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

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Abstract

Complex Post Traumatic Stress Disorder 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 for information. This study investigated the question, “What is the nature, purpose and outcomes of Self-directed Learning in an online self-help group?” Nineteen members of Out of the Storm, an online group for those with the disorder completed an anonymous questionnaire which gathered qualitative and quantitative data via open-ended and Likert questions. Data were analyzed through the lenses of Connectivism, Actor Network Theory, Social Constructivism and Self Determination Theory. The findings indicate that members possess lay expertise of the disorder which is highly valued and contributes to the co-construction of knowledge.

Further, when undertaken in a positive, supportive discussion forum in which members are active participants, SDL fosters: understanding, validation and acceptance of the disorder; a sense of empowerment, autonomy, competence and relatedness; and, a degree of recovery.

Keywords: Complex PTSD, self-directed learning, online learning, online self-help groups, social constructivism, connectivism, actor network theory, self determination theory
Introduction

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 to engage in self-directed learning (SDL) about a medical problem they are experiencing (Grover, 2015; Kazmer et al., 2014; Sosnowy, 2014). SDL is defined by Knowles as a process “in which individuals take the initiative with or without the help of others in diagnosing their learning needs” and then locating relevant resources to find the information and develop 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, & Mak, 2011).

This study will investigate the nature, process and outcomes of SDL in an online self-help group for people with Complex Post Traumatic Stress Disorder (PTSD). Despite the fact that this disorder is an emerging psychological construct and has rapidly been gaining attention in mental health circles and by the public, it has not been recognized as an official diagnosis (Hyland et al., 2016). It is in the midst of this debate by clinicians and researchers that those who suffer from the disorder seek support and information from peers at Out of the Storm (OOTS), an online forum which has grown from two members to over three thousand since it started in August 2014.

Theoretical Framework

Complex PTSD 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 which distinguishes Complex PTSD from (simple) PTSD in which trauma is typically impersonal involving an event of limited duration (e.g., an accident or disaster) (Courtois, 2014).

The term Complex PTSD was first used by Herman in 1992, but there has been debate by mental health professionals since then over its viability as a distinct diagnostic construct (Bryant, 2012; Herman, 2012; Resick et al., 2012a, 2012b; Weiss, 2012). Despite the confusion and lack of clarity, it is being used increasingly by health professionals and the public. A search on the internet will bring up a myriad of books and articles, indicating that the construct is one likely to be formally recognized in the near future. Until such time, however, those with the disorder are faced with confusing and oftentimes conflicting information and thus, turn to peers online to learn more.
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 and Hill, 2008). As already highlighted in the introduction, SDL is one theoretical perspective to use as lens in informal online networks. ANT and Connectivism add additional dimensions. 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 knowledge creation and learning. Again social interactions are seen to be important in the process. Interacting and sharing experiences on OOTS seems to fit with these theoretical perspectives, but what might also influence people’s participation is motivation and 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 focusses 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. In the words of Ryan and Deci (2013):

Social environments can, according to this perspective, either facilitate and enable the growth and integration propensities with which the human psyche is endowed, or they can disrupt, forestall, and fragment these processes resulting in behaviors and inner experiences that represent the darker side of humanity. (p. 6)

There has been some related research into SDL in online self-help groups. For example, Morrison and Seaton (2014) conducted an exploratory study into SDL in a “how to” online forum for motorcycle touring enthusiasts. Their main focus was on knowledge building and one of their key findings is that personal, lived experience is considered an invaluable source of knowledge by participants. 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 found to be the “exchange of knowledge and sharing of experience” (p. 406). Their findings about disempowering processes lead 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.

A study by Grover (2015) into the online SDL of mothers of children who suffered a pediatric stroke sheds light on the often critical nature of this type of learning when little or no information is available from professionals about the condition. Her data indicated
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 when at the same time that community building technologies are emerging, 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 learning and the future development of networks.

Beyond the obvious desire for support, the ability to engage in informal peer-to-peer SDL to deal with confusion regarding Complex PTSD seems to be a major reason many are drawn to OOTS. We found it important to confirm this empirically by gathering data regarding this and what was involved in this learning. Thus, the overarching research question that has been investigated in this study is: “What is the nature, purpose and outcomes of self-directed learning in an online self-help forum for adults with Complex PTSD?”

Research Methodology

Both qualitative and quantitative data have been gathered in an anonymous online questionnaire involving Likert and open-ended questions respectively. Nineteen active OOTS members have volunteered to participate after a recruitment message was posted on the network. They 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 non-identifying demographic information has been requested. The questionnaire was based on our review of the literature and has investigated: the participants’ experience of Complex CPTSD; their experience of SDL at OOTS; their desire for formal learning (e.g., instructor led course); and, the desirability of involving professionals in developing/offering formal learning.

Ethical Considerations

The study adheres 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 which 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) in her role in which she has the administrative responsibility and capability to edit or remove posts, and to warn and/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 signed the Informed Consent form.

Findings and Discussion

Morrison and Seaton (2014) suggest 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 about this “new frontier” as Kop and Fournier (2010) refer to it, is that disparate people can come together easily to learn in a way that would not have been possible in the past. This is quite apparent in this study which involves nineteen respondents from seven countries (America 9, Australia 1; Canada 1; Holland 1; United Kingdom 4; New Zealand 1; Unspecified 2. As discussed in the following sections, the findings of this study confirm that it’s not just support members seek, they also join to engage in SDL.

Connectivism and Actor Network Theory in SDL

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 & Hill, 2008; Kop & Fournier, 2015; 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 self-help groups such as OOTS. Grover (2015) suggests that the ability to connect with peers online is especially important, perhaps even crucial, for those who are dealing with a disorder or illness which is not well known. She found that mothers of children who had had a stroke turned to the Internet and other parents because little or no information was available from physicians, and that most felt their SDL was critical to their children’s health and in some cases their survival. Similarly, in this study not a single participant learned about Complex PTSD from a physician. Also, all but one had learned about (OOTS) via an Internet search (15) or another online forum (3). Further, only half of participants (11) reported they were diagnosed by a mental health professional (Psychiatrist 2; Psychologist 5; Masters Clinician 4), while just under half (7) said they self-diagnosed based on what they had read on the Internet (7) or in books (1).

This may be one reason so many with Complex PTSD 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. 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. As Kazmer et al. (2014) found in their study of an online community for people with Amyotrophic Lateral Sclerosis (ALS), participants “socially construct their own authoritative knowledge … apart from the enforced hierarchy of the clinical setting, a separation that allows the community freedom about what knowledge they can consider to be legitimate” (p. 10). This is also an important aspect of SDL at OOTS. That is, members often post about being misdiagnosed and/or receiving inappropriate/ineffective, even harmful treatment by professionals who do
know about (simple) PTSD, but not Complex PTSD. For example, EMDR (Eye Movement Desensitization and Reprocessing) is a common and effective treatment for PTSD, but when used to treat Complex PTSD can trigger overwhelming emotional flashbacks. These involve an accumulation of interpersonal trauma while for those with PTSD, flashbacks are visual and involve short term, impersonal trauma (e.g., car accident).

All respondents said they joined OOTS because it is accessible 24/7 (True 1, Very True 17), and free (True 3, Very True 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 “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 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. As discussed in the next section, a significant finding in this study is the importance and value of lay expertise and Social Constructivism in SDL.

**Lay Expertise and SDL**

In a study of bloggers with Multiple Sclerosis (MS), Sosnowy (2014) found that “the most intimate knowledge of the disease came from living with it” and that this “embodied knowledge” represents a form of “lay expertise” (p. 323) which is highly valued by those seeking to learn about a chronic illness like MS. In a study about an online “Do It Yourself” group, Morrison and Seaton (2014) found that “lived experience is a cornerstone of expertise, a highly regard commodity” (p. 37). Given that Complex PTSD is a disorder that is not particularly well known, data was gathered about the lived experience of sufferers to provide readers with insight into their daily struggle and the reasons they choose to connect and learn online.

All respondents indicated being traumatized by emotional abuse/neglect. For a third of participants’ trauma began and ended in childhood (6), while for over half (11) it carried on into adulthood. It is worth noting that these latter respondents are not in fact “post” trauma, but are still in the throes of it. As one participant rightly remarked, “…it is understood that long-term childhood abuse and trauma can make people more vulnerable to adult trauma and cause the consequences to be severe, long term and difficult to treat.” Only one participant developed the disorder as an adult (although it should be noted that more people with this background have joined OOTS recently). In addition to emotional abuse/neglect, over half of participants reported being abused sexually (11) and physically (10). A number indicated they suffered other forms of trauma including: spiritual/emotional abuse by a religion/cult (3); domestic violence (2); medical trauma (1); childhood epilepsy and bullying; and, abuse by an institution (1).

In terms of who/what had traumatized them, all respondents reported at least one or more people had perpetrated the trauma (versus ongoing, impersonal trauma such as being in a war zone). For the majority, this involved family members (Parents 17, Spouses/Partners 5; Siblings 5; Grandparents 2; Child 1). Professionals (7) were also identified (Religious Leaders 2; Teacher 2; Therapist 2; and, a Surgeon 1), and to a lesser
extent Friends/Acquaintances (4). Clearly, these data support the notion that the core wound in Complex PTSD is emotional and results from ongoing, interpersonal traumatization by significant others -- in particular, by adults in a position of trust and/or authority, and from which there is no real or perceived avenue of escape (Courtois, 2014).

With respect to the major symptoms of the disorder, all reported experiencing these to some degree (18), two thirds Often or Always (Figure 1) and of Medium or High intensity (Figure 2). As one respondent wrote, “These [symptoms] are very steady; it's excruciating, almost crippling work even just to consider the why/what/how of turning the corner on these.” On top of the major symptoms of Complex PTSD, over half (11) indicated that they suffer from a variety of related psychological/physical problems; that is, mood related difficulties such as depression (8); physical illnesses/chronic pain (7); problems with sleep (4); addictive/compulsive behaviours (2); cognitive/memory issues (2); and, suicide ideation (1).

**Figure 1. Frequency of Symptoms of Complex PTSD**

**Figure 2. Intensity of Symptoms of Complex PTSD**
This latter finding reflects the results of the Adverse Childhood Experiences Study (Felitti et al., 1998) which found that childhood trauma results in a significantly higher incidence of ill health and lowered emotional well-being in adulthood compared to the general population. Among other measures, the researchers concluded that “increased physician training is needed to recognize and coordinate the management of all persons affected by child abuse, domestic violence, and other forms of family adversity such as alcohol abuse or mental illness” (p. 255). Clearly more work is needed in this respect given none of the respondents in this study learned about Complex PTSD from a physician. That said, according to Grover (2015), this may not be as dire a problem as it may have been in the past due in large part to the connectivity of Social Media:

The ability to access and retrieve data when it is needed via the Internet is transforming healthcare because people can now quickly and easily gather information, direct their own learning, and share their knowledge. Individuals are not limited to their physicians as their only source of information (p. 4).

As this section has highlighted, participants in online self-help groups such as OOTS possess expertise in the lived experience of the disorder which as will be discussed in the next section, they can draw on to inform and advance SDL in a peer-to-peer context. Ziegler, Paulus and Woodside (2014) suggest that, “what is noteworthy about this type of learning, and what makes it important as an area of study for adult education, is that it is peer-initiated and controlled, showing how people learn through talk when there is no one in the role of expert “other” (p. 75).

Social Constructivism and SDL

The data in the previous section paint a sobering picture about the lived experience of Complex PTSD, and underscore another major finding of this study. That is, it is of great importance to participants to be able to learn with and from peers. Dr. Judith Herman who first identified Complex Post Traumatic Stress Disorder in 1992 contends that for sufferers, group learning, validation and support are key to recovery:

Traumatic events destroy the sustaining bonds between individual and community. Those who have survived learn that their sense of self, of worth, of humanity, depends upon a feeling of connection with others. The solidarity of a group provides the strongest protection against terror and despair, and the strongest antidote to traumatic experience. Trauma isolates; the group re-creates a sense of belonging. Trauma shames and stigmatizes; the group bears witness and affirms. Trauma degrades the victim; the group exalts her. Trauma dehumanizes the victim; the group restores her humanity (p. 1).

When asked to rate the statement “Learning from others at OOTS is important to me” all respondents answered in the affirmative (True 1; Very True 17). Moreover, as depicted in Figure 3 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.

Figure 3. Quality, relevance and helpfulness of learning at OOTS.

From a Social Constructivist perspective, SDL is enhanced by actively engaging with others and exploring multiple perspectives about an issue or topic in which “the source of knowledge lies primarily in experiences” (Anderson & Dron, 2011, p. 4). Similar to other research (Grover, 2015; Morrison & Seaton, 2014; van Uden-Kraan, 2012), the findings in this study confirm that shared experience is a valuable and valued resource in online groups. For example, one respondent said “I feel relieved meeting someone else with a similar situation - I can learn what is based on the Complex PTSD 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 (17) of respondents said they learned about Complex PTSD by posting back and forth with other members (Moderate Amount 5; A Lot 9), and by reading members’ posts (Moderate Amount 5; A Lot 12). Only a small number indicated they also learned via emailing privately with other members (Not at all 14; A little 3; Moderate 1; A lot 0), 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 (3) or Very True (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,” sixteen responded True (1) or Very
True (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, it is anonymity that 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.

**Self Determination Theory (SDT) and SDL**

Self Determination Theory (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—“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 Complex PTSD that allows members to relate and connect with one another despite the anonymity of the forum.

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 (8) reported feeling uncomfortable posting and/or experiencing difficulties with other member as barriers to their learnings; 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 Complex PTSD 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.

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 Complex PTSD (Somewhat True 1; True 4; Very True 14), and more accepting of having the disorder (Somewhat True 4; True 3; Very True 11). Two thirds said their learning had empowered
them in their daily lives (Somewhat True 5; True 3; Very True 6), and when dealing with professionals involved in their care (Somewhat True 6; True 4; Very True 4). This last finding reflects a similar finding by Grover (2015). “Membership in the group made visits to the doctor more valuable because the patients were armed with information and questions and could take a more active role in their treatment” (p. 5). This reflects one of the main benefits of SDL. That is, “individual learners can become empowered to take increasingly more responsibility for various decisions associated with the learning endeavor” (Hiemstra, 1994, p. 1).

These data highlight a major aspect of SDT which “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 and Ryan, 2016, p. 9). Those who join OOTS are intrinsically motivated to learn more about Complex PTSD and doing so in a positive, peer-to-peer context enhances learning which in turn can foster hope and recovery. Almost all respondents (17) in this study reported feeling more optimistic/hopeful about recovering due to what they had learned at OOTS (Somewhat True 8; True 6; Very True 3). Over half (14) said what they had learned at OOTS had helped them to recover (Somewhat True 10; True 1; Very True 3).

Some researchers have suggested that informal online SDL may in fact diminish competence. For example, Fischer (2009) contends that the transition from Web 1.0 to 2.0 and Social Media created a fundamental shift from a “consumer culture (in which people passively consume finished goods produced by others) to a culture of participation (in which all people are provided with the means to participate in personally meaningful activities),” but suggests that “Although this shift provides power, freedom and control …it has forced people to act as contributors in contexts for which they lack experience and interest” (p. 4). In the case of this study, however, it is clear that respondents have both the experience (i.e., developed via the lived experience of the disorder), and certainly the interest to engage in SDL (i.e., about a disorder which is not overly well-known and there is some confusion/debate over the diagnosis). The positive learning outcomes identified in this study suggest participants’ feelings of competence were enhanced rather than diminished.

Sosnowy (2014) investigated the SDL of sufferers of Multiple Sclerosis (MS) who blog about the illness online. Prompted by a study in which Salmon and Hall (2004) found their respondents felt overly burdened by a perceived expectation in the medical community that they should become more “participatory patients” she wanted to see if this were the case with her participants. In contrast to their findings, her participants felt empowered and did not see SDL as a burden so much as an “opportunity and necessity” (p. 317). She speculated that her findings were likely because patient participation has become “more embedded in our cultural conceptions of healthcare practice and patienthood through social media” (p. 322) in the ten years since Salmon and Hall’s study. This may indeed be the case given there were few negative comments in this study about SDL at OOTS.

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 (6) or A lot (9) from the resources at the web
site, and rated the quality, relevance and usefulness of these resources as Medium (2, 1, 1) to High (13, 14, 14). This is likely because members contribute resources to the forum on an ongoing basis which means they are relevant, timely and enhance learning. As Morrison and Seaton (2014) found in their study of SDL in an online “DIY” forum, resources frequently show up in discussion threads to add depth or clarity to what is 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 Complex PTSD a majority of respondents reported learning a Moderate Amount or A Lot about the: diagnosis (6, 8); causes (4, 13); symptoms (3, 15); treatment (7, 7); and, self-help strategies (6, 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 (5) topped the list, followed by symptoms (4), self-help strategies (4), relationships (4), parenting (4), the diagnosis of Complex PTSD (3), employment (3), education (2), raising awareness (2), and advocacy, prevention and causes (1). Again, the fact that no new content was requested is likely because members regularly contribute resources and suggest new discussion forums/sub-forums.

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 is the process of building networks of information, contacts, and resources that can be applied to real life problems” (Anderson & Dron, 2011, p. 4).

Figure 4. Ratings of how much respondents learned about Complex PTSD at OOTS.
As will be discussed in the next section, the findings of this study also indicated a degree of interest by respondents about the possibility of adding more *formal/directed* learning opportunities at OOTS.

**Professional/Stakeholder Expertise and Directed, Formal Learning**

In terms of future learning opportunities at OOTS, almost all participants said that *formal courses* were important to them (Somewhat Important 4, Important 9, Very Important 4). Nearly half indicated it was important to learn from professionals/stakeholders such as therapists (Somewhat Important 4, Important 6, Very Important 6) and/or organizations involved with psychological trauma (Somewhat Important 4, Important 7, Very Important 4).

Just over half said it was Not Important (6) or Somewhat Important (4) for forum members to be involved in developing learning opportunities/resources. This latter finding was somewhat surprising considering the value participants accorded peer-to-peer knowledge sharing and creation. However, this may be due to a “leave it to the experts or professionals” attitude in that two thirds of respondents (14) indicated it was important to involve professionals in their learning (Somewhat Important 3; Important 3; Very Important 4). Participants may not understand/accept that as individuals who have the disorder they are in fact *lay experts* in the lived experience of Complex PTSD, and can serve as valuable contributors to the development of learning resources/opportunities. As Kazmer et al (2014) found in their study of distributed knowledge in an online patient support group, participants “share valuable information and actionable advice” based on their daily struggle with an illness and this leads to “co-constructing authoritative knowledge” (p. 28). Accordingly, both patients and professionals “whose authority is externally vested in them by their positions” can be considered as sources of expertise (p. 25). The data in this study support the notion that the socially constructed, authoritative knowledge or lay expertise of sufferers should be considered a legitimate source of information when planning learning opportunities/ resources and/or designing similar online groups. It may be, however, that group members need assistance to understand they possess valuable lay expertise that would enhance the development of formal learning opportunities such as a course. For example, forum members could be reminded that they have shed light on the fact that common treatments for PTSD like EMDR or strategies like mindfulness and mediation are not suitable and can even be harmful to those with the disorder.

It is worth considering whether and how the addition of professionals/ stakeholders might undermine the very benefits (e.g., validation, empowerment, relatedness, competency and autonomy), which members of peer-to-peer online groups such as OOTS gain through learning, and sharing and creating knowledge together. A study by Smithson, Jones and Ashurst (2012) of an online community for mental health professionals and service users found that despite their efforts to provide a “non-hierarchical space” for their participants to interact in, professionals focused on technical matters and patients deferred to them. (p. 8). As they suggest, “technical expertise tends to be privileged over lived experience” and in their study this served to marginalize the patient participants (p. 8).

It is notable that there was little support for the idea of *learning in real time* via Skype or similar synchronous applications. Of those who responded to this question (13),
over half felt this was Not Important (8) which, as was discussed in an earlier section, suggests that anonymity is especially important to this type of self-help group. However, it may also reflect the fact that OOTS is open to English speaking individuals from around the world and the time differences between countries would make any synchronous activities difficult to participate in/coordinate. It may be that asynchronous delivery options such as having a guest post a video talk or written article followed by an asynchronous Q&A would be relatively benign in this respect. A Q&A session could fulfill the needs of learners for some professional expertise in certain areas relating to the disorder, while allowing members to remain active and at the forefront of their community. Similarly, stakeholders/professional and sufferers could work together to develop a formal course that learners can work through asynchronously rather than as a live, moderated course.

**Conclusion**

Complex PTSD 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 for information. This study investigated the question, “What is the nature, purpose and outcomes of SDL in an online self-help group?” Nineteen members of Out of the Storm, an online group for those with the disorder volunteered and completed an anonymous questionnaire which gathered qualitative and quantitative data via open-ended and Likert questions. Data were analyzed through the lenses of Connectivism, Actor Network Theory, Social Constructivism and Self Determination Theory. The findings indicate that members possess lay expertise of the disorder which is highly valued and contributes to SDL and the co-construction of knowledge. Further, when undertaken in a positive, supportive discussion forum in which members are active participants, SDL fosters: understanding, validation and acceptance of the disorder; a sense of empowerment, autonomy, competence and relatedness; and, a degree of recovery. Finally, a number of questions for future research were identified in this study. First, what is the role of lay expertise and knowledge building in online, informal peer-to-peer SDL? Second, what if any measures can be taken in these groups to encourage autonomy, competence and relatedness and thereby enhance members’ SDL? Last, what are the benefits and drawbacks of involving professionals/stakeholders in developing/facilitating more *formal* learning opportunities in online health related groups like OOTS? Data regarding any or all of these questions would undoubtedly add to our knowledge about the “exciting and relatively unexplored territory” that is online SDL (Morrison & Seaton, 2014, pp. 30-31).
References


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