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## **CHAPTER X: Online Support Groups: Enhancing the User Experience with Cyber-psychological Theory**

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### **Abstract**

The Internet has the potential to support individuals living with various psychological and physical conditions, those experiencing major life changes (e.g. bereavement) and those who have limited opportunities to gain support offline. In this chapter Fullwood will consider the main differences between offline support and more traditional face-to-face support, as well as the pros and cons associated with receiving social support online. The chapter will also evaluate the academic literature pertaining to the psychological outcomes for individuals associated with engaging in online support communities, for example the impact on well-being. Finally, drawing on contemporary theory and evidence, there will be some consideration of design principles and user-interface. In other words, how might we use this knowledge to facilitate support provision and enhance the user experience?

### **X.1 Introduction**

'No man is an island,  
Entire of itself,  
Every man is a piece of the continent,  
A part of the main' (John Donne, 1624)

Most of us will be familiar with the well-known expression 'a problem shared is a problem halved.' Conventional wisdom at least then would seem to suggest that there are distinct psychological benefits associated with unburdening your problems onto others. Perhaps there is something cathartic about getting a few things off your chest. Perhaps discussing your problems with others allows you to gain new insights from someone else's perspective or maybe there is just some comfort in simply knowing that others are there for you when you need them. Whatever the case, no matter how resilient you might think you are, there comes a time in all of our lives when (to quote a very famous song) 'we all need somebody to lean on' (Withers, 1972).

If I asked you to dredge your memory banks for either an example of a major incident in your life where you needed support from others or an instance where you were called upon to assist someone else in their time of need, I would bet that you would be hard pushed not to come up with at least one example. Most of you will likely conjure up abundant cases. This would almost certainly

be true if you (or a close friend or family member) have experienced one or more of the major life events listed on Holmes and Rahe's (1967) Social Readjustment Rating Scale. Divorce, marital separation, the death of a close family member, marriage, pregnancy and dismissal from work represent just a few examples of major life events where support from others in some shape or form is likely to be required to help you through. Research also suggests that there is a positive correlation between the number of these stress events experienced and the onset of illness (e.g. see Rahe et al., 1970). Even though we should be cautious about inferring causality here because there are likely to be a myriad of additional factors which mediate this relationship (e.g. individual coping strategies), as we will see later in this chapter the strength of social support received may help to 'buffer' against some of the negative impacts of stressful life events, including illness. For this reason, increasing access to social support provision, whether this is from friends/family, community organisations or government agencies would seem to be of paramount importance, particularly given the increasing demand on health services as the population continues to grow.

While most of us are able to call upon members of our support network in times of need, we know that there are certain individuals in society who, for various reasons, have limited access to social support. Additionally, there may be some people who will find it difficult to locate individuals within their offline networks who can relate to, empathise with or provide valuable advice on their situation. This might be, for example, because they are living with an uncommon condition or illness or are experiencing problems that others cannot readily identify with. For these types of individuals, the Internet may be a particularly valuable resource to gain support that may have otherwise been exceptionally difficult to locate. Knowing that more and more of us are turning to the Internet in times of need, it is imperative that we evaluate the efficacy of support offered in this environment and consider how we might maximize social support delivery online. Therefore, this chapter will address a number of key questions: 1) What are the major benefits to offering and receiving social support online? 2) Are there any unique elements to the online world which make providing support more problematic? 3) How can psychological theory inform the design of such websites to improve the user experience? Before we do this however, we will begin by defining social support and considering why it is so valuable to the individual.

## **X.2 What is Social Support and Why is it Important?**

Social support can be broadly defined as a "transactional communicative process, including verbal and/or nonverbal communication, that aims to improve an individual's feelings of coping, competence, belonging, and/or esteem" (Mattson & Hall, 2011, pg. 184). This definition acknowledges that support can be offered in a variety of different ways. For example, if your friend

disclosed to you that he/she was considering splitting from their husband/wife, you might offer support in various capacities. A simple hug might communicate that you are sympathetic towards their plight and are there for them on an emotional level and this would send a powerful message to your friend that he/she is not alone. On the other hand, whereas recommending a good solicitor in the event of a divorce might not help your friend to cope with the emotional aftermath of the split, it would be supporting them in a more practical sense by helping them to better understand the legal processes involved. This definition is also a good one because it recognizes that there is potentially an assortment of benefits for the individual who is receiving the support, for example becoming better informed or increasing self-confidence and competence with dealing with the problems faced.

It is also worthwhile at this juncture to differentiate between *actual* and *perceived* support. Whereas actual support refers to concrete examples of things that others might do for us in times of need (e.g. offering practical advice, talking through our issues with us etc.), perceived support refers to the support-seeker's perceptions regarding the availability and usefulness of the support provided (Sarason et al., 1990; Mattson & Hall, 2011). It is important to make this distinction because the two can be mutually exclusive. For example, an individual on the surface may receive abundant support from his/her network, but importantly may not perceive this support to be adequate or effective for their specific needs. For example, if you were living with a stigmatized illness, let's say depression, although your friends may offer you sympathy and words of encouragement, at the same time they might not fully understand what you are going through because they have not experienced depression personally. Of course, there is also the possibility that although members of your network may attempt to support you through your difficult patches, their naivety of the issues you face may also mean that even with the best of intentions they cannot offer you the type of support that you really desire. In some cases they may even make matters worse by advising you inappropriately or frustrating you by over-simplifying your problems or demonstrating their ignorance (e.g. by suggesting that you should 'just get over it'). Sometimes there are instances when only someone who has walked in our shoes can truly appreciate what we are going through.

Schaefer et al. (1981) distinguished between five types of social support: emotional, esteem, network, information and tangible. Emotional support refers to any type of supportive behaviour which attempts to impact positively on another individual's mood or emotional state. For example, this might include physical contact (e.g. a hug), messages of support or even telling a joke to lift someone's spirits. Esteem support is concerned with attempts to strengthen another individual's self-worth or trying to instill them with the self-belief that they can face their problems and prosper. Network support relates to supportive behavior which affirms that the person in need is not facing

their problems alone and that others are there for them when required. Information support consists of the communication of beneficial or necessary information. For example, this could include making a person aware of the types of options that are available to treat their specific illness or discussing with them what they might expect from a certain medical procedure. Finally, tangible support includes access to material resources (e.g. letting someone sleep in your spare room), physical assistance (e.g. driving someone to the hospital for an appointment) and financial assistance (House, 1981; Schaefer et al., 1981; Mattson & Hall, 2011). Clearly these different types of support are not necessarily mutually exclusive and members of any social support network can offer multiple types of support simultaneously. Notably, it is possible for all of these types of support to be offered online, except for most aspects of tangible support as this is the only form which is primarily communicated with physical actions rather than words.

An abundance of research evidence points to the notion that increased social support has been linked with improvements in both physical and mental health (e.g. see Broadhead et al., 1983; House et al., 2001; Coker et al., 2002; Lyyra & Heikinnen, 2006). There are a number of theories to explain this effect; including the often cited *stress-buffering hypothesis* (Cobb, 1976; Cohen & Wills, 1985). Put simply, the perception that others are responsive to our needs and able to support us through difficult times may strengthen our own resolve and perceived capacity to deal with stresses, therefore leading to a reappraisal of the stressful event(s). In essence, the supported individual will feel more able to cope with any demands that are placed on him/her and therefore this will lessen or eradicate the stress reaction (Cohen & Wills, 1985). Because we know that there are physiological symptoms associated with stress (e.g. heart disease, disturbed sleep patterns) and that people experiencing stress are likely to adopt more unhealthy habits (e.g. taking drugs, misusing alcohol, over-eating), the negative health consequences associated with these symptoms and behaviours may be minimized when effective social support is in place (Cohen & Wills, 1985; Mattson & Hall, 2011). Fundamental to this theory is also the idea that the benefits of social support are only really evident when a person is experiencing high levels of stress (Cohen & Wills, 1985). This is in contrast to the *direct effects hypothesis*, which predicts that social support will provide continuous benefits. There is evidence in the experimental literature to support both models (see Cohen & Wills, 1985), so consensus has yet to be reached as to which hypothesis is the most accurate. However, irrespective of which of these theories has the most predictive power, the common link between them is that receiving social support from others comes with a host of physiological and psychological benefits for the individual. Of course, there are also many other potential explanations for this relationship. For example, with a larger support network, it is likely that individuals will receive increased amounts of tangible and information support which would not only help them to

stay healthy (e.g. offering advice on healthy living, making sure that appointments are met and medication is taken) but also to recover from their illness (e.g. assisting with basic needs so the person can recuperate) (Mattson & Hall, 2011). So, we have a relatively clear idea about how we can support people in our offline lives, but how might we support people in the online world?

### **X.3 How is Social Support Offered Online?**

Online support groups can be defined as a “type of virtual community with a health-related focus, which provide an online environment where individuals can connect and interact with other people who have had similar experiences to exchange information, social support or advice” (Coulson & Smedley, 2015, pg. 198). Online support groups are typically set up to support individuals with particular medical conditions (e.g. diabetes, cancer, narcolepsy) and therefore communication normally centres on the condition itself, but can also extend to other topics, including relationships and politics (Finn, 1999; Coulson & Smedley, 2015). Online communities are not however restricted to a health focus and there are innumerable topics that cover the gamut of human experience and the problems and issues that we all face in our everyday lives. A brief search of [dailystrength.org](http://dailystrength.org) for example uncovered support groups on topics as diverse as ‘acne’, ‘body modification’, ‘divorce’, ‘bullying’, ‘empty nests’, ‘pet bereavement’ and ‘coming out’. Individuals can communicate with one another in various different ways via support communities; however forums tend to be the most common mode of interaction (Coulson & Smedley, 2015). Forums have many distinct advantages over other forms of online communication (e.g. chat rooms). Most notably, because communication is asynchronous in nature (i.e. it does not take place in real time), members can post messages and respond to others at their own convenience and do not need to be online at the same time as the individual(s) with whom they are interacting (Barak et al., 2008; Coulson & Smedley, 2015). Additionally, the fact that messages are archived in different threads or topics means that members can benefit from the responses given to other individuals in addition to those which are directed solely at them. As previously noted, it is not possible to physically interact with someone else (e.g. hug them) online but all of the other types of social support outlined by Schaefer et al. (1981) can be offered in an online setting.

### **X.4 Why Might People Seek Support Online Instead of Offline?**

Although the range of topics that online support communities cover are diverse, scholars suggest that there are likely to be specific socio-psychological characteristics which predict ones inclination to join an online support group. For example, it has been argued that finding satisfactory support in the offline world might be difficult if the individual is living with a condition which is rare (i.e.

because it would be hard to find others who could relate to them), hidden (i.e. because others might not appreciate the full impact that it has on the person) or not valued highly by society (i.e. because people might not see the condition as having genuine health repercussions) (McKenna & Bargh, 1998; Mickelson, 1997). Individuals who fall into these specific groups may be particularly motivated to seek support from others online (Cummings et al., 2002). If individuals perceive support in their offline networks to be inadequate, but support in their online communities as satisfactory, then they are likely to spend more time engaging with online support groups (Turner et al., 2001). In essence, people turn to online support communities when they feel that they cannot receive the depth of support that they require in the offline world, however they will only continue to participate if their online support group can offer them the quality of support that they desire. Turner et al. (2001) also provided support for Cutrona and Russell's (1990) 'optimal matching' hypothesis, which proposes that different types of supportive behaviour are required under different types of stress events. Moreover, they assert that the extent to which the individual has control over the stress event(s) plays an important role in dictating their social support requirements. In situations where the person has little control over their circumstances, for example the sudden onset of a medical illness, a strong need for emotional support is created, partly because this generates a sense of helplessness in the individual. When these emotional needs cannot be met via offline networks, the person may seek support elsewhere, for instance in the online world. Because we know that for certain types of individuals online communities will be their primary source of social support, it would seem necessary to evaluate whether satisfactory support can be provided in this context. We will now therefore turn our attention to the advantages and disadvantages of providing support online.

#### **X.5 Advantages of Online Support**

There are potentially numerous advantages to offering and receiving support in an online environment. At a very basic level, unlike offline support groups, the individual would not need to travel to the support venue and could access the group at his/her own convenience and in the comfort of their own home (Turner et al, 2001). Clearly this has the potential to save the person time and money and may present a more relaxing and comfortable environment in which to converse with others, which may be attractive to those who are shy or who find it difficult, stressful or embarrassing to communicate face-to-face. Indeed, cyberpsychological theory suggests that we have far more control over our presentation of self in cyberspace. For example, Walther's 'hyperpersonal' theory of communication argues that asynchronous forms of communication may lead to optimal self-presentation because, for example, the individual can more carefully consider the messages they write before posting them (Walther, 1996; Walther and Parks, 2002).

Additionally, this should be particularly advantageous to individuals who live in geographically remote areas or who may have difficulties leaving the house (e.g. individuals with physical disabilities or people who suffer from agoraphobia). Because online groups are not restricted in the same way as offline groups in terms of space, group sizes can be much larger. Individuals from all corners of the planet could potentially contribute in an online community, meaning that members will be exposed to a wide array of different outlooks, experiences and ideas (White & Dorman, 2001). Additionally, online interaction should be more socially liberating and egalitarian because individuals can communicate with less inhibition. The online world can be a great leveller because many of the cues that we might traditionally associate status and authority (e.g. body language) are missing or attenuated, meaning that, theoretically at least, people can interact on a level playing field (Suler, 2004; Fullwood et al, 2011). Individuals can also choose to hide specific characteristics (e.g. ethnicity, disability, sexuality, sex) if they feel that there is a potential that they may be discriminated against or excluded from interactions (White & Dorman, 2001).

One of the major advantages of online support groups comes with the freedom that users have to choose which aspects of their identity they reveal. A member of an online support community may choose to remain completely anonymous if he/she wishes to do so. In addition, members will communicate predominantly with strangers or individuals whom they have never met face-to-face. Therefore, even when some identity information is disclosed, individuals should still feel a sense of protection and safety because it is highly unlikely that they will bump into fellow support members in their offline lives by mere chance (Fullwood et al., 2013). An upshot of increased perceived anonymity is that some members (particularly those who live with stigmatised conditions) may feel more comfortable discussing difficult, sensitive or potentially embarrassing issues, partly because the level of risk is reduced (Adelman et al, 1987; White & Dorman, 2001). This is important because a cognitive reappraisal of a difficult emotion or distressing experience (which may help to reduce emotional distress) is more likely to take place when effective comforting communication is given. Moreover, it is argued that a number of conditions need to be met for effective comforting communication to occur; namely: self-disclosure, discussion concerning thoughts and feelings and discussion concerning reappraisals (Burlison & Goldsmith, 1998). In essence, a person will receive more effective emotional support if they are willing to talk honestly and in detail about their problems and emotional issues in an environment which fosters reappraisals (i.e. one which allows them to work through the difficulties that they are facing). Fullwood and Wootton (2009) provided some evidence to suggest that in an online forum dedicated to epilepsy, members who were anonymous spent more time discussing their thoughts and feelings about upsetting experiences and emotions than members who identified themselves. On the surface



this suggests that anonymity helps people to feel more comfortable about opening up and overcoming the self-presentation dilemma that people often face when discussing sensitive and personal issues face-to-face (Burlison & Goldsmith, 1998; Caplan & Turner, 2007). Finally, communicating primarily with strangers may mean that members receive a much more objective and honest appraisal of their situation than they might get from someone who is more emotionally involved, for example a friend or family member (Adelman et al., 1987; Walther & Boyd, 2002).

## **X.6 Disadvantages of Online Support**

Perhaps the biggest drawback to offering support online is the assumption that the individual in need of support will actually have access to the Internet and/or is capable of navigating the World Wide Web effectively. We know, for example, that a digital divide still exists for many elements of society, for example those with learning difficulties are still less likely to enter the online world (e.g. see Chadwick et al, 2013 and **Chapter X**). The unfortunate irony is that these groups of individuals often stand to gain the most (e.g. developmentally, socially) from being online. For those who can get online, being a member of an online support community is not unproblematic. Moderators may be stretched to capacity, particularly in larger groups, and may not always be able to monitor and shut down dangerous, hostile or dishonest communications. In any online community, misinformation or unsuitable advice is always a possibility, particularly from members who are not medical experts. Clearly this has the potential to pose risks to the individual who might follow this advice unwittingly (Culver et al., 1997; Dickerson et al., 2000). Online communities may also attract people who purposefully desire to abuse and attack other members and remain undetected whilst doing so (White & Dorman, 2001). Even those who do not have this aim may find themselves being drawn into hostile interactions because people are less inhibited online (see Suler, 2004). Moreover, these types of negative experiences are likely to discourage people from returning.

Interacting with others online is also likely to have a number of impacts on communication dynamics. There has been some suggestion for example that online messages can be more difficult to interpret because of the lack of contextual cues (White & Dorman, 2001). We know that paralinguistic features of speech are particularly important in terms of communicating emotion or affect. If we take sarcasm for instance, this is communicated almost entirely with tone and intonation, which would be absent from text-based communication. Group members may also find it more difficult to express emotions because they cannot make use of nonverbal communication (e.g. facial expressions, touch, gestures). Although this can be compensated for to some extent with the use of paralinguistic features of text, for example emoticons, capitalisation and multiple punctuation (Crystal, 2001; White & Dorman, 2001), interacting online may encourage a more loosely-structured

and informal pattern of communication, including the use of more slang and textspeak (e.g. acronyms like 'LOL' for 'Laugh out Loud') (Scott et al., 2014). Moreover, some aspects of textspeak may result in less favourable impressions of those who use them (Fullwood et al., 2015), however the implications of how this might affect ones inclination to offer support to others has not been investigated.

Whereas in face-to-face groups participation is encouraged and often mandatory, members of online groups can 'lurk' in the background, only reading others' messages and without making any real contribution to the community (White & Dorman, 2001; Dickerson et al., 2000). Clearly, this has implications for the practicability of a group to continue if more members lurk than participate. There are likely to be a number of explanations for why people lurk, for example not understanding how to use the site, not feeling that they can make a valuable contribution or not feeling that their needs can be met (Preece et al., 2004). Further, lurkers feel that they receive less social support than those who do contribute and are less satisfied with their relationships with other members of the group (Mo & Coulson, 2010), so more should be done to encourage their participation (and this will be addressed in the next section).

Of those who do participate, there may also be an issue regarding whether their contributions are beneficial to others in the community or whether they use the site purely to meet their own needs. Clearly an online group can only function if members offer support in addition to seeking it. Research by Venner et al. (2012) suggests that anonymity may play a key role in determining the type of participation that members make. Drawing on SIDE theory (Social Identity of Deindividuation Effects) (Reicher, Spears & Postmes, 1995; Spears & Lea, 1992) their research suggests that the balance of anonymous vs. identifiable individuals in a support community is likely to have a strong impact on participation activity. When a group contains a mixture of anonymous and identifiable members, those who are anonymous will be more likely to use the group to meet their own needs (i.e. by asking for help) and less likely to support others. This has implications for group cohesion and whether or not support groups should encourage members to identify themselves and this will be discussed later.

## **X.7 Design Implications and Enhancing the User Experience**

In attempting to improve the user experience, perhaps the most obvious issue to address relates to the non-participation of lurkers, particularly given estimates which suggest that lurking rates can range anywhere from 45.5% to 90% of an entire community (e.g. see Mason, 1999; Nonnecke, 2000; Nonnecke & Preece, 2000). Lurking may be problematic if it means that very few people are making contributions and members are likely to turn to other groups when they do not receive responses to

their posts. Further, online communities will thrive from the richness that is provided by more members sharing different experiences, ideas and perspectives. Therefore, turning lurkers into active participators should be one key goal of any online support community. Preece et al.'s (2004) research into the reasons why people lurk on online support groups is not only enlightening because it suggests that lurkers are not always "selfish free riders" (pg. 221), but also because it offers a number of tips to site developers and moderators to encourage participation. For example, a clear policy statement (preferably communicated somewhere visible, e.g. in a welcome statement) should be included on the site outlining how contributions from all members are welcome and vital for the group to function. Moderators may also take the lead on personally inviting lurkers to get involved and may use tracking tools to monitor contributions. Finally, they suggest that online communities should take a leaf out of the book of e-commerce sites by rewarding contributors for the quality and quantity of contributions that they make. Although it may not be feasible to offer financial incentives, rewards may be offered in other ways. For example, the site could publish a list of 'top contributors' and update this regularly. The powerful influence of reward on reinforcing behaviours has been well documented in the psychological literature (e.g. see Skinner, 1938). Additionally, members could be encouraged to rate and leave reviews on other contributors, much in the same way that customers leave feedback for sellers on Amazon for example. At the same time however the authors acknowledge that close monitoring of activities would be necessary to ensure that competitors do not purposefully leave negative reviews to bolster their own status in the community or that members do not simply get their friends to write false positive reviews about them.

Another challenge faced by an online support group is in how to attract new members to their community. New members are always needed to substitute for those who have left the site. In addition, new members can help to keep the community fresh by offering new perspectives and ways of thinking about problems (Ren et al., 2007). In the first instance, a search engine optimisation strategy should be in place (for example, ensuring that relevant keywords are included in the content of the pages) to help increase traffic to the site. Strategies may also be used to transform visitors into fully-fledged members. For example, Ren et al. (2007) suggest lowering barriers to entry (e.g. only asking for necessary information upon joining), actively encouraging members to post once they have signed up and providing rapid feedback to any questions that are asked early in the membership cycle. Although a support community should take all steps necessary to recruit new members, this should be balanced against the potential that this might upset or irritate more established members. For example, new members will likely pose questions that longer-term members would have seen before on countless occasions. They may also be more likely to disregard or unintentionally violate the rules and conventions of the community, partly due to a lack of

experience but also owing to the fact that they haven't built up the same level of emotional investment in the site (Ren et al., 2007). Certain approaches may therefore be employed to ensure that newcomers do not disrupt group cohesion. For example, the site would benefit from a frequently asked questions section as well as a highly visible mission statement and 'rules of conduct'. Additionally, new members could begin their journey in a 'newbie garden' or be paired up with a more regular user of the site for the purpose of mentorship (Ren et al., 2007).

One of the biggest challenges faced by online support communities is in promoting and maintaining a collective identity. It would be beneficial for members to feel like they are part of the community and have a strong affiliation to the group; particularly given that one's social identity (i.e. the extent to which our self-concept is derived from our membership to specific groups) (Tajfel & Turner, 1979; Turner, 1985) has been shown to positively correlate with perceived social support and life satisfaction (Haslam et al., 2005). In essence, members will be more likely to remain loyal to the group if they feel a strong connection to it and a sense of shared identity provides a strong foundation for both providing and receiving support (Levine et al., 2002; Haslam et al., 2004; Haslam et al., 2005; Levine et al., 2005). Building and maintaining a collective identity might be hard to achieve as a community expands and as individual members' contributions get lost amongst the multitude of posts. One way to overcome this might be to break down the larger community into smaller 'neighbourhoods' and this might be based on geographical location for example (Ren et al., 2007). In addition, it is likely that members will create more meaningful bonds with other users if they actively engage in both helping and seeking behaviours. Finding ways to encourage participation on both fronts would therefore likely pay dividends. One possible method to achieve this would be to create both 'anonymous' and 'identified' neighbourhoods. Theoretically, it should be easier to create a sense of shared purpose in a community if all members are on a level-playing field and, as previously noted, a group which contains a mixture of anonymous and identified members tends to result in the anonymous individuals using the group in a more selfish fashion (Venner et al., 2012). Additionally, online support communities should encourage users to identify themselves where possible. However, clearly this must be balanced against the potential benefits associated with remaining anonymous from other users and might not be feasible for all types of communities. Encouraging members to offer support as well as seek it will not only help promote a collective identity, but should also produce a variety of other benefits. For example, research has shown that in helping others, we might increase our own self-worth, sense of purpose and belonging (e.g. see Taylor & Turner, 2001).

Finally, a number of additional strategies may be undertaken to improve the user experience. Communities need a strong presence from moderators who should be selected carefully

on the basis of their dedication and subject-specific knowledge. Moderators should play a key role in monitoring illegal, anti-social and inappropriate conduct. A clear policy on dealing with aggressive and anti-social users should be in place. For example, persistent offenders should have their membership revoked to maintain a sense of harmony in the community. It is also important that codes of conduct are made clear so no doubt will be left in the minds of members as to what is acceptable behaviour and what is not. Communities may also consider requiring their members to log-in to the site and ensuring that contributions to the forum are password protected and not in the public domain. This will create a sense of protection and may encourage more members to reveal their identities while at the same time giving them a sense of freedom to self-disclose. In addition, this would likely discourage those whose sole purpose would be to harass and attack other members as signing up would entail some effort. Furthermore, considering the limitations that text-only communication places on our ability to express ourselves (particularly on an emotional level), sites could incorporate elaborate emoticon creation facilities and the ability to communicate via other modalities (e.g. video chat) if required. Lastly, some consideration should be given to make online communities as inclusive and accessible to all as possible. This should include adherence to Universal Design principles to ensure that people with disabilities can make effective use of the support community (see **Chapter X** for wider coverage of these issues).

## **X.8 Summary and Conclusion**

In this chapter we have noted that for some individuals, joining online communities may be the most effective option available to have their support needs met. This might be, for example, because the condition that they are living with is uncommon and finding others who understand their experiences offline would not be easy. We have also discussed the many benefits that come with providing and seeking support in cyberspace. For example, members have more control over the amount of identity information that they disclose which gives them a greater sense of freedom and protection to discuss sensitive, embarrassing and private topics. As well as there being a host of advantages, we have also outlined a number of shortcomings associated with online support groups. For instance, the distanced and often anonymous nature of interaction means that members are under no obligation to participate. There are a number of challenges faced by online support communities (e.g. attracting new members, dealing with lurkers); however within this chapter a variety of strategies have been proposed, grounded in research evidence and theory, which may be employed to enhance the user experience. Adopting some or all of these strategies should produce a more comfortable, safe and inclusive environment in which to discuss experiences with others, leading to more effective social support provision.

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