism of receiving **support messages** online. Community members share stressful experiences online and receive supportive responses from peers, and it can be expected that these support messages affect the psychological well-being of the recipient. To test this proposition, we conducted an experiment that examined the underlying psychological mechanisms. Due to ethical issues this study covered "healthy" participants. When experiencing a negative (traumatic) life event, individuals go through different phases to psychologically process the experience¹⁸. During these different phases individuals talk or write differently about their experience. For example, in a crisis situation individuals mainly disclose emotions, while during moments of transition there is a focus on re-creation of meaning^{18,19}.

Study results showed that different support messages (*response style*) produce different psychological effects, depending on how the recipient initially writes about a negative experience (*disclosure style*). When someone just expressed their deepest emotions, it is more effective to support that person with a cognitive reappraisal response (which focuses on reinterpreting the negative life experience) than a socio-affective response (which is understanding and validates emotions); a cognitive reappraisal response decreased the level of emotional distress. Although recipients positively evaluated the supportive value of the socio-affective response, this response did not show any effect on levels of emotional distress. Hence, cognitive reappraisal responses may be most effective during emotional upheaval because they provide a positive way out of negative emotions.

To recapitulate, being part of an online support community produces different psychological effects for different members, dependent on their emotional coping style, their social comparison strategy, and the kind of support message one receives after disclosing a stressful experience.

The third conclusion of this dissertation concerns the added value of online community participation when also considering patients' **offline world**. An unanswered question so far was whether online communities trigger significant changes in psychological well-being on top of 'offline' aspects that influence patients' wellbeing. In other words, does Internet technology - by facilitating these online peer connections - really make a difference in patients' lives? As expected, we found throughout all our studies that factors outside the online environment, such as illness characteristics, physical well-being of the patient and the support the patient receives from family and friends, were significantly related to members' psychological well-being (see Chapter 2 to 6). Nevertheless, beneficial effects of online participation remained significant in the longitudinal studies, on top of these 'offline' well-being modifiers.

Practical recommendations

Current findings are relevant for patients, caregivers and health professionals. Internet usage has undeniably become a pervasive 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, we can make patients aware of the possibility to connect with peers online, and provide patients, and other important stakeholders, with the information necessary to gain the greatest benefit from online support communities. Although the longitudinal studies did not reveal negative psychological effects of online support community participation over time, the current dissertation did show that online participation is not equally beneficial to all patients. For example, especially for patients who pay less attention to their emotions, actively participating in an online support community seems to be helpful.

Furthermore, patients can help each other to psychologically process moments of distress. In order to overcome mental perseveration and to temper emotional distress, especially supportive messages that carefully change an individual's perspective may be helpful. Although one should always acknowledge another patient's feelings and perspective²⁰, carefully helping someone to move from a crisis situation (eliciting emotional arousal) to a transitional state (reinterpretation of the experience), seems to be helpful.

A possible downside of online participation is the presence of social comparisons. On the one hand, reading stories from others might provide patients with role models, who may set the example how to cope with illness-related issues and provide hope through survivor stories. On the other hand, for patients who have a tendency to draw pessimistic conclusions from comparisons with peers, active online participation might increase their breast cancer-related concerns. If patients recognize such negative side-effects of reading stories from others online, based on this dissertation they are advised to (temporarily) withdraw from the online community and rather let others look up the information the patient is looking for (for instance by asking a relative to look up stories about treatment experiences).

Though with caution, because future studies are still needed, patients could be encouraged to look for support from their peers online; 'being online together' appears to increase psychological wellbeing over time, it provides benefit regardless of patients' offline situations and seems to add value to offline support.

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