IT’S NOT JUST ABOUT SUPPORT: SELF-DIRECTED LEARNING IN AN ONLINE SELF-HELP GROUP

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Emerging technologies have opened up the field of education and made it possible for human beings to connect with other people, create and exchange information and digital resources, and support and learn from others in an open networked environment. Numerous self-help groups have sprung up online, and suggestions have been made that talking and listening to a screen does improve mental health. It is further suggested that when undertaken in a positive, supportive discussion forum in which members are active participants, self-directed learning (SDL) will foster understanding, validation, and acceptance of mental health challenges. It is also claimed that this will enhance a sense of empowerment, autonomy, competence, relatedness, and a degree of recovery. But does it really? We critically analysed participants’ SDL in one such open online network, Out of the Storm, that has in excess of 3,500 members with Complex Post Traumatic Stress Disorder. Empirical research using the lenses of connectivism, actor network theory, social constructivism, and self-determination theory was carried out to find out more about the SDL experiences of participants.

Keywords: self-directed learning, online learning, open education, online self-help groups, social constructivism, connectivism, actor network theory, self-determination theory, lay expertise, Complex PTSD

The purpose of this research was to investigate the self-directed learning (SDL) experiences of members of an online self-help group for people with Complex Post Traumatic Stress Disorder (CPTSD). The data from this study will add to a growing body of knowledge about informal SDL in online groups and its nature, purpose, and outcomes. Our question was the following: How do participants in an online self-help group experience SDL?

In the case of this study, the precipitating issue relates to a psychological stress disorder. CPTSD is an emerging psychological construct that has rapidly been gaining attention in mental health circles and by those who suffer from it. However, it has not yet been recognized as an official diagnosis (Hyland et al., 2016). It is in the midst of ongoing debate by clinicians and researchers about the diagnosis that those who suffer from the disorder must look online for information and support from peers. Out of the Storm (OOTS) is an online self-help forum that started in August 2014 and has grown from two to over 3,500 members. This rapid growth led us to ask about SDL in this peer-to-peer learning environment.

Online self-help groups framed around a physical or mental health issue are becoming increasingly popular as an easily accessible and widely available option for people not only to find support in trying times but also to engage in SDL about a
In an online self-help group, individuals may seek help for a medical/psychological problem they are experiencing (Grover, 2015; Kazmer et al., 2014; Sosnowy, 2014). SDL was defined by Knowles (1975) as a process “in which individuals take the initiative with or without the help of others in diagnosing their learning needs” and then locate relevant resources to find the information and develop the skills they need (p. 18). However, as suggested by Bouchard (2011), SDL is not only seen by researchers as a process but also as related to a personal predisposition and as an environmentally determined phenomenon. The choice to engage in a SDL episode might be triggered by a personal important life event that calls for a personal investigation, or it could be caused by the opportunities that the environment has to offer such as the availability of technology to develop communities of interest around a certain topic. The wave of emerging open networked technologies has in fact facilitated a proliferation of informal and self-directed learning and are heralded as the solution to deal with an abundance of information while at the same time providing opportunities for community building and communication at a scale not seen before (Kop & Fournier, 2010).

**Literature Review**

Online self-help networks and communities of interest have sprung up to support people in this quest for quality knowledge and information. In an educational context, online learning networks have materialized. These are sometimes organized and sometimes free flowing, depending on the needs and interests of the participants in the networks. This development has even contributed to the emergence of new theories of knowledge and learning such as actor network theory (ANT; Latour, 2005) and connectivism (Kop & Hill, 2008). As already suggested, SDL is one theoretical perspective to use as a lens in informal online networks. ANT and connectivism add additional dimensions related to SDL in a technology rich informal context. ANT fits with a social constructivist perspective of learning and knowing and posits that there is a symbiotic relationship between the materials humans use and the humans themselves when interacting on networks. Connectivism suggests that the openness of online networks, the diversity of participants, the willingness to share resources and information, and the autonomy of participants all contribute to SDL and knowledge creation. From a social constructivist perspective, SDL is enhanced by active engagement with others while engaging in a variety of experiences. Connectivism and ANT espouse that the two-way communication capacity of social media creates a symbiotic relationship between people and technology (Anderson & Dron, 2011; Kop & Fournier, 2010; Latour, 2005). It is within and because of this symbiosis that people are able to engage in the type of informal SDL that takes place in online self-help groups such as OOTS.

Social interactions are seen to be important in the process of SDL. Interacting and sharing experiences on OOTS seems to fit with these theoretical perspectives, but what might also influence people’s participation is motivation; thus, we suggest that self-determination theory (SDT) would also be an important theoretical perspective to use for our research in an online learning network such as OOTS. It is clearly related to SDL and especially focuses on human motivation. According to Ryan and Deci (2013), our abilities to grow and learn might be innate abilities, but our motivation to do so is, as
current perspectives of motivation in the SDT perspective suggest, heavily influenced by social-contextual factors that will help or hinder this inner process.

CPTSD is a psychological stress disorder that develops as a result of ongoing exposure to trauma and from which there is no real or perceived possibility of escape (e.g., childhood emotional/physical/sexual abuse; Cloitre et al., 2012; Courtois, n.d.). It is an accumulation of interpersonal trauma that distinguishes CPTSD from (simple) PTSD in which trauma is typically impersonal involving an event of limited duration (e.g., an accident or disaster; Courtois, 2014). The rapid growth of the OOTS network to support people with CPTSD suggests a need to connect with people with the disorder. Grover (2015) suggested that the ability to connect with peers online is especially important, perhaps even crucial, for those who are dealing with a disorder or illness that is not well known. She found that mothers of children who had had a pediatric stroke turned to the Internet and other parents because little or no information was available from physicians. Most felt their SDL was critical to their children’s health and in some cases their survival.

There has been some related research into SDL in online self-help groups. Van Uden-Kraan et al. (2008) studied participation in three different online self-help groups for people with breast cancer, fibromyalgia, and arthritis. They identified a range of empowering and disempowering processes and outcomes of which the key empowering process was the “exchange of knowledge and sharing of experience” (p. 406). Their findings regarding disempowering processes led us to believe that uncertainty about the quality of the information gleaned from others, any negative aspects of the knowledge learned, and the negative behaviour of some participants would be important issues to consider in our study on SDL of online self-help groups.

However, as Kazmer et al. (2014) found in their study of an online community for people with Amyotrophic Lateral Sclerosis, participants “socially construct their own authoritative knowledge” (p. 10) away from the knowledge and diagnoses provided by the medical profession. This is similar to one of the findings of Grover’s (2015) research that SDL involved a “peer-to-peer network where participants became co-creators of knowledge and a repository of resources” (p. 8), which was crucial to the treatment and ongoing management of their children’s health.

This is an interesting finding at a time that community building technologies are emerging and also theories of knowledge and learning are developing that highlight the importance of contextual factors in learning such as technology. The emergence of particular technologies has given a new interest in theories of knowledge and learning, ranging from social constructivism to connectivism (Anderson & Dron, 2011). The essence of these theories is the suggestion that the emerging social networks can help people in their need for critical analysis and validation of knowledge and information to support their SDL and the future development of networks. Morrison and Seaton (2014) suggested that “the conjoining of self-directed learning strategies within the context of an informal learning community, using online communication tools and affordances, is an exciting and relatively unexplored territory” (pp. 30-31). From an adult education perspective, what is exciting is that disparate people can come together easily in their SDL endeavours in a way that would not have been possible in the past when the emphasis on learning was on formal education.
The recent proliferation of peer-to-peer online connectivity means that learners do not necessarily need to engage in formal learning coordinated by institutions. Instead they can “rely on the aggregation of information and informal communication and collaboration available through social media to advance their learning” (Kop & Fournier, 2010, p. 2). As espoused by ANT, this attests to the power and possibilities of bringing humans and technology (“actants”) together in the creation of something new (Latour, 2005). In the case of online self-help groups such as OOTS, it is a dynamic and fluid context in which isolated/stigmatized sufferers can connect, validate, and engage in SDL about a topic.

However, some researchers have suggested that informal online SDL may in fact diminish competence. For example, Fischer (2009) contended that while the transition from Web 1.0 to 2.0 and social media created a fundamental shift from a consumer to an active engagement culture, participants might not always have the experience to be able to make the most of the possibilities offered by the technologies. In contrast, in a study of bloggers with Multiple Sclerosis (MS), Sosnowy (2014) found that living with the disease provided powerful “lay expertise” that is highly valued by those seeking to learn about a chronic illness such as MS. Similarly, Morrison and Seaton (2014) found that “lived experience is a cornerstone of expertise, a highly regard commodity” (p. 37).

The suggestions from the literature led us to this research project as we found it to be valuable to understand how people in one online self-help group, OOTS, would actually experience their SDL.

Method

Beyond the obvious desire for support, the ability to engage in informal peer-to-peer SDL to deal with confusion regarding CPTSD seems to be a major reason many are drawn to OOTS. We found it important to confirm this empirically by gathering data on what was involved in this learning. Thus, the overarching research question was the following: How do participants in an online self-help group experience SDL?

Design

To gather data a mixed methods paradigm was used that involved both qualitative and quantitative methods through an anonymous online questionnaire involving Likert and open-ended questions respectively. This was a pragmatic choice and seen to be the best fit with the research question and with the context of gathering data from participants with CPTSD. This meant that more direct data gathering methods, such as interviews or focus groups, might negatively affect their condition and be undesirable.

Sampling

A recruitment message was posted at OOTS asking for participants. Nineteen active members volunteered and were asked to complete an online questionnaire anonymously. Neither the real identities nor the forum names of participants were known to the researchers, and only nonidentifying demographic information was requested.

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questionnaire was based on our review of the literature and involved questions related to the participants’ experience of SDL at OOTS.

Analysis

For the quantitative data analysis, the online software’s capacity for analysis was used. The qualitative data were coded and analysed according to emerging themes in the data.

Ethical Considerations

The study adhered to the Canadian Tri-Council ethics principles for carrying out research on human participants. One of the researchers is the site founder and a regular participant at OOTS that raised the potential for ethical and confidentiality issues for both her and the participants. To lower any risk, each participant completed the questionnaire anonymously. This measure was intended to reduce or eliminate any possibility of biased behaviour (positive or negative) by the researcher in her role in which she has the administrative responsibility and capability to edit or remove posts and to warn or ban members. It was also decided to take the unusual step of not revealing her real identity so that she may avoid any OOTS members gaining access to her email or other personal information. Both the recruitment letter (forum post) and the informed consent form advised OOTS members of this and suggested that any questions or concerns might be directed to the other investigator. Thus, there was little to no risk to participants given that the questionnaire was completely anonymous, they were aware that they would not be told the researcher’s real identity, participation in the study was voluntary, and that they could withdraw at any time. All participants read and agreed with the informed consent form before completing the questionnaire.

Findings

The study offered the potential to question a global audience as was apparent from the data that included responses from 19 participants representing seven countries. There were nine respondents from America; four from the United Kingdom; one each from Australia, Canada, Holland, and New Zealand; and two who did not specify their country. As discussed in the following sections, the findings of this study confirm members joined not only for support but also to engage in SDL.

Connectivism and Actor Network Theory in SDL

Connecting online with others with the condition was important, and moreover necessary, given that not a single participant learned about CPTSD from a physician. This may be one reason why so many with CPTSD turn to the Internet for information; that is, the medical community’s knowledge about the disorder lags behind the mental health field and sufferers must look elsewhere for information. All but one participant had learned about CPTSD and OOTS via an Internet search \( (n = 15) \) or another online forum \( (n = 3) \). In keeping with connectivism and ANT, this suggests that the two-way

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communication facilitated by social media creates a symbiotic relationship between people and technology (Anderson & Dron, 2011; Latour, 2005). It seems that because of this symbiosis people are able to engage in the type of SDL that takes place in self-help groups such as OOTS. In effect, social media allow sufferers to connect, validate, and legitimize the disorder for themselves without having to wait for front line health care providers to become knowledgeable enough to diagnose and refer them to treatment.

This was an important aspect of SDL at OOTS. For example, members often post about being misdiagnosed because of a lack of knowledge about CPTSD or receiving inappropriate/ineffective or even harmful treatment by mental health professionals who know about PTSD but not CPTSD. One such treatment is Eye Movement Desensitization and Reprocessing (EMDR), which is a common and effective treatment for PSTD. However, when used to treat CPTSD, EMDR can trigger overwhelming emotional flashbacks by tapping into an accumulation of unresolved, interpersonal trauma. This contrasts with PTSD in which treatment involves visual flashbacks and short term, impersonal trauma (e.g., car accident). By identifying the differences in effectiveness for PTSD and CPTSD through lived experiences, OOTS members coconstruct knowledge and take action (e.g., consider alternate treatments) they might not otherwise be able to if not for this informal learning network. This also highlights a finding in a study by Kazmer et al. (2014) that the users of the community make decisions on the value of the knowledge and information to the particular community.

All respondents said they joined OOTS because it is accessible 24/7 (True, n = 1; Very True, n = 17), and free (True, n = 3; Very True, n = 11), which supports the notion that two-way networked communication creates opportunities for informal SDL. Learners do not necessarily need to engage in formal learning coordinated by institutions but can instead make use of the aggregation of information and informal communication and collaboration available through social media to advance their learning. In the case of online self-help groups such as OOTS, it is a dynamic and fluid context in which isolated/stigmatized sufferers can connect, validate, and engage in SDL about a topic. As discussed in the next section, a significant finding in this study is the value of lay expertise and social constructivism in SDL.

Lay Expertise and Social Constructivism in SDL

When asked to rate the statement “Learning from others at OOTS is important to me,” almost all respondents answered in the affirmative (True, n = 1; Very True, n = 17). Moreover, as depicted in Figure 1 over two-thirds of respondents rated the quality, relevance, and usefulness of their learning from other members as High, which reflects the value and credibility respondents accord what they learn from peers. This was confirmed by Sosnowy (2014) who suggested that “lay expertise” is highly valued by participants of self-help groups and similarly by Morrison and Seaton (2014) who found in their study of SDL in an online self-help group that it is of great importance to participants to be able to learn with and from peers. According to Merriam and Bierema (2014), “the social construction of knowledge [is] central to self-directed learning” (p. 37).
The findings in this study confirm that SDL is enhanced by shared experience, which was seen to be a valuable and valued resource. For example, one respondent stated the following:

I feel relieved meeting someone else with a similar situation - I can learn what is based on the CPTSD and what is just regular life, from others who understand why I can't tell the difference all the time. I don’t feel judged for my ignorance when working with and learning from peers.

Another participant wrote, “I try to relate with other people’s experiences rather than reading books. I prefer to address what I know is going on with me, and see what I do and do not have in common with other participants.”

Over two-thirds ($n = 17$) of respondents said they learned about CPTSD by posting back and forth with other members ($Moderate Amount, n = 5; A Lot, n = 9$), and by reading members’ posts ($Moderate Amount, n = 5; A Lot, n = 12$). Only a small number indicated they also learned via emailing privately with other members ($A Little, n = 3; Moderate, n = 1; A Lot, n = 0; Not At All, n = 14$), and none of the respondents reported learning by talking with other members via Skype or phone. These data suggest that while learning from/with peers is important, group learning is more desirable than one-on-one. One reason for this may relate to the fact that members receive individualized feedback from numerous members when posting in a forum of thousands of members as opposed to emailing privately with a select few. When asked to rate the truth of the statement, “Learning at OOTS is important to me because I receive individualized answers to questions,” over half said this was True ($n = 3$) or Very True ($n = 10$).
Another reason for this may be the anonymity SDL in the OOTS community affords members many of whom suffer from high levels of social anxiety. When asked to rate the statement “Anonymity is important to me,” 16 responded True (n = 1) or Very True (n = 15). This is an interesting finding that led us to wonder what role anonymity plays in the SDL of respondents. One clue may lie in a respondent’s comment, “I have been able to share things on OOTS forums I have not yet divulged in therapy.” That is, anonymity creates a safe space in which stigmatized/isolated sufferers can connect and explore difficult issues with fewer repercussions than in a face-to-face environment.

SDT and SDL

SDT posits that people have three main psychological needs—autonomy, competence and relatedness—that contribute to intrinsic motivation and are important to one’s self-concept and health and sense of well-being (Deci & Ryan, 2016). It is this last construct of “relatability” or an individual’s need to feel a sense of belonging that may help to understand the apparent contradiction between the connection respondents in this study felt to other members and the anonymity of the forum. For example, one respondent wrote, “I cannot relate to anyone in my personal life more than I relate to the members of this site. It has been instrumental to my recovery.” Another wrote, “I do not feel alone, and there is so much validation here. There has never once been an instance of ‘you’re doing something wrong,’ ‘you need to change how....’ There has only been positive reinforcement, encouragement and advice.” A third said, “It’s hard for me to relate to people who don’t have complex trauma in a meaningful or healing way.” Thus, it is the shared lived experience of CPTSD that allows members to relate and connect with one another despite the anonymity of the forum. This is also what propels their SDL forward.

The findings also indicate that SDL at OOTS contributes to members’ need for competence (to feel effective in life) and autonomy (to have control over one’s life). All respondents in this study indicated that they were better informed about CPTSD (Somewhat True, n = 1; True, n = 4; Very True, n = 14) and more accepting of having the disorder (Somewhat True, n = 4; True, n = 3; Very True, n = 11). Two-thirds said their learning had empowered them in their daily lives (Somewhat True, n = 5; True, n = 3; Very True, n = 6) and when dealing with professionals involved in their care (Somewhat True, n = 6; True, n = 4; Very True, n = 4).

However, not all the comments about learning from others in the forum were positive and reflect the notion that many who come to OOTS do have difficulty relating to others because of the disorder. For example, one participant wrote, “I find that most members are too involved in their own issues and of course they often introduce bias into their advice. Based on their own experiences and knowledge or lack of.” Several respondents (n = 8) reported feeling uncomfortable posting or experiencing difficulties with other member as barriers to their learning; that is, concern or fear of being rejected, judged, or left out. One commented, “As to not ‘feeling comfortable’ posting—yes, but not because OOTS has many mean people; it’s more my fear of always feeling judged.” Another wrote, “Often participants will answer those they have developed a relationship with and I’ve often been ignored on there.” A third said, “Sometimes I’m so paranoid and take it personally when I don’t get a response or people can’t help me.” Given that a
major symptom of CPTSD pertains to difficulties with relationships (e.g., mistrust of others, feeling like an outsider, fear of rejection), it is understandable that even anonymous posting might be problematic for some members and may explain the high numbers of members who read but do not post at OOTS. In general, however, it can be said that the anonymity of online self-groups such as OOTS affords those with a stigmatizing/isolating disorder the opportunity to connect with others who share the same lived experience and fulfill their need to belong in relative safety. This also fosters the learning experience.

This last finding reflects a similar finding by Grover (2015); that is, membership in the group of mothers whose child suffered a pediatric stroke meant a better understanding and information of issues when meeting with health professionals. This reflects one of the main benefits of SDL: “individual learners can become empowered to take increasingly more responsibility for various decisions associated with the learning endeavor” (Hiemstra, 1994, p. 1). In the case of OOTS members, it may be to seek out mental health professionals who are specifically trained and experienced in treating Complex PTSD versus (simple) PTSD.

These data highlight a major aspect of SDT that “begins with the assumption that people are by nature active and engaged. When in supportive or nurturing social conditions, they are naturally inclined to take in knowledge and values and to more fully integrate the regulation of behaviors” (Deci & Ryan, 2016, p. 9). Those who join OOTS are intrinsically motivated to learn more about CPTSD and doing so in a positive, peer-to-peer context enhances learning which in turn can foster hope and recovery. Almost all respondents in this study reported feeling more optimistic/hopeful about recovering due to what they had learned at OOTS (Somewhat True, n = 8; True, n = 6; Very True, n = 3). Over half said what they had learned at OOTS had helped them to recover (Somewhat True, n = 10; True, n = 1; Very True, n = 3). The positive learning outcomes identified in this study suggest participants’ feelings of competence were enhanced rather than diminished.

The findings in this study with respect to learning from OOTS resources support the notion that being active participants in SDL fosters feelings of competence. A majority said they had learned a Moderate Amount (n = 6) or A Lot (n = 9) from the resources at the website and rated the quality (Q), relevance (R), and usefulness (U) of these resources as Medium (Q, n = 2; R, n = 1; U, n = 1) to High (Q, n = 13; R, n = 14; U, n = 14). This is likely because members contribute resources to the forum on an ongoing basis, which means they are relevant, timely, and enhance learning. This is supported in a study by Morrison and Seaton (2014) who found that resources frequently showed up in discussion threads to add depth or clarity to what was being discussed, resulting in “incremental growth of knowledge via multiple and focused resource contributions” (p. 35).

As depicted in Figure 2, when asked what they had learned about various aspects of CPTSD, a majority of respondents reported learning a Moderate Amount or A Lot, respectively, about the diagnosis (n = 6, n = 8), causes (n = 4, n = 13), symptoms (n = 3, n = 15), treatment (n = 7, n = 7), and self-help strategies (n = 6, n = 8). When asked what if anything they would like to see more of in terms of learning content/resources at OOTS, respondents only suggested expanding existing topics. Treatment (n = 5) topped
the list followed by symptoms \((n = 4)\); self-help strategies \((n = 4)\); relationships \((n = 4)\); parenting \((n = 4)\); diagnosis of CPTSD \((n = 3)\); employment \((n = 3)\); education \((n = 2)\); raising awareness \((n = 2)\); and advocacy, prevention, and causes \((n = 1)\). Again, the fact that no new content was requested is likely because members regularly contribute resources and suggest new discussion forums/subforums. This type of active and engaged participation is also considered a key characteristic of SDL (Merriam & Bierema, 2014).

![Figure 2: Ratings of how much respondents learned about CPTSD at OOTS.](image)

These findings suggest that one benefit of SDL is that participants are *contributors* to rather than mere *consumers* of learning resources and opportunities (Fischer, 2009). From the perspective of SDT, being actively involved in shaping, growing, and refining the learning environment in an ongoing and as needed basis can contribute in a positive way to the affective needs of members (i.e., competence, autonomy, and relatedness; Ryan & Deci, 2013). They also illustrate a characteristic of connectivism in which learning constitutes making connections and sharing resources and experiences (Anderson & Dron, 2011).

**Conclusion**

CPTSD is a relatively recent diagnostic construct which is the subject of some debate by mental health professionals, and confusion on the part of sufferers who consequently turn to the Internet to learn from others who have the disorder. The ubiquity and accessibility of social media provides people in this situation with the opportunity to engage easily in
informal SDL. This was not possible in the past and represents a major shift in adult education and learning. Thus, the intent of this research was to add to the knowledge regarding SDL via social networking. This study investigated the experience of informal SDL by members of OOTS, an online self-group for people with CPTSD.

The findings of this study confirmed what other research has recently demonstrated; that is, social networking can be an effective way for people with a concern or interest to engage in informal SDL autonomously outside of more formal education. In accordance with connectivism and ANT, key to this is the symbiosis of human and technology created by social media. Further, as demonstrated in this study the two-way communication capability of these networks fosters the coconstruction of knowledge by members of the network. This is in keeping with social constructivist theory in which learners make meaning of their experience through interaction with others and the environment; that is, the “sociocultural context” (Merriam & Bierema, 2014, p. 36). Surprisingly, it was the anonymity of the forum that participants said helped them to connect with others and open up thereby enhancing their SDL. SDT offers some insight into why this may be the case.

It was clear from the findings of this study that the social aspects of online networking also contributed to participants’ sense of relatability. That is, they felt a sense of belonging and of being understood, validated, and supported. In turn, this appears to have contributed to participants’ feelings of competence and autonomy in learning about, managing, and recovering from the disorder. Two other contributors that were identified with respect to these characteristics of self-determination included the lay expertise of participants and their active involvement in various aspects of the forum. As in other research regarding informal, online SDL, lay expertise was highly valued by the community. OOTS members possess expertise because of their lived experience of CPTSD and, thus, competence and the autonomy to make decisions regarding treatment and recovery. Being active in their learning sets members up as contributors rather than simple consumers of information that also may engender a sense of competence and autonomy. In the case of OOTS members specifically, this study highlights that informal SDL led to understanding, validation, and acceptance of the disorder as well as a degree of recovery. In more general terms, the findings confirm that when undertaken in a positive, supportive forum, informal SDL fosters a sense of empowerment, autonomy, competence, and relatedness.

Finally, a number of questions related to SDL and the theoretical lenses used in this study were identified for future research. A first question related to SDL and social constructivism is “What is the role of lay expertise in knowledge building and SDL in online self-help groups?” A second question regarding SDL, connectivism, and ANT is “What is the role of Social Media in informal, online SDL and the co-construction of knowledge?” Finally, a third question related to SDT is “What if any measures can be taken in online self-help groups to encourage feelings of autonomy, competence, and relatedness?” Data regarding these questions would undoubtedly add to our knowledge about informal, online SDL via social media.

References


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