## Original Paper

# Reaching the parts offline support can’t: Long-term condition illness work in online communities. A meta-synthesis of qualitative studies

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## Abstract

**Background:** Recent years have seen an exponential increase in people with a long-term condition (LTC) using the internet for information and support. Prior research has examined support for LTC self-management (SM) through the provision of illness, every day and emotional work in the context of traditional offline communities. However, less is known about how communities hosted in digital spaces contribute through the creation of social ties and the mobilisation of an online illness ‘workforce’.

**Objectives:** To understand the negotiation of LTC illness work in patient online communities and how such work may assist the SM of LTCs in daily life.

**Methods:** A systematic search of qualitative papers was undertaken using AMED, CINAHL, Cochrane Database, Delphis, Embase, International Bibliography of Social Sciences, Medline, PsychInfo, Scopus, Sociological Abstracts and Web of Science for papers published since 2004. 21 papers met the inclusion criteria of using qualitative methods and examined the use of peer-led online communities in those with a LTC. A qualitative meta-synthesis was undertaken and the review followed a line of argument synthesis.

**Results:** The main themes identified in relation to the negotiation of Self-Management Support (SMS) were: 1) Redressing offline experiential information and knowledge deficits; 2) The influence of modelling and learning behaviours from others on SM; 3) Engagement which validates illness and negates offline frustrations; 4) Tie formation and community building; 5) Narrative expression and cathartic release; 6) Dissociative anonymity and invisibility. These translated into a line of argument synthesis in which four network mechanisms for SMS in patient online communities were identified. These were *collective knowledge and identification through lived experience*; *support, information and engagement through readily accessible gifting relationships; sociability that extends beyond illness;* and *online disinhibition as a facilitator in the negotiation of SMS.*

**Conclusion:** Social ties forged in online spaces provide the bases for performing relevant SM work that can improve an individual’s illness experience, tackling aspects of SM that are particularly difficult to meet offline. Membership of online groups can provide those living with a LTC with ready access to a SMS illness ‘workforce’ and illness and emotional support. The substitutability of offline illness work may be particularly important to those whose access to support offline is either limited or absent. Furthermore, such resources require little negotiation online, since information and support is seemingly gifted to the community by its members.

**Keywords:** social media; patient online communities; long-term conditions; chronic disease; self-management; illness work; social networks; qualitative meta-synthesis.

## Introduction

Population aging has resulted in an increased prevalence of long-term conditions (LTC), which in turn, has resulted in increased expenditure on the provision of care for those affected [1, 2]. As a consequence, self-management (SM) has become an increasingly important paradigm in healthcare delivery and the promotion of LTC SM is now an enduring feature of health care policy [3-6]. This meta-synthesis of qualitative papers seeks to explore the SM of LTC’s in the relatively new context of online communities.

The current economic and philosophical landscape of the National Health Service (NHS) necessitates the need for illness work to be delegated to those with a LTC and policy makers hope this will reduce health service utilisation [7] and improve health outcomes [2, 3, 5]. The need for SM is reinforced by the fact that those living with a LTC spend very little time engaged with healthcare professionals compared to the time spent on activities that are required to manage their condition in daily life [1, 8].

Recent research has gone someway to examining the social context of LTC SM and more specifically, the role of others in shaping and supporting SM practices [1, 7, 9, 10]. In particular, research conducted by Vassilev et al [9] demonstrates the importance of work in LTC SM, particularly in respect of one’s illness work force, those in one’s network, who provide assistance in the SM of their condition through illness, every day and emotional work (including a biographical dimension) [9, 11, 12] (Textbox 1) as well as further illness work signposted by Rogers et al [1] (Textbox 2). Weak social ties also contribute to illness work, by affording greater access and transmission of information between network members, the value of these ties lays in their quantity, rather than their intensity [8].

Textbox 1. Types of illness work

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| **Illness (specific) work**- work such as taking medication, taking and interpreting measurements, understanding condition and its symptoms, making appointments. **Everyday work-** tasks such as housekeeping, occupational labour, support and activities relating to diet and exercise, shopping and personal care **Emotional work-** work related to comforting when worried/anxious about everyday matters such as health, well-being and companionship (including a biographical dimension which relates to the reassessment of personal expectations, capabilities, future plans, personal identity, relationships and biographical events)Vassilev, I., et al., Social networks, the ‘work’ and Work Force of Chronic Illness Self-Management: A Survey Analysis of Personal Communities. PLOS ONE, 2013. **8**(4): p. 61-69 |

Textbox 2. Further types of illness work suggested Rogers et al [1]

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| **Contingency/improvisation-** the work involved in getting things back on track**Translation, mediation-** the work involved in translating abstract knowledge into practical knowledge that can then be implemented **Co-ordination-**the negotiations and renegotiations in the ways in which work is done such as what work is done, by whom, when, how and why**Advocacy work-** work done by others on one’s behalf Rogers, A., et al., Social networks, work and network-based resources for the management of long-term conditions: a framework and study protocol for developing self-care support. Implementation Science, 2011. **6** (56).  |

Online communities are particularly good at facilitating the creation of weak ties [13-16]. As a result, community membership may afford people a larger, more diverse social network than would otherwise be available, since ties mediated online are not restricted by temporal, spatial or geographical limitations that typically define offline social networks [16, 17]. Those with more diverse social networks are said to self-manage their LTC better compared to those with fewer social ties [10], however this has only been explored in the context of offline social networks and there is a clear need to better understand the role of online contacts in the SM of LTC’s.

An existing review by Ziebland and Wyke [18] conceptualises seven domains through which patient experiences online influence health. These domains were: finding information, feeling supported, maintaining relationships, affecting behaviour, experiencing health services, learning to tell the story and visualising the disease [18]. Whilst this review was useful in framing the landscape of peer to peer support online due to its focus on understanding the exchange of experiential information on health, it did not specifically focus on LTC SM. Moreover the changing landscape of online communities in relation to the proliferation in the ways in which people access them, makes them more relevant to our daily lives since ties mediated online are now more immediately available [19, 20].

In this context, its relevant to understand the extent to which social ties created in these online spaces contribute to LTC SM through the negotiation of illness work (illness work is described as the visible and invisible activities of LTC SM) [9]. In recent years the study of SM support (SMS) has introduced a focus on the mechanisms of networks that mediate SMS for LTCs and the influence this has on the mobilisation of resources [1, 7, 9, 21]. Whilst there has been increasing awareness of the significance of the internet as a forum for support and engagement for SMS [18], previous studies have not specifically focused on the mechanisms of such networks and how they may mediate LTC SMS. We know that offline, three mechanisms linking social networks and health related outcomes exist; sharing knowledge and experience within a community, access and mediation of resources and an awareness and ability to deal with network relationships [21]. From this, it is clear that in offline networks, those with a LTC need to be able to navigate their personal social networks and negotiate and re-negotiate existing relationships [21]. Whilst Vassilev et al’s [21] paper successfully demonstrates the negotiation of SM support in traditional offline social networks, these specific aspects have not been explored in terms of online communities. Thus this meta-synthesis aims to generate an elaborated understanding of the negotiation of SMS and illness work in patient online communities for those with a LTC. This is relevant for informing the design of online interventions.

## Methods

#### **Qualitative Meta-Synthesis**

A meta-synthesis draws on the subjective and interpretive nature of existing qualitative research to construct more complete and plausible understandings of reality than what is currently available from the existing literature. There are several approaches to qualitative synthesis, in this instance Paterson’s [22] process of meta-synthesis was used. Like secondary analysis, qualitative synthesis involves reinterpretations, but such analysis is not generated from primary data, but is instead the product of already existing published findings of other authors [23]. Such data exists in the form of first and second order constructs [22]. The first order constructs represent direct feedback from the study participants and the second order constructs represent the key findings of the researchers [22]. The third order constructs, relate to the interpretation of the findings of the papers based on the synthesised first and second order constructs [22]. Paterson et al [22] explains this process by stating that: “the authors of primary research reports have constructed the research findings in accordance with their own understanding and interpretation of the data” [22](p.6) subsequently, “the meta-synthesists have constructed an aggregated account based on their own interpretations of the primary researchers’ constructions. Consequently, the meta-synthesists deals with constructions of constructions” [22](p. 7). As such, the process moves beyond the findings of the original papers to generate more complete understandings of the phenomena being investigated, since it pulls together and makes use of concepts derived from multiple studies, using a wide variety of methods, contexts and interpretive frameworks [21, 22].

By including papers that used different methods, examined different types of online community and different conditions, this meta-synthesis is able to add to the existing evidence base, bringing research data from an initially narrow foci (i.e. a specific condition and online community) towards broader interpretations of LTC illness work in online settings.

#### Inclusion/exclusion criteria

To guide the systematic search of the literature the research team (CA, IV, AK, AR) agreed on the following, pre-determined inclusion and exclusion criteria, taking into account the aims of the meta-synthesis. These can be seen in (textbox 3) below.

Textbox 3.Pre-determined inclusion/exclusion criteria

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| **Inclusion criteria**  [1] Studies examining the use of online communities in those with a long term condition (including communities hosted on social media sites such as Facebook and Twitter). [2] Studies that focus on online communities from a naturalistic open setting. [3] Research between 2004 (the year the term ‘web 2.0’ became popularized)– current [4] Research that used qualitative methods. **Exclusion criteria** [1] Studies not written in English. [2] Research including interventions. [3] Research from the perspective of healthcare professionals/careers/relatives. [4] Research that only used quantitative methods. [5] Literature reviews and review papers, letters to the editor and editorials, commentaries and feature articles, dissertation theses, review papers, reports, conference papers and abstracts. [6] Studies only on traditional internet use and without an interactive social component, i.e. Web 1.0 and blogs [8] Studies with a commercial, advertising or marketing focus, where levels of bias could be seen as high. |

#### Search Strategy

A systematic approach was used to locate the relevant published research studies in the area of online communities and LTC’s. Since online communities in relation to health have been explored across a multitude of professional and theoretical concepts; health, social care, psychology and sociology databases were searched. The systematic search of the research literature used the following databases: AMED, CINAHL, COCHRANE DATABASE, DELPHIS, EMBASE, INTERNATIONAL BIBLIOGRAPHY OF SOCIAL SCIENCES, MEDLINE, PSYCINFO, SCOPUS, SOCIOLOGICAL ABSTRACTS, and WEB OF SCIENCE. The searches were conducted using a pre-determined search strategy, using the search terms in (Textbox 4).

Textbox 4. Pre-determined search terms

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|  *“Social media” OR “Social network\* site\*” OR “web 2.0” OR “Health 2.0” OR “discussion board\*” OR “discussion forum\*” OR “forum\*” OR “online support group\*” OR “electronic support group\*” OR “online communit\*” OR “patient online communit\*” OR “facebook” OR “twitter” OR “tweet\*” OR “myspace” OR “patientslikeme” OR “patients like me” OR “second* life”AND *“Chronic” OR “Chronic disease\*” OR “Chronic Illness\*” OR “Long term condition\*” OR “Long-term condition\*” OR “Long term health condition\*” OR “LTC\*” OR “chronic pain\*” OR “pain\*” OR “fibromyalgia” OR “chronic obstructive pulmonary disease” OR “COPD” OR “diabet\*” OR “irritable bowel syndrome” OR “IBS” OR “heart disease” OR “HIV” OR “AIDS” OR “Stroke”*AND *“Self-management” OR “self management” OR “Self-care” OR “Self care”* |

The systematic review of the available literature occurred in August 2015. The search strategy using the aforementioned databases located 1,944 research articles. Titles and abstracts were reviewed against the inclusion criteria (Textbox 3) and from this; hard copies of 79 papers were obtained. These were screened against the inclusion/ exclusion criteria (Textbox 3) (by CA, AK and IV), resulting in a total of 14 papers. A further 10 papers were found through submersion in the research literature and through the reference lists of e-health papers read by the research team. From this a further 7 papers met the criteria for inclusion. All selected papers were discussed by the team in view of the objectives of better understanding the contribution of online social networks in LTC SM.

This process can be seen in (Figure 1) and a summary of the included papers can be seen in (Table 1).

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| Figure 1. Flowchart of systematic search strategy, process and selection of research papers for review.  |

Table 1. Papers included in the meta-synthesis and quality appraisal of the included papers using the CASP tool

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| --- | --- | --- | --- | --- | --- | --- |
| **Study**  | **Condition**  | **Platform** | **Method**  | **Sample**  | **Study details** | **CASP tool score** |
| Attard and Coulson (2012) | Parkinson’s disease  | Disease specific discussion board/forum  | Qualitative thematic analysis of messages posted to a discussion board  | 1013 messages posted to the board between 2003-2010 | To explore the experiences of members of a Parkinson’s disease forum  | 9/10 |
| Barker (2008) | Fibromyalgia  | Disease specific discussion board/forum | Thematic analysis  | 249 participants in Fibrospot  | Examines the conflicts between lay and expert knowledge in electronic support groups  | 9/10 |
| Brown and Altice (2014) | Opioid dependence  | Disease specific discussion board/forum  | Grounded theory approach  | 121 threads from 13 discussion boards between a 26 month period  | To identify facilitators of self-treatment by online buprenorphine/naloxone users  | 9/10 |
| Coulson (2014) | Alcohol Use Disorder (AUD)  | Disease specific discussion board/forum | Inductive thematic analysis- netnography  | 738 messages on 3 UK based discussion boards | To explore in depth how members of online alcohol use disorder communities engage with peer to peer support  | 9/10 |
| Coursaris and Liu (2009) | HIV/AIDS | Disease specific discussion board/forum  | Content and thematic analysis  | 5000 postings- not disclosed how many participants contributed to this | To provide an in depth understanding of social support exchanges in online HIV/AIDS self- help groups.  | 8/10 |
| Greene et al (2011)  | Diabetes  | Facebook  | Content analysis | 233 wall posts and 457 discussion topics  | Examine the content of communication in Facebook communities dedicated to Diabetes  | 8/10 |
| Hadert and Rodham (2008) | Arthritis  | Disease specific discussion board/forum  | Interpretive phenomenological approach  | 60 users- who posted 87 initial messages+314 users who posted 981 replies  | To discover how and why the online arthritis message board was used  | 9/10 |
| Kazmer et al (2014).  | ALS | Patients like me (a specific online community that connects people with the same condition)  | Inductive thematic analysis | 1,000 randomly selected messages from an available 2,500 messages posted between feb 2006-nov 2008 | How and why is knowledge shared among the distributed participants in the PLM-ALS threaded discussion forum?  | 9/10 |
| Kirk and Milnes (2015)  | Cystic Fibrosis  | Disease specific discussion board/forum  | Online ethnographical approach  | 279 individuals who participated in forum over a 4 month period  | To explore how online peer support is used by young people and parents to support self-care in relation to cystic fibrosis | 9/10 |
| Loanne and D’Alessandro (2013) | Motor Neurone Disease/ALS  | Disease specific discussion board/forum  | Content analysis  | 499 posts made by 133 participants  | Explores whether social capital can exist in an online health community for people affected by MND/ALS.  | 8/10 |
| Matura et al (2012)  | Pulmonary Hypertension  | Disease specific discussion board/forum  | Qualitative descriptive methodology  | Convenience sample- all posts in 2010 | To determine how patients with pulmonary hypertension use online discussion boards  | 9/10 |
| Mazzoni and Cicognani (2013) | Systematic Lupus Erythematosus  | Disease specific discussion board/forum  | Content analysis  | 118 posts corresponding to 118 authors | To explain the demand/supply of social support through the internet in relation to the description of personal illness experience | 9/10 |
| Merolli et al (2014) | Chronic Pain  | Did not specify- Patients recruited through Facebook, Twitter, Daily Strength and Patients Like Me | Thematic Content Analysis- online survey  | 218 people with chronic pain who completed an online survey  | To examine what social media therapeutically affords people with chronic pain who are self-managing their condition.  | 9/10 |
| Mo and Coulson (2014)  | HIV/AIDS | Disease specific discussion board/forum | Thematic analysis of completed online surveys  | 115 participants who completed an online survey  | To explore the potential empowering and disempowering outcomes of online support group use by those with HIV/AIDS | 9/10 |
| Rodham et al (2009) | Complex regional pain syndrome  | Disease specific discussion board/forum.  | Interpretive phenomenological analysis  | 60 participants who posted or commented on a post on a discussion forum in a 4 month period | To explore how an online message board designed for patients and carers of patients with CRPS was used. Specifically, the paper sought to explore the exchanges that took place on the online message board.  | 10/10 |
| Van Berkel et al (2015) | ALS, Diabetes, ADHD | Disease specific discussion board/forum  | Deductive thematic analysis  | 5532 posts from 7 message boards  | To examine whether empowerment processes occur on message boards discussing medicines used to treat three chronic conditions as well as examining the quality of information that is shared.  | 9/10 |
| Van Uden-Kraan et al (2008a)  | Fibromyalgia, Arthritis, Breast Cancer  | Disease specific discussion board/ forum  | Content analysis of postings to a discussion board/forum  | Random sample of 500 postings to discussion board/forum for Fibromyalgia, Arthritis, Breast Cancer.  | To explore who uses online support groups? What topics are discussed and what self-help mechanisms are used in these groups?  | 8/10 |
| Van Uden-Kraan et al (2008b) | Fibromyalgia, Breast Cancer, Arthritis  | Disease specific discussion board/forum  | Semi structured interviews, inductive analysis  | 32 participants  | To explore if, and in which ways patients feel empowered by participation in patient online communities | 9/10 |
| Wentzer and Bygholm (2013) | COPD and fertility problems  | Disease specific discussion board/forum | Qualitative analysis using critical interpretation and narrative analysis  | 4301 posts to two forums  | Is communication in online patient support groups a source of individual and/or collective empowerment?  | 8/10 |
| Willis (2014) | Arthritis  | Disease specific discussion board/forum  | Ethnomethodology  | 20 members across 4 communities  | To understand how patient with arthritis use patient online communities to exchange illness related information to better manage their long term condition.  | 9/10 |
| Zhang et al (2013) | Diabetes | Facebook  | Case study  | Case study of a Facebook group with 30,000 users | Explores Facebook as a platform for health information and communication, specifically what the characteristics of the Facebook diabetes group and its members.  | 8/10 |

#### Quality appraisal

The included papers were critically appraised according to the CASP (Critical Appraisal Skills Programme) checklist for qualitative research (by CA)[24]. The checklist allows qualitative research evidence to be appraised systematically, guiding the reviewer as to the results, their validity and their transferability [24]. The results can be seen in (Table 1) and demonstrate that the included papers represented high quality research and were therefore all included in the analysis.

The findings of this synthesis are limited by the methodology of many of the included papers [17, 25-41] which used either ‘netnography’ (a specific form of ethnography adapted to computer mediated communities) [42] or other approaches that did not directly engage participants or consent them into the study. Whilst the approach of using the comments of others in public online communities without their specific consent is seen as ethical in the current British Psychological Society (BPS) (a representative body for psychology and psychologists in the UK) guidelines [43], it meant that it was not possible to observe more intimate encounters (such as direct messaging, email, texting, telephone conversations or even meeting offline) that may have emerged over time. Although this meant the behaviour of participants was not affected by the presence of a researcher in the community, it meant that only what members elected to post could be used as research data.

Only three papers [44-46] specifically engaged network members. It is possible that because these papers directly engaged those using these communities, that they permitted a greater discussion of how people experienced them. Thus, they were perhaps more likely to discuss the negative as well as the positive aspects of community membership. It may have been that in the other papers, those with bad experiences were less likely to post negative experiences such as flaming (a hostile online interaction), caused by toxic disinhibition; which led to people being rude or angry towards others in ways that they would not do offline [47, 48]. This kind of behaviour had the potential to make people feel personally attacked if they expressed opinions that were different to other members [46]. Additionally, these papers were perhaps more likely to demonstrate concerns about misinformation (such as people sharing inaccurate or harmful information) and people presenting themselves as experts [44, 45]. Therefore, to some extent the positive feel of the other papers may be a result of their methodology (there is however no shortage of papers that identify the potential harms [49-57] and ethical issues [57, 58] surrounding online communities).

## Results

The LTC’s examined in relation to online communities were diverse and clearly projected different illness experiences. They included heavily stigmatised conditions such as; alcohol and substance use disorders [17, 25] and HIV/AIDS [26, 46], medically contested conditions such as Fibromyalgia [27, 28, 44, 45] and extremely physically disabling conditions, such as Parkinson’s disease [29], arthritis [28, 30, 45], COPD [31], cystic fibrosis [32] and motor neurones disease [33, 34].

### Patient online communities’ involvement in LTC SM: second order synthesis of concepts

To synthesise the data, the papers identified were read and logged into extraction forms (by CA). The extraction form used was adapted from a previous meta-synthesis. These were used to ensure the multiple concepts in the included papers were translated into one another. The extraction form included: demographics, condition, group type, principle research question/aims, methodology/data collection strategy, principle findings, subthemes, theoretical concepts, conclusions and study limitations. Within these extraction forms we also included all the verbatim quotes from the participants (first order constructs); this allowed us to see that the quotes from the participants fitted logically into the second order constructs (the original author’s interpretations) of the original papers.

Since the second order constructs are interpretive, the concepts across the papers are presented in different ways. To synthesise the findings and concepts of the different papers into one another (second order synthesis), we experimented with different visualisations of the second order constructs used in the existing papers and examined the different arrangements of the key concepts from these studies. This involved a number of iterations before the final conceptualisation of second order constructs were agreed (by CA, IV, AK, AR). Following the synthesis of the second order constructs, six second order constructs were identified that illuminated how the social connections forged online, contribute to LTC SM. From this, the synthesised second order constructs (taken from translating the key themes in the included papers) were brought together and then reconfigured as a line of argument, towards better understanding the negotiation of illness work in patient online communities.

#### Redressing offline experiential information and knowledge deficits

Members were frequently drawn to online groups through an unmet offline need for condition specific information that is: easy to understand [45], can be customised to their specific needs [25, 35, 40, 45], is based on patient experience [33, 41, 46] and is freely available at their convenience [46]. The need for accessible, accurate and up to date information was often directed by inadequate access to information offline, whereby community members felt let down by information providers in their offline worlds [30, 46]. This was often fuelled by time restraints and power relationships experienced in offline consultations which appeared to inhibit information seeking [30]. Membership of an online community appeared to be a useful way of mitigating this, by affording members with greater access to information [28, 30, 35, 46]. Network members were able to use these online communities to filter and navigate condition specific information created by peers, in accessible language, at their convenience. This allowed the redressing of information asymmetry by affording individuals information their health care professional (HCP) did not feel they needed, withheld from them or provided in a format they did not understand [46].

The information available in the groups frequently pertained to lived illness experience [27, 33, 35]. Members favoured this information over the presumed expert knowledge of HCPs, whereby validity was bestowed on embodied illness experience [27, 33, 35]. Indeed, posts would insinuate that ‘expert patients’ had a higher degree of condition specific knowledge than HCPs [33]. These ‘expert patients’ were able to, through community action and shared knowledge, assist one another to locate information elsewhere [26, 33] (both online and offline). Whilst some had concerns about the validity of the information posted [45], the information was frequently validated using a process of community vetting [35, 41] with members intervening when bad information was posted [45]. This suggests that membership in these communities facilitates improved health literacy and resource navigation by pooling the collective knowledge and lay expertise of its members who have a vested interest in better understanding their condition [26, 35].

#### The influence of modelling and learning behaviours from others on SM

The included papers all demonstrated online communities’ ability to enable members to reach out to peers for practical, illness specific advice. The peers that they connected with were able to develop expertise about daily treatment practices through trial and error, giving them valuable knowledge and information about the daily practicalities of self-managing a LTC that extended beyond the empirical evidence available to HCPs [33, 35, 40]. This afforded members an enhanced understanding of how to integrate multifaceted treatment regimes to balance the complexities of SM in daily life [32, 33, 35, 40]. Users learnt from the SM approaches of others by observing their SM strategies, discovering new more efficient strategies and subsequently testing out these new strategies with their peers [40]. From this, they were able to select an approach that best met their needs [40].

The sharing of experiential information in online communities is an important feature in shaping the experience of those living with a LTC because the information shared in these communities frequently favoured patient centred goals as supposed to HCP centred metrics [30, 32, 35]. This information was easier for members to configure to their specific needs and was less rigid than the information and SM strategies provided offline [25, 30, 32, 35, 40].

#### Engagement which validates illness and negates offline frustrations

Having access to the online community made members feel less alone and provided a reference for what was a normal illness experience [17, 27, 29, 30, 32, 45, 46]. Members, who often lacked solidarity offline, were able to build a collection of symptoms into a shared identity [27, 29, 32, 36, 37]. Offline, members found it difficult to get a real understanding from friends and family and were able to use these online spaces to express these frustrations with a network of people who seemingly understood the challenging nature of self-managing their illness [27, 30, 37, 38, 45, 46]. This was particularly the case in communities for conditions that lacked visible external cues or where the somatic nature of the illness was contested [27, 30, 44]. This disparagement strengthened group solidarity and allowed users to feel validated and believed through engaging and identifying with other network members [27, 30].

Meeting people who understood the challenging nature of SM, allowed members the opportunity to be positively appraised for accomplishments that their offline contacts might not recognise as achievements [35, 38]. Members were commended for the achievement of smaller self-directed goals as opposed to ones set by HCPs [35, 38]. This worked to motivate group members to believe in treatment recommendations, shared beliefs and practices, thus encouraging treatment compliance [29, 31].

The sharing of condition narratives, enabled members the opportunity to re-evaluate their situation through lateral and downwards social comparison. Being able to see how others cope with their condition reassured members that they could manage their condition through education, adjustment, adaptation and acceptance [17, 30, 36, 40, 44, 45].

#### Tie formation and community building

Communities often demonstrated a clear sense of comradery, with the communities inferring strong community structures, cultural norms and group orthodoxies [29, 32, 34, 35, 41, 45]. Many of these communities appeared to promote a positive, inclusive culture, bringing people of diverse backgrounds together to meet a shared purpose [29, 34, 41, 46]. This sense of belonging, coupled with a shared lived experience of the condition and frustrations with offline support, facilitated the creation of friendships [29]. This creation of community led to members integrating the community into their everyday lives [34, 45]. Members used endearing terms such as ‘family’ and ‘friends’ and would frequently engage in non-condition related conversations, suggesting that the communities had facilitated strong bonds between members [26, 29, 45, 46], with relationships evolving into offline spaces [45, 46] where tangible benefits such as offers of accommodation could be realised [46].

In several instances users connected with these communities to mitigate loneliness and isolation in their offline worlds [34, 44, 45], which appeared to be particularly important in instances where the disabling nature of the condition had led to an erosion of offline support and a reduced ability to form social ties in offline settings [34, 44, 45]. Often, network members faced clear social disadvantage in their offline worlds, but online belonged to lively, vivacious communities with resources of information and support being offered freely as a public good to community members [34].

#### Narrative expression and cathartic release

These communities provided a safe environment for the sharing of condition narratives. The process of narrative sharing offered immediate psychological relief since members often felt unable to express negative emotions offline due to the perceived need to maintain a positive social front [30, 38]. Some members found sharing experiences easier online, preferring to talk to strangers online about their illness experience than with their offline contacts [44-46]. These online spaces provided them with a community of people ready to listen to their concerns and provide them emotional support and refuge [44-46]. Because these communities made members feel more able to openly express the need for support, they were possibly more likely to receive it and it is therefore perhaps unsurprising that some users felt more supported online [30].

#### Dissociative anonymity and invisibility

Acquiring certain types of sensitive information, that may be important in developing a holistic SM strategy such as information pertaining to sex and incontinence, appears to be easier to navigate in these online communities due to the presence of benign disinhibition and dissociative anonymity [47]. This appears to have an empowering effect, by allowing members to ask questions that they would otherwise be too embarrassed to seek in their physical worlds [29, 46].

### Understanding the significance of negotiating SMS and ‘illness work’ in online communities- third order synthesis

Following a process of synthesis the second order constructs described above were reconfigured towards understanding what is significant about the negotiation of SMS and ‘illness work’ in online communities for those living with a LTC. This translated into a line of argument synthesis in which four network mechanisms for SMS in online communities were identified. A summary of the 2nd and 3rd order constructs is shown in (Figure 2). In exploring the significance of online support networks compared to traditional offline ones, we drew on previous research examining the social context of LTC SM and the network mechanisms involved in negotiating illness work [1, 7, 9, 21]. This allowed us to examine whether similar mechanisms of SMS exist and are mobilised online.

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| Figure 2. Summary of 2nd (blue) and 3rd order (grey) constructs in relation to the negotiation of SMS in patient online communities.  |

#### Collective knowledge and identification through lived experience

Given that “the internet has changed people’s relationship with information” [59](p. 1) it is perhaps unsurprising that the ability of these communities to provide information featured highly in the included papers. Information and actionable advice based on lived experience contained highly specialized forms of experiential information that was unobtainable offline. These communities facilitated patient empowerment by affording members the right to explore the SM of their condition in the context of their daily lives. This patient empowerment perspective facilitated by membership in these groups, promoted a fundamentally different set of roles for HCPs and patients, whereby the collective knowledge created through lived experience is seen as more useful in the SM of a LTC in daily life than medical knowledge. In line with previous research, these communities appear to foster empowerment and the potential to change the relationship between healthcare professional and patient, from one of compliance to one of shared ownership [60, 61].

In addition to the availability of co-created experiential knowledge, the presence of distributed health literacy enabled community members to find the information they required. Online social ties can act as health literacy mediators [62] in a process of distributed health literacy between network members, allowing people to benefit from the health literacy of others in their network; who may give them greater access to the information needed to manage their condition.

In offline consultations, a mediator such as close friend or family member is often present to help the person comprehend what is being discussed [7] and individuals can capitalise on the resources and links made with members of their social networks offline [62]. People’s knowledge about their condition is often shaped by others with the same condition in their personal networks [7, 21]. However, this resource may not be available to everyone, for example in rare conditions, or in situations where open discussion is difficult. People appear to be able to substitute offline information deficits with online contacts, whereby community members benefit from the health literacy skills of their peers. Examples included network members assisting in resource navigation [26] and explaining medical terminology [30, 41, 46].

Additionally distributed knowledge and information in these communities constituted a by-product of the continued engagement of network members [36, 37]. Communities generated value through members “co-creating their own service encounter” [37](p.167). Members were able to select the features that they required and request, receive or search for information at their convenience [37]. Unlike offline encounters, a permanent record is made, which allows members to benefit from cumulative experiential information generated over time [33, 34]. Though for some, the sheer volume of information available, made it difficult to find the specific information they needed [45], which further signposts the need for community members to assist in the navigation of resources in these communities. Essentially, the strength of these communities drives the availability of the information. Many communities have a defined core group of members [63, 64] whose informational and experiential knowledge can be disseminated to other members who may be less well informed. As Lester et al [65] hypothesizes, whilst not everyone in the group knows as much as this expert core, they do know how to access expert members, who in turn know how to access information.

Whilst the provision of information should be considered an important component of any LTC SM package [66], information on its own has been found to have very little or no effect on SM [67] and it is these communities ability to tie information to real life parables that is most fascinating. Each individual’s needs are highly specific, therefore SMS must be tailorable. Members of these communities felt restricted by a lack of flexibility, choice and control in SM strategiesdictated by HCPs, but could use these communities to observe the practice of others, adapting their SM strategy to meet a specific problem or a change in their condition [35, 44], through navigating the available information and deciding the approach which best met their needs [40]. This is perhaps why the co-constructed authoritative knowledge of community members built around the lived experience of self-managing a LTC in daily life was so valuable. Patient online communities appear to deliver a highly individual experience through the co-creation of community content. For example, it is perhaps unlikely that the traditional patient education perspective model of information would be able to disseminate highly experiential information such as how someone with diabetes can count carbohydrates to enable drinking sessions without risking ketoacidosis [35], but such facets of information are clearly useful to someone with diabetes wanting to SM their condition.

In addition to information and health literacy mediation, these communities facilitate the negotiation of illness emotional work and its biographical dimension, whereby emotional work relates to the provision of comfort when someone is upset, anxious or worried about everyday issues such as their health, wellbeing and companionship [1]. Biographical dimensions of emotional work are associated with the revision of expectations, capabilities, plans, identity, relationships and biographical events [1] and these online communities have a role in the realisation of these components, particularly in allowing members the opportunity to reframe their lives [17, 30, 36, 40, 44, 45].

By engaging in online communities, individuals were able to gain emotional support that they had been unable to access in their offline worlds and by connecting with those with a shared embodied experience were able to feel normal [17, 27, 29, 30, 44-46]. Through collective identification these groups facilitate engagement, allow individuals to make sense of their situation and allow them to receive positive appraisal for successful SM practices [35, 38]. Furthermore, through lateral and downwards social comparison these online communities allowed members the opportunity to compare their illness narratives with one another, enabling them to reassess their expectations, capabilities and plans, whilst empowering them to realise that successful SM is achievable [17, 30, 31, 36, 40, 44, 45]. Thus through collective identification and engagement these online communities provided the opportunity for validation, reassessment, and appraisal. But for some, this was upsetting as it made many negative aspects of the disease visible, some of which they may not have considered [45].

#### Support, information and engagement through readily available gifting relationships

In addition to navigating network contacts, those with a LTC need to negotiate and renegotiate existing relationships, roles and engagement with network members. Negotiating help offline is frequently accompanied by obligations and expectations and may be restricted by time [21]. Such obligations and expectations were not visible in the online communities explored here. Requests for help (resource mobilisation) were rarely targeted at a specific network member; often requests for assistance were to the group as a whole, leading to many replying. This information is frequently gifted, with no reciprocal expectation, making help less tangible but potentially easier to obtain online than off.

In much the same way as gifting relationships stock UK blood banks [68] members of these networks gift these communities with information and support freely [28, 30, 34, 41, 44, 46]. Much like donating blood, the decision to volunteer information cannot “of course, be characterised by complete, disinterested, spontaneous altruism” [68](p. 89). Information and emotional labour is gifted to these communities by its members, who are potentially motivated to do this through a sense of obligation or through some awareness of need. Like donating blood, there may be “some expectation and assurance that a return gift may be needed and received at some future time” [68](p. 89). In this sense these online communities operate much like a gift economy with information and support being freely given, with little expectation of reciprocation, but fuelled by the desire that someone else may find the information useful and the pride of building a community [34, 35, 37, 44, 46].

The process of sharing information appeared to have a useful dual purpose, providing information for those in need, but also affording others with their altruistic need to impart the knowledge that they had accumulated [34, 35, 37, 44, 46]. Being able to offer information that others may find helpful appeared to foster feelings of validation and self-worth, feelings that are often suppressed by illness [44]. The voluntary provision of information was part of these groups culture and occurred more frequently than in response to direct questioning. Whilst offline peer mentors have benefited from providing support through finding meaning and social reinforcement of their own SM behaviours, gift exchange in these online communities is different to that in offline support groups. Offline, the process of sharing has been found to improve the internal capacity of individuals to cope with stress and can be a motivating factor in LTC SM through mediating lifestyle changes and affording new SM tools [21]. However, offline these gift exchanges may fail because the recipients of the intended gift may not turn up. Because of the asynchronous nature of the internet, members can post information and support which others may benefit from at a later time. Furthermore, these gifts have the potential to benefit anyone who accesses the group, whereas this kind of gift offered offline can only benefit those physically present, since no lasting record is made of the encounter. Because of the giving nature of such communities, there is a wealth of information and support that requires little or no negotiation.

#### Sociability that extends beyond illness

In these communities, conversations frequently extended beyond illness into everyday matters and interests [30, 45, 46] which seemed to provide ‘social hooks’ for continued community involvement. Whilst people appear to migrate into these online communities due to offline information and emotional deficits, it is perhaps these hooks that result in continued engagement. Members spent time relaxing in these online communities [45] and enjoyed being able to socialise [44] which appeared to be particularly appreciated in circumstances where the presence of illness had led to the erosion of offline contacts [44, 45]. Members looked forward to their online interactions with one another and enjoyed telling others about their day: “I have just got in from a lovely evening and couldn’t wait to get on and see if there was any mail for me….I thought I would share with you the events of the evening” [30] (p.189). For many, engagement with these online communities had become part of their daily routine: “You should really see it as a book. You’re in the middle of a story. And when you put the book down at night, you really want to continue reading the next morning.” [45] (p.409). These communities accompanied members throughout their day [45] and this may become increasingly important in the future as smart phones continue to integrate these technologies into our daily lives [69].

The presence of a LTC may place greater salience on support from family and close friends, reducing the opportunities to build and maintain contacts that extend beyond this. Socialising with people online and being able to build relationships with new people allows individuals to build new networks of influence that extend beyond intimate offline contacts. Consequently, those whose condition may have eroded the ease with which they can build and maintain weak social ties, appear to benefit from being able to substitute for this by building new networks of contacts in patient online communities. However, that this support often remained online was a source of frustration for some who wanted to extend their relationship into offline spaces but were restricted by geography [29]. Despite this, the ability to proactively extend networks that may have been eroded by the presence of a LTC is important since research suggests that those with a larger network of contacts consisting of both friends and family typically see the most favourable outcomes [70].

The ‘internet paradox’ paper contains an argument that the internet, as a social technology may reduce socialisation and psychological well-being [71]. Such concerns were voiced in Mo and Coulson’s [46] paper: “…I noticed that my real-life relationships were declining due to the time I invested in the on-line community” [46] (p. 990). However, being able to access these communities enabled those whose social ties had been eroded through illness [38, 44] to build new opportunities for sociability: “through fibromyalgia you lose a lot of personal contact. Because you can’t go to birthday celebrations anymore, because you forget things, you’re often too tired and so on. And in this way you can rebuild your social contacts” [45] (p.412). These communities may allow members to reach out to peers when offline socialisation is not possible. Thus being able to access peers online has the potential to mediate feelings of isolation and loneliness. Later research by Kraut et al [72] into the internet paradox found that whilst those using the internet generally experienced positive effects on social involvement, communication and emotional well-being, the extent to which these benefits were realised was associated with offline support, whereby extraverts with good pre-existing offline social networks fared better than introverts with reduced offline support. Additionally research by Kuss and Griffiths [73] found that extroverts use social media for social enhancement, whereas introverts use them as a means of social compensation [73]. Whilst these findings weren’t in the context of patient online communities it does suggest that introverts managing a LTC in these online communities may be distanced from offline social networks able to provide more tangible support in spite of being able to use the internet to access a more diverse network.

#### Online disinhibition as a facilitator in the negotiation of SMS

Being able to act anonymously online highlights the presence of managing moral identity work operating in these communities. Those with a LTC may decide that the need to be both independent and autonomous is so important that they choose not to activate offline support despite it being available [21]. As such these online communities may protect offline relationships and allow those living with a LTC to negotiate illness work whilst remaining both independent and autonomous.

Suler’s [47, 48] theory of an online disinhibition effect suggests that people behave differently on the internet due to the presence of dissociative anonymity, invisibility, asynchronocity, solipsistic introjection, dissociative imagination and minimization of status and authority (Textbox 5)

Textbox 5. The Online Disinhibition Effect

|  |
| --- |
| **Dissociative Anonymity:** People may feel that their online actions cannot be attributed to their person. In a process of dissociation, people may feel they do not own their online behaviours. **Invisibility:** Online, people know that others do not know what they look like. This may make people feel more able to do things on the internet that they would not do offline. **Asynchronicity:** Online interactions often do not occur in real time. Not having to cope with someone’s immediate reaction to something that has been said or done may disinhibit people. **Solipsistic Introjection:** The absence of face-to-face cues may alter normal self-boundaries. Because people cannot see what others look or sound like online, they may introject others into their own psyche. **Dissociative Imagination:** People may feel the online world is not real and that the people they interact with online are not real people. **Minimization of Status and Authority:** Online, there is often an absence of authority figures, this means people may feel they can act more freely. Suler, J. The Online Disinhibition Effect. Cyber Psychology and Behaviour, 2004. 7(3): p. 321-326.  |

Dissociative anonymity, invisibility and the minimization of status and authority appear to have a positive impact on the negotiation of SMS online in the included papers. The presence of ‘benign’ disinhibition appears to facilitate the negotiation of SMS in patient online communities since people may be reluctant to seek certain types of support in their offline worlds due to societal and self-stigmatisations. Whilst the online disinhibition effect may explain some of the harmful behaviours driven by toxic disinhibition that is visible in some of these communities [46], the disinhibiting nature of online communication appears to be mostly positive in allowing people to reach out to others for SMS.

People are able to move around the internet anonymously [47, 48]. Whilst in some of these groups people reveal their identity, many used pseudonyms. As Suler [47, 48] highlights, the internet gives people the opportunity to separate their offline persona from their online actions. As such, through a process of dissociation, “The online self becomes a compartmentalized self” [47](p. 322), which in the context of patient online communities appears to allow people to reach out to peers for information and emotional support without endangering their offline self. Suler [47, 48] suggests that this can facilitate rapid, or falsely intimate relationships, which might explain why such strong bonds appear to form in these online communities. Talking about stigmatised conditions is challenging offline. These online communities enable people to talk about their illness whilst remaining anonymous: “…at the time I wasn’t capable nor [ready] to approach an [aids service organization] nor disclose my status. I had so many guilty questions that I needed to talk to someone who would not know anything about my life nor recognise me” [46] (p.987).

Even when everyone’s identity is known, people can feel invisible online [47, 48]. This is protective and facilitates the negotiation of SMS. Since online communication lacks non-verbal cues, people don’t have to worry about how they look or sound [47]. They can write, examine and edit posts before sending, allowing complete control over disclosures and expressions. This editorial control is lacking in offline communications. This disclosure scrutiny and editorial freedom can lead to people feeling more comfortable discussing even everyday matters online [74]. Community members felt empowered to disclose due to this increased control: “this is an excellent medium for me to be able to control my interactions” [44] (unpaginated). But because of the lasting record associated with computer mediated communication, some were sceptical in spite of this increased control: “I do not want to disclose my personal and painful journey via a social network site for it to be highlighted by others and ‘used’ as a way to finish me in my job” [44](unpaginated)

Additionally, since online communication lacks non-verbal cues people don’t have to worry about the non-verbal responses such as frowns, shaking of heads or other non-verbal signs of disapproval [47, 48], which may inhibit offline disclosures. Offline, when people discuss emotional matters, they often avoid eye contact, thus these online communities offer “a built in opportunity to keep one’s eyes averted” [47] (p. 322), thus avoiding awkward moments where “the rheumatologist sneers a bit” [45] (p.410).

The presence of benign disinhibition generates group resources as it facilitates conversations about stigmatised or taboo subjects which others may find useful and validating. It also provides a safe and effective environment for the negotiation of support, allowing people to freely discuss personal and/or embarrassing health narratives, which may be particularly important to those whose condition is heavily stigmatised as well as potentially enabling those with less stigmatised conditions to ask questions about more sensitive aspects of living with a LTC [17, 47]. For some, these online communities represent the only place where information and support for SM can be negotiated: “only they know that I have HIV and my doctor, nobody else. They are my virtual family” [46] (p.988).

## Conclusion

This research strengthens our socialized understanding of LTC SM by taking into account the illness work of social ties mediated online and the role such ties may have in the management of a LTC in daily life. Effective SMS utilises resources and networks that are available in the everyday lives of those with a LTC, which operate outside of formal healthcare and this meta-synthesis has shown that these are available online and important to people. Those with a LTC appeared to reach out to these online communities due to an unmet offline need for information and/or emotional support. This substitutability of illness work has been seen before in offline social networks [7] and in this instance it clearly signposts the importance of these online communities in negotiating illness work particularly where access to support offline is absent or limited.

It is clear that these communities afforded many benefits that have the potential to positively shape someone’s experience of living with a LTC. In this regard, to some extent, the findings of this meta-synthesis necessarily overlap with the work of Ziebland and Wyke [18]. Certainly the facility of these online communities to help people: find information, feel supported, maintain relationships, experience health services, learn to relate, visualise their disease and affect behaviour [18] were all visible in the included papers and may all help to positively shape SM. The distinction between this paper and that of Ziebland and Wyke [18] is the specific focus on online social networks contribution to LTC SM illness work and the affordances of community membership rather than the impact of online patients’ accounts of experiences with health and healthcare.

This meta-synthesis has demonstrated that there are several benefits to members of patient online communities over and above those available to people simply searching for the experiential accounts of others. Membership of these online communities affords those living with a LTC ready access to a SMS illness workforce, particularly in relation to illness and emotional work. However, in contrast to offline social ties, these online communities provide social ties that require significantly less maintenance, less reciprocation and are easier to negotiate, potentially due to the presence of benign disinhibition and the gifting economic relationships of these online spaces whereby information and support is donated freely, as a public good, with no immediate expectation of reciprocation. Unsurprisingly, everyday work appears largely absent in online SMS perhaps due to the need for physical presence to assist in household tasks, shopping or personal care. There is some suggestion in the research literature of relationships evolving into more intimate communication channels and offline spaces [45, 46] and it is therefore not unreasonable to suggest that ‘everyday work’ may emerge in these relationships over time.

Importantly, social ties forged in online spaces can perform SM work that can improve an individual’s illness experience and can reach areas that are particularly difficult to navigate offline. Because of this patient online communities appear to be a promising place for the negotiation of SMS for LTC’s that may supplement and support offline information and support and should be included in future papers exploring the social context of LTC SM.

### Study limitations and future research

The majority of the included papers examined patient online communities that existed on condition specific discussion forums and boards. In contrast, newer applications such as Facebook and Twitter are poorly represented in the existing research literature with no existing research examining LTC SMS in the context of Twitter. There is also a need for future research to conceptualise how best to support those wishing to utilise these resources in their SM strategy (such as computer literacy, resource navigation and training). Additionally, interventions that seek to better engage the lay natural helpers and super users present in these communities could allow us to understand and use this underutilised resource.

The process of group formation in these online worlds appears to be wholly underexplored in the current research literature. It is clear that social characteristics such as trust and reciprocity do exist in these online spaces, but far less is known about the process that facilitates them. Additionally, we know little about how the community is created, how issues of brokerage bring new faces into these communities, how people navigate the mass of communities online to pick one that is suitable to them, or what specific features of an online community they see as important (i.e. the presence of a moderator, charity run, professional recognition, site architecture). A case study specifically looking at the social processes within these groups could illuminate this and a longitudinal approach would allow us to see how the relationships in these communities evolve over time.

Since many of the papers involved in this review used methods that did not directly engage those using these communities, there is potentially a bias towards the sharing of positive experiences. There is a need for future research to directly engage with members of these communities to find out why people are reluctant to post and illuminate how these communities help people manage their condition in daily life. Such research would also allow us to further develop our understanding of illness work online, whilst also helping us better understand such work in the context of pre-existing offline support.

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### Conflicts of Interest

None declared.

### Abbreviations

SM: Self-management

SMS: Self-management support

LTC: Long-term condition(s)

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