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**Online peer-to-peer communities in the daily lives of people with chronic illness:**

**A qualitative systematic review**

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## **Abstract**

This qualitative systematic review investigated how individuals with chronic illness experience online peer-to-peer support and how their experiences influence daily life with illness. Selected studies were appraised by quality criteria focused upon; research questions and study design, participant selection, methods of data collection and methods of analysis. Four themes were identified: 1) illness-associated identity work; 2) social support and connectivity; 3) experiential knowledge sharing; and 4) collective voice and mobilization. Findings indicate that online peer-to-peer communities provide a supportive space for daily self-care related to chronic illness. Online communities provided a valued space to strengthen social ties and exchange knowledge that supported offline ties and patient-doctor relationships. Individuals used online communities to exchange experiential knowledge about everyday life with illness. This type of knowledge was perceived as extending far beyond medical care. Online communities were also used to mobilize and raise collective awareness about illness-specific concerns.

**Keywords:** chronic illness & disease; internet, social support, thematic analysis, systematic review

## **Introduction**

People with chronic illness increasingly use online environments to support daily self-management (Barak, Boniel-Nissim, & Suler, 2008). Studies indicate that people with chronic conditions go online when looking for insights on health-related problems, symptoms, and treatments and to connect with others who share the same illness (Barak et al., 2008). Nevertheless, more knowledge is needed about how online communities intersect with and influence living with a chronic illness on a daily basis.

Online searches for illness-related information date back to early stages in the existence of the Internet, with many health care professionals raising safety concerns about the quality of much of the available information (Jadad & Gagliardi, 1998). More recently, with the emergence of Web 2.0, platforms offering peer-to-peer features have attained global popularity among people with chronic health conditions (Van der Eijk et al., 2013; Eysenbach & Till, 2001). Interactive social media platforms such as Facebook and Twitter, as well as patient portals for people with specific chronic illnesses, provide ways for peers to communicate about health and illness and to share experiences and mutual support (Miller, 2011). Daily support in a variety of forms is crucial because living with a chronic illness such as cancer, diabetes, chronic low back pain, and other conditions often requires a combination of behavioral practices (Mattingly, Groen, & Meinert, 2011). These practices, which can be viewed as daily ‘homework’ tasks, often require technological skills and know-how and include taking medication, monitoring

blood-sugar levels, engaging in physical activity, and managing diet and weight (Mattingly et al., 2011). Self-management of chronic illness has traditionally been supported by regular ambulatory clinic visits in combination with patient education (Nielsen & Groen, 2012). Great efforts have been made to meet individual needs in, for instance, traditional group-based patient education. Nevertheless, traditional forms of support are not always a sufficient means of providing individuals with the skills required to navigate the challenges of daily life with chronic illness (Nielsen & Groen, 2012; Corbin & Strauss, 1987; Bury, 1982; Strauss & Glaser, 1975). Although there is an increased focus on establishing a person-centered approach in one-to-one consultations and group-based patient education, it is still difficult to meet needs that arise in individuals' home settings (Nielsen and Groen, 2012).

In the context of chronic illness self-management, peer-to-peer support is defined as linking people with the same illness and similar characteristics to enable them to share knowledge and experience (Gilbert, Dodson, Gill, & McKenzie, 2012; Dennis, 2003; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004.) Recently, offline peer-to-peer support has been highlighted as a process that can complement patient education programs and interventions led by health care professionals (Carolan, 2011). A recent systematic review of offline peer-to-peer support interventions concluded that peer-to-peer support is effective in promoting health behavior changes across a variety of diseases and settings (Fisher et al., 2012). Peer-to-peer support is now used by a

number of health care professionals in combination with existing patient education programs to address the fact that chronic illness management requires various forms of support in daily life (Kristiansen, Antoft, Primdahl, & Petersen, 2015).

Peer-to-peer support can be delivered in many forms. A few studies have focused on the ways in which online peer-to-peer support can augment face-to-face consultations (Van der Eijk et al., 2013; Hordern, Georgiou, Whetton, & Prgomet, 2011). With the rise and influence of information and communication technologies, interest is increasing in the potential for health-related online peer-to-peer support (Eysenbach et al., 2004; Armstrong & Powell, 2009; Greene, Choudhry, Kilabuk, & Shrank, 2011). In a systematic review, Eysenbach et al. (2004) concluded that online peer-to-peer support is harmless, but it also lacks any significant empowering effect. In a similar vein, Dedding, van Doorn, Winkler, and Reis (2011) identified contradictory conclusions within the e-health literature concerning potential harm or benefits of online communities. Conversely, Demiris (2006) and Barak et al. (2008) concluded that online communities have the capability to empower individuals.

Other studies have shown that online peer-to-peer support is highly valued among people with a chronic illness as an expedient means to receive information about how to manage their illness (Lian & Nettleton, 2005; Greene et al., 2011). Some identified advantages of online peer-to-peer support, in contrast to offline peer support, include instant information exchange, easy access, the self-paced nature of interaction

and lack of restrictions regarding time and location (Horst & Miller, 2012; Brown & Duguid, 2000; Chung, 2013).

Even though previous studies have pointed to the potential empowering effect of online peer-to-peer support, it is still not evident how peer-to-peer support through online communities supports individuals in daily life with chronic illness. The aim of this review is to examine findings across qualitative studies to understand how individuals with chronic illness experience online peer-to-peer communities (which include both forums and interactive groups) and how these experiences influence daily life with illness.

## **Methods**

### **Systematic Qualitative Review**

To address the question of how people with chronic illness experience online peer-to-peer communities and the influence that this has on their daily lives we determined to undertake a systematic review of qualitative literature pertinent to this. The systematic review has, of course, a long and well-established place within medical research of a quantitative orientation. More recently, however, systematic reviews have been adapted to qualitative studies (Eager, Davey Smith, & Phillips, 1997). The impetus for this can be found in the need to pose research questions which involve complex concepts that resist easy quantification. As this implies, however, systematic qualitative reviews have



a different purpose to systematic reviews in which the aim is to achieve a formal aggregation of the selected material. In looking systematically at the literature relating to the topics identified, our aim is to critically reflect on the material and thereby capture some of the complexity that inheres in the question of apprehending people's experiences. Adopting this approach it is necessary to acknowledge the important and ongoing debates that have followed in the wake of the method's migration from the quantitative to the qualitative. In these debates researchers have been compelled to focus on elements in the construction of a review (Lloyd Jones, 2004); methods for searching for qualitative research (Eakin & Mykhalovskiy, 2003); and appraisal of qualitative research as well as methods for synthesis (Dixon-Woods et al. 2006; Dixon-Woods, Agarwal, & Jones, 2005). For this review we have combined elements from the existing literature on how to synthesize qualitative studies such as the appraisal tool for assessing qualitative studies developed by Carroll, Booth, and Lloyd-Jones (2012) and a systematic approach to searching the literature guided by Dixon-Woods et al. (2006) and Eakin and Mykhalovskiy (2003). As such, what follows is a qualitative systematic review of research findings that shed light on how people with a chronic illness experience online peer-to-peer support.

### **Search strategy and inclusion criteria**

Our original aim was to identify qualitative studies of online peer-to-peer support communities for adults with type 1 diabetes. However, our initial literature search revealed a single qualitative study of adults with type 1 diabetes and online peer-to-peer support, and we subsequently broadened our aim to include other somatic chronic illnesses. The research question has been used as a compass to guide the search field, however with the flexibility of being modified in the process as our original focus changed (Dixon-Woods et al., 2006; Eakin, & Mykhalovskiy, 2003). We conducted systematic and comprehensive searches in the autumn (September-October) of 2015 in six electronic databases: PubMed (1426), Scopus (184), Web of Science (86), and PsychINFO and Cinahl via the EBSCO database (164). We used database filters to select peer-reviewed and qualitative studies in English that pertained only to adults. **(Insert table 1)**

Identifying social science and qualitative studies through systematic database searches is challenging, so we also manually searched five qualitative journals online: *Qualitative Health Research* (198), *Sociology of Health and Illness* (120), *Health* (87), *Anthropology and Medicine* (0), and *Medical Anthropology Quarterly* (0). The search process resulted in a total of 2,265 articles. We eliminated duplicates and reviewed titles and abstracts of studies, excluding those that did not address: 1) interactive patient-to-patient web-based solutions; 2) social support for adults with chronic illness; and 3) peer-to-peer interactive online groups, forums, or communities. For example, studies

that addressed Internet searches, doctor-patient communication through email or text messaging, and blogs with one-way posting and little peer interaction were excluded. Disagreement or uncertainty about articles was resolved by discussion within the research team.

Thirteen articles met our criteria. They were published in *Qualitative Health Research* (5), *Sociology of Health and Illness* (3), *Health* (1), *Patient Education and Counselling* (1), *Societies* (1), *Journal of Health and Social Behavior* (1) and *Journal of Health Psychology* (1).

### **Quality assessment**

We assessed the quality of the 13 articles, including only those with an explicit and rigorous qualitative methodology and theoretical analytical research frame (Carroll et al., 2012). Even though the quality assessment checklist was originally designed for studies in offline settings, we found it was adaptable and suitable for the included studies which addressed online settings. Qualitative research methods used in the selected articles frequently included observations of interactions (posts) in online communities. These were sometimes combined with more traditional qualitative methods, such as semi-structured interviews or focus groups.

The checklist focuses on the quality of reporting in terms of: 1) research questions and study design; 2) participant selection; 3) methods of data collection; and 4) methods of analysis. Following Carroll et al. (2012), studies that were assigned a clear *yes* in at least three criteria were included in the analysis. We found no methodological weaknesses disqualifying any of the 13 studies from the review.

**(Insert Table 2)**

### **Data analysis and categorization**

We grouped findings by themes to identify and analyze patterns within data related to the research aim (Braun & Clarke, 2006). Thematic analysis is a flexible and useful research tool that provides a rich, detailed, and complex account of data (Braun & Clarke, 2006). It has been referred to as an independent and reliable qualitative approach to analysis that is unmistakably undervalued (Vaismoradi, Turunen, & Bondas, 2013). Thematic analysis involves searching for and identifying common themes across material (DeSantis & Ugarriza, 2000). It is used in cases where there are no previous studies dealing with the phenomenon; therefore, the coded categories are derived directly from the text data (Hsieh & Shannon, 2005). It can also be referred to as a descriptive approach of identifying, analyzing, and reporting themes within the data. A theme is defined as a coherent integration of disparate pieces of data that constitute the findings (Sandelowski & Leeman, 2012). The importance of a theme is

not necessarily dependent on quantifiable measures, but rather on whether it captures something important in relation to the research aim (Braun & Clarke, 2006).

We followed the six analytical phases defined by Braun and Clarke (2006): 1) familiarizing oneself with the data, 2) generating initial codes, 3) searching for themes among codes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the final report. The familiarization process yielded a broad understanding of the selected articles. We read the 13 articles several times and grouped them using preliminary codes to identify sub-themes across articles. The sub-themes consisted of descriptive content within the data and can be seen as an expression of the manifest sub-themes of the text (Graneheim & Lundman, 2004). This semantic approach to sub-themes was based on explicit meaning, rather than on interpretation.

After the familiarization process, we systematically generated initial codes for sub-themes of interest across all papers. Even though our overall aim guided the analysis, the initial sub-themes were data-driven; we did not attempt to fit sub-themes into a pre-existing thematic framework. We carefully discussed sub-themes emerging from the data and began to arrange them into overall themes. All themes were analyzed in a recursive process in which we constantly moved back and forth between the studies and the identified themes (Braun & Clarke, 2006). As the process of developing themes progressed, we conducted comprehensive latent analysis by examining underlying sub-thematic concepts and meaning, which provided further definition and iteratively

refined theme names. We also reviewed the themes several times to verify that they comprehensively and exclusively represented coded semantic extracts of the data set. We then summarized findings from each sub-theme within the four overall themes, describing them as closely as possible to the source article, using direct quotations whenever appropriate.

Table 3 shows the variability of manifest sub-themes and the grouping into final overall latent themes. Thematic analysis research requires considerations of both manifest and latent content before proceeding to the next stage of data analysis (Braun & Clarke, 2006).

**(Insert table 3).**

## **Results**

Overall, four themes were identified: illness associated identity work; social support and connectivity; experiential knowledge sharing; and collective voice and mobilization.

### **Illness associated identity work**

This theme refers to the kind of emotional work people with a chronic illness undertake in order to renegotiate and normalize their identities in the wake of an illness diagnosis. A number of studies showed how identity work was carried out online in reciprocal ways among peers in order to reshape a fragmented identity caused by the diagnosis of

an illness. Online interaction among peers with the same condition was also a resource for self-expression in the wake of illness onset. Identity work was articulated through online narratives and even though these autobiographical stories were rather short, they often drew on profound psychological experiences and expressed emotionally difficult topics in the context of daily life with chronic illness. Peers supported each other emotionally with replies of solidarity as a way to validate illness stories and provide emotional relief. This identity work was done in a reciprocal way; it often encouraged both posting one's own illness stories and replying in a supportive and acknowledging way to those of other community participants. Illness-specific issues were common, such as moral and ethical discussions surrounding the disclosure of HIV/AIDS and uncertainty in the challenges of obtaining a definitive diagnosis for symptoms of low back pain, arthritis and fibromyalgia. However, many findings related to this theme were consistent across all illness groups.

Online communities became a space where users dealt reciprocally with difficult emotions. Sub-themes most evident across studies were fear, hope, and uncertainty. The heavy emotional burden that accompanied a chronic illness included fear of an uncertain future. In the study by Saundaneet (2008) on women with breast cancer in some instances fear seemed to involve withdrawal from the community. However in other studies, one way that study participants dealt with this fear was to turn it into something positive. In the case of women with breast cancer, identity work aimed at reaching a

state of hope and emotional relief as a way to address emotional fear. In the study by Sandaunet (2008a), 40 Norwegian women with breast cancer used an online community as a tool for reframing negative and painful emotions into something positive.

Reciprocal illness stories generated hope when they emphasized opportunities instead of challenges.

*To turn the illness into something positive creates meaning and the awareness that I can influence my own life – during serious illness as well. (Woman with breast cancer [Sandaunet, 2008a, p. 6]).*

In this way, breast cancer sufferers strived to establish meaning in relation to their illness that supported a positive account of their integrity as agents. Humor was also used as a strategy to re-frame a negative illness identity into a positive one (van Uden-Kraan et al., 2008; Hoeybye, Johansen, & Tjoernhoej-Thomsen, 2005). For example, Hoeybye et al. (2005) highlight jocular exchanges among women with breast cancer, referring to ‘shampoo for bald-headed people’ or ‘chemo-brains’ when experiencing forgetfulness.

Another sub-theme within this theme was peers encouraging each other to fight the emotional effects of illness. Shared stories of encouragement were seen to provide strength to cope with the uncertainty raised by illness (Hoeybye et al. 2005; Armstrong,



Koteyko, & Powell, 2012; Rier, 2007; Bar-lev, 2008). Sharing stories became an important survival tool for some users, just as writing about their illness became a work of self-actualization when dealing with a disrupted identity caused by a new illness.

### **Social support and connectivity**

This theme elucidates how people with chronic illnesses connect with and supports each other online and, in so doing, how they also attempt to manage social relations in their daily lives. Thus, another reason for consulting peers with the same illness was to alleviate strains on relationships with family and friends. Users created a social network in which it was socially acceptable to have a very explicit focus on disease and illness, in contrast to other social networks. The study by van Uden-Kraan et al. (2008) illustrates how chronically ill people found online peer-to-peer support communities an ideal space to share experiences. They did not want to bore, annoy, or worry people in their surroundings, although they still needed to talk about their situation.

Several studies identified the potential of online communities to rebuild a social network lost due to feelings of isolation and loneliness (Hoeybye et al., 2005). The importance of initiating new friendships through participation in online communities was further highlighted in Mazzoni and Cicognani (2014, p. 4), as they showed how people with lupus joined online communities with the aim of connecting with others with the same illness:

*In those moments I felt that I was missing someone for sharing my feelings, my fears, my discouragement. My family is close to me, but it is not the same. Please feel free to contact me, if you want to listen to my story and to tell me yours. (Female, 24, with systemic lupus erythematosus).*

Similarly, in van Uden-Kraan et al. (2008), a woman with fibromyalgia explained that she lost offline relationships due to the illness and intentionally used the online community to strengthen her social ties. Another area of social support concerned the strengthening of relationships with health care professionals. Through exchanges in online communities, peers equipped one another with the critical skills required to experience more rewarding interactions in their consultations with health care professionals. This was related to the fact that people with chronic illnesses often found it difficult to address their concerns and formulate them in terms that physicians would understand and accept. Furthermore, people expressed frustration due to their lack of understanding of medical terms. In online communities, peers supplied each other with information given in language that was closer to real-life situations (van Uden-Kraan et al., 2008). This prepared participants in online communities for their interactions with doctors as they became more adept at expressing their concerns in illness-specific

vocabularies that made it easier to discuss treatment choices with their doctors as showed in Caiata Zufferey and Schulz (2009, p. 3):

*I have had the chance to clarify some things concerning the problem and thus be able to discuss it better with my doctor. (Person with low back pain).*

### **Experiential knowledge sharing**

This theme shows how people with chronic illnesses share knowledge online on how to live with chronic illness. Online communities were often used to share experiential knowledge tailored to specific needs and illnesses. The urge to seek out knowledge from people who have gone through similar experiences is illustrated in Armstrong et al. (2012, p. 10):

*...I've got so many questions and I just need anyone who has either gone through it, or knows any words of wisdom to put my little mind at rest. (Woman with type 1 diabetes).*

Peers exchanged knowledge that emerged from their own experiences of living with illness. This knowledge was not something that could be generated by health care

professionals because it arose from real-life experiences and situations. Reciprocal exchange of experiential knowledge gave people a feeling of embodied control that supported them in daily illness self-management. Hoeybye et al. (2005) demonstrated how women with breast cancer felt empowered by the exchange of experiential knowledge. In many of the studies, it was evident that a form of peer mentoring took place in which individuals with more lived experience of a particular condition shared the knowledge they had acquired with individuals who were less familiar with the chronic illness experience (van Uden-Kraan et al., 2008; Gillett, 2003). Knowledge about how to overcome specific difficult situations had a particularly empowering effect, in part because it helped restore some sense of control that was threatened by chronic illness. This corresponds to Caiata Zufferey and Schultz (2009), in which the process of reading and acknowledging online testimonies had a supporting and empowering effect among people with low back pain.

### **Collective voice and mobilization**

This theme illustrates how individual voices congregate online with the explicit aim of collective mobilization and the promotion of perspectives and discourses relevant to their situation and condition. Several studies illustrated how online peer-to-peer communities were used to promote collective agendas, such as advocating for changes

in health care services addressing the condition of interest (van Uden-Kraan et al., 2008; Radin, 2006; Gillet, 2003).

Even though online communities were used to express individual illness stories, they were also used to articulate a strong united voice through which participants sought to address issues of a more structural nature. Lian and Nettleton (2015) defined this shared collective voice articulated through online peer-to-peer communities as a tool to obtain political awareness for myalgic encephalomyelitis, for example through an online announcement on a Facebook community aiming to raise awareness about the illness and attract more members. The same method of raising awareness about a chronic illness was evident in studies of people with fibromyalgia (van Uden-Kraan et al., 2008; Barker, 2008). Online communities explicitly addressed the political domain, as a means of promoting patient-centered biomedical research and clinical guidelines. In another study, an online community for people with breast cancer worked as a social movement in the way it encouraged people with the same illness to interact and work cooperatively (Radin, 2006). Similarly, van Uden-Kraan et al. (2008) reported that people with breast cancer collectively decided to ask for a different type of medical examination. In regard to type 1 diabetes, an online community was used to question and contradict medical advice, creating a movement of expert 'patient-hood' (Armstrong et al. 2012). Interactions in online communities were seen to legitimize

lay knowledge, challenging the notion that expertise in this area is solely synonymous with biomedical expertise (Gillett, 2003).

## **Discussion**

In the course of our systematic qualitative review, we found that online peer-to-peer communities are used in various ways in the daily ‘homework’ of people diagnosed with chronic illnesses (Mattingly et al, 2011). Through their online interactions, individuals with chronic illness animated illness associated identities, sought and provided social support and connectivity, shared experiential knowledge only available from those living with particular chronic illnesses, while also mobilizing collective voices for the purposes of promoting otherwise neglected perspectives concerning life with chronic illness.

A key finding is that the longing for mutual solidarity and emotional support in relation to the day-to-day management of illness motivates people with a chronic illness to seek advice and inspiration among peers with the same condition. Identity work in the wake of a chronic illness is not a new phenomenon and has been described in several studies across different illness groups. The study by Mathieson and Stam (1995) details how people with cancer are involved with collaborative identity work including processes of ‘fitting’ disrupted feelings. The identity work carried out is aimed to renegotiate identities and attribute meaning to illness within the contexts of various

social relationships. Nevertheless, with the availability of online communities' new ways of renegotiating identity is evident. The collaborative identity work in the form of sharing of feelings and experiences is an online phenomenon. Across illness groups in online environments the sharing of autobiographical stories seemed to help them through processes of self-realization, providing a kind of emotional relief and enabling identity work. Kaufman and Whitehead (2016) describe this process as 'reciprocal empathic practices' in a study investigating how people with chronic illness use shared feelings and experiences as a resource for producing empathy. They argue that the reciprocal activity of sharing empathy has a strong supportive effect in daily illness associated identity work (Kaufman & Whitehead, 2016). Other studies have demonstrated that people with a chronic illness recover and obtain a sense of normalcy by mirroring each other's illness stories (Chung, 2013; Lowe, Powell, Griffiths, Thorogood, & Locock, 2009). It was evident in our review that online peer-to-peer communities strengthen the process of attaining a 'normal identity' through shared emotional identity work. Online communities were a means to offer rapid responses of emotional support which, in contrast to offline peer-to-peer emotional support, seemed to be more adapted to a situational and individual day-to-day need.

Our review identified different ways that social support took place. Online communities were a valued space to seek out new friendships. This was important for the chronically ill because illness-related thoughts could not always be shared with

family and friends without putting a strain on these relationships. Online social support provided a forum for articulating thoughts and feelings that might be deemed burdensome for family members. This had the effect of alleviating any strain that was experienced in relation to existing offline ties and was seen to actually strengthen offline relationships. Chung (2013) supports this view of online social support in a study on preference for online interaction over offline interaction; in particular, people who lack sufficient support from offline networks regard online interaction as supportive (Chung, 2013).

Another type of social support we identified was the translation of information from medical terms to patient knowledge and experiences and vice versa. This seemed to enhance patient-doctor understanding and cooperation and reduce feelings of stress and despair, particularly for individuals who had chronic illnesses with diffuse and ambiguous diagnostic profiles. In our review, this type of support was mostly perceived as strengthening patient-doctor relationships.

However, Conrad and Stults (2010) suggest another view of the effect of this type of online support; the Internet empowers patients who occasionally challenge the expertise of health care professionals, which might negatively impact doctor-patient relationships. Although this may certainly be the case in some instances, potentially negative impacts on doctor-patient relations were not apparent in the studies we reviewed, at least from the point of view of people with chronic illness. The benefit we



identified in the thematic analysis was that people became experts in their illness and symptoms, which empowered them to take control. This view is also supported by Bartlett and Coulson (2011).

The findings in our review regarding experiential knowledge sharing were related to how peers used online communities to share day-to-day self-care experiences. The online communities provided a space to search for and to supply more practical and situated knowledge on how to live with illness on a daily basis. Participants in online communities accelerated the acquisition of knowledge adapted to daily life that supplemented the more formal information provided by health care professionals. This type of knowledge has been termed ‘patient knowledge’ by the sociologist and anthropologist Jeannette Pols (2013, 2014). She explicates how patients use this knowledge to transform medical and technical knowledge into something useful. She further states that patients develop knowledge and techniques to interpret, appreciate, and shape their daily lives with a chronic illness in a good way (Pols, 2014). In the studies we reviewed, people with a chronic illness used knowledge generated from daily experiences with the illness to navigate life in various situated ways on a day-to-day basis.

In terms of collective voice and mobilization, although online communities elicited individual stories, they also worked as a space to mobilize collective action and solicit individual and illness-specific issues at a societal level. In the political sphere,

online peer support communities for people with chronic illnesses are increasingly used to challenge the paradigms of biomedical knowledge. Conrad, Bandini, and Vasquez (2016) argue that patients are increasingly active consumers of their own medical care and health-related knowledge. Nielsen and Groen (2012) also suggest that peer-to-peer communities represent a contemporary expression of what people with chronic illnesses require, both with respect to influence and in relation to active participation in care and treatment. Active patient mobilization is represented in several studies included in this review, reflected in online groups being used to raise awareness about specific illnesses and to generate a collective identity.

We sought to understand what participation in online communities provides people living with chronic illness. Our findings are centered on acute needs that revolve around rebuilding life, reassembling a fragmented identity, and acquiring skills that support the process of coping with the challenges inherent in daily life with a chronic illness (Conrad et al., 2016). Online peer-to-peer communities supported the ability of individuals to meet these needs. Nielsen and Groen (2012) view the growth of online peer-to-peer communities as a consequence of the growing trend of encouraging people with chronic illness to become active participants in managing their health and further legitimize the use of online peer-to-peer communities by highlighting that some offline chronic illness management programs are not designed to give space to illness narratives and identity work. We believe that online peer-to-peer communities offer a

platform for sharing feelings and knowledge relevant to people with chronic illness and should be further investigated for their potential as an important resource in the daily business of chronic illness homework.

This study has implications for advocates and health care practitioners who want to improve social support systems for individuals with chronic illness. However, a limitation of this review is the overrepresentation of some chronic illnesses and underrepresentation of others, even though they share commonalities in relation to the four overall themes. We recommend further studies on individual chronic illnesses, especially those that are underrepresented in this review, to fully understand how online peer-to-peer communities are experienced and might influence daily life with specific illnesses. Another limitation is that most of the selected studies focused on online communities and not on the realities of participants' daily experiences offline. Consequently, it was difficult to fully grasp the essence of their daily lives aside from the areas mentioned in the results. We expect that peer-to-peer interaction might influence areas of life other than those discussed here. The reviewed articles demonstrate a tendency to conduct studies on online groups, forums, and communities in a disembodied and disintegrated way with limited interface into the physical and mundane dimensions of daily life with a chronic illness. More studies are needed that use methods combining online and offline ethnography with an integrated time and space dimension to fully understand how interlinked and overlapping online and offline

dimensions construct, reshape, and constitute daily life with chronic illness.

Furthermore, we acknowledge that people, ill or not, may not actively use social media platforms or may use them to varying degrees, which further emphasizes the need for online and offline methods of inquiry.

## **Conclusion**

Online peer-to-peer communities for people with chronic illnesses have generated a public space in which issues and concerns relevant to their daily lives can be articulated and exchanged. Generally speaking, online peer-to-peer interaction supports people with a chronic illness emotionally, socially, practically, and politically, as represented in the four overall themes. Online communities can be seen as a unique space for peer-to-peer interaction in daily life with the potential for producing rich, embodied, and situated knowledge for people with chronicity who engages in them. Reciprocal emotional and social support was found to be especially empowering at an individual, social, practical and collective level. Further studies are needed to ensure a better understanding of boundaries of online and offline social dimensions and the relevance and influence of peer-to-peer online communities in the daily self-care 'homework' of people with chronic illnesses.

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## **Declaration of Conflicting Interests**

The authors declare that there is no conflict of interest.

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**Table 1.** Example of a search string in Scopus.

History Search Terms ( ( ( ( TITLE-ABS-KEY ( chronic W/5 ( illness OR disease* ) ) ) OR ( TITLE-ABS-KEY ( t1dm OR "type 1 diabetes" OR iddm OR "diabetes mellitus type 1" OR "insulin dependent diabetes" ) ) ) AND ( TITLE-ABS-KEY ( 'web' OR 'internet' OR 'online' OR digital OR facebook ) ) ) AND ( TITLE-ABS-KEY ( adult OR "Middle Aged" ) ) ) AND ( TITLE-ABS-KEY ( qualitative ) ) AND ( LIMIT-TO ( LANGUAGE , "English" ) ) AND ( LIMIT-TO ( SRCTYPE , "j" ) ) )
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**Table 2.** Quality assessment of studies

	Study design and questions		Participant selection		Methods of data collection		Methods of analysis		Journal
	Description	Check	Description	Check	Description	Check	Description	Check	
Armstrong, Koteyko & Powell (2012)	Understand the rhetorical nature and content of peer-to-peer exchanges	✓	17 patients with type 1 diabetes using an online self-management clinic with peer-to-peer chat	✓	Download of online data	✓	Thematic discourse analysis	✓	Health
Barker (2008)	Understand the role electronic social groups and how new technology play in the process of consumer-driven medicalization	✓	1 electronic support group of fibromyalgia patients	✓	Observations of online sites	✓	Thematic content analysis and coding in Nvivo	✓	Journal of Health and Social Behaviour
Bar-lev (2008)	Study of how emotional scripts are constructed	✓	1 online community for people with HIV/AIDS	✓	Online observation	✓		✗	Qualitative Health Research
Caiata Zufferey & Schultz (2009)	Examine self-management attitudes and behaviours	✓	18 chronic back pain sufferers in an online community	✓	In-depth interviews	✓	Grounded theory	✓	Patient Education and Counselling
Gillet (2003)	Study of media practices	✓	23 online sites including chat rooms for people with HIV/AIDS	✓	Online observations and surveys	✓	Grounded theory	✓	Sociology of Health and Illness
Hoeybye, Johansen & Tjoernhoej-Thomsen (2005)	Explore how social isolation is reduced	✓	40 women with breast cancer in an online community	✓	Online observations, online interviews and semi structured face-to-face interviews	✓	Story-telling	✓	Psycho-oncology
Lian & Nettleton (2014)	Explore how ME is negotiated	✓	14 internet forums, 10 blogs and 4 Facebook communities of ME	✓	Observations of online sites	✓	Analysis of discursive domain and discursive frame	✗	Qualitative Health Research
Mazzoni & Cicognani (2014)	Understand the demand/supply of social support	✓	1 online community for people with systemic lupus erythematosus	✓	Online post, observations	✓	Content analysis and statistical textual analysis	✓	Journal of Health Psychology
Radin (2005)	Explore mechanisms of social capital	✓	1 online community for women with	✓	Online participant observations	✓	Medium theory & Social capital theory	✓	Social Science and



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		breast cancer				Medicine			
Rier (2007)	Study of how ethics of disclosure is discussed	✓	16 communities for people with HIV/AIDS	✓	Online observation	✓	Grounded theory	✓	Sociology of Health and Illness
Sandaunet (2008a)	Study of a potential liberating realm for alternative discourses on disease and socially desirable exchanges	✓	40 women with breast cancer in an online community	✓	Online observation, individual and telephone interviews	✓	Issue-focused analysis	✓	Qualitative Health Research
Sanduanet (2008b)	Study of non-participation and withdrawal	✓	40 women with breast cancer in an online community	✓	Online observations and face-to-face interviews	✓	Issue-focused analysis	✓	Sociology of Health and Illness
van Uden-Kraan et al. (2008)	Study of processes and outcomes of empowerment in online groups	✓	32 patients with breast cancer, fibromyalgia, and arthritis in online communities	✓	Semi-structured interviews	✓	Inductive analysis	✓	Qualitative Health Research

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✓ reflects passing the assessment category; ✗ reflects not meeting assessment criteria.