

Online support groups: An overlooked resource for patients

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Summary: Online support groups: history, research, and sources

History

The Internet has enabled people to interact in new ways. ‘Virtual communities’ long predate the World Wide Web (WWW) and online support groups exist in huge numbers, yet they are little researched.

Computer-based virtual communities allowing many-to-many communication date back to at least 1971 and their implementation on the Internet (or ARPANET as it then was) date back to somewhere between 1971 and 1973. (1,2) The idea was invented multiple times and emerged in many forms. Communication can either be synchronous or asynchronous. An example of synchronous communication is a chat room where multiple users can log on, the messages they type appearing in real time. The commonest asynchronous form is the email list: individuals send emails to a common address, which are automatically forwarded to everybody on a list. The favoured technology for online groups has changed over the years. By the late 1980s, email lists (using software like LISTSERV) and Usenet were dominant. The end of the 1990s saw a new generation of email lists with easy-to-use Web-based controls, like the popular Yahoo!Groups <http://groups.yahoo.com/>. Meanwhile, Web-based discussion boards have led to a resurgence in online groups. A 2001 US survey found that 84% of Internet users had contacted an online group. (3) Commercial Web sites see the value of establishing online groups these days. (4) Online groups are central to Internet use.

Online support groups (OSGs) date back to at least 1982 and possibly the late seventies. (5) So, what is an OSG? For this article, I am defining them as online communities for those affected by a common problem, in particular those related to health or social circumstances. They involve mutual support and information provision (and the two can be inseparable). Compared to the use of Web sites, research on OSGs has lagged behind, despite the fact they are very numerous. Yahoo!Groups lists almost 25,000 support groups, although this may represent only 7000 active groups, (6) and there are many other sources of OSGs. The aforementioned US survey found that 28% of Internet users had contacted an OSG, (3) a figure that has grown since. (7)

OSGs are hugely diverse. Some are connected to organisations, many have an independent existence. Most are set up by individuals with problems rather than by healthcare professionals (HCPs), which means what they cover and who they are for is defined by the users, not clinicians. OSGs exist for everything from alcoholism to

Zollinger-Ellison syndrome and cover a range of issues beyond medical conditions (e.g. parenting, bereavement, victims of professional misconduct). There are OSGs set up for particular social groups with problems (e.g. lesbians with breast cancer <<http://health.groups.yahoo.com/group/LBCKIT/>>, Jewish individuals with alcoholism or drug dependency <www.jacsweb.org/Join_us/discussion_list.html>). There are OSGs for carers as well as those directly affected by ill health (e.g. families and carers of children with Wolf-Hirschhorn syndrome <www.4p-supportgroup.org>).

Research evidence for benefits of OSGs

OSGs are much used, but are they useful? Systematic reviews suggest they are, although the lack of research is a common theme. (8-10) Research is also biased in what groups it covers, tending to concentrate on groups set up by the researchers or HCPs. So in what way are OSGs useful? Key advantages of OSGs are that they are informative, specific, flexible, and disinhibited. OSGs have many of the same advantages and disadvantages as face-to-face groups: they bring together people with common experiences and allow them to share mutual support and information. They can share the sort of practical knowledge that HCPs can overlook. The commonality or specificity of the group is important both in terms of information being relevant and in terms of support, knowing others have gone or are going through the same experiences and allowing individuals to put their experiences in a context. A difference with online groups is that they can be more specific than face-to-face groups as they have a potential worldwide reach. Your local hospital may have a face-to-face breast cancer support group, but there will not be enough affected people locally for a Wolf-Hirschhorn syndrome group or a group just for lesbians with breast cancer. Moreover, once you have an Internet connection, OSGs can be more flexible and easier to access, not restricted to certain times and places.

Online communication is also known to be disinhibited. (11) The nature of online communication, the absence of social cues, the perceived intimacy and anonymity, mean that people may be less inhibited in their online behaviour. This may be a positive thing in the context of a support group, helping people to discuss difficult issues, overcoming problems of embarrassment. (12) Disinhibition, however, is seen as problematic in many online communities when it leads to 'flaming' (deliberately provocative or insulting posts). This can be a problem in OSGs, (12) although it seems less frequent. 'Spamming', unsolicited commercial messages, are another problem for many virtual communities. Note that most English-language groups are predominantly American and UK users can experience a culture shock.

A key use of OSGs identified by participants and researchers is the sharing of information and the quality of that information is probably the biggest concern for HCPs. Many early studies looked at the content of messages in OSGs, but this approach may be misleading. What matters is the effect that participation in the group has on the individual. (13) We need to move away from considering single messages and looking at the larger conversation. We need to understand the use of personal experiences rather than an evidence-based approach. While there is much mutual information sharing on OSGs, these groups also impact on how individuals *use* information. They can help

people learn how to find and use information: for example, users swap Web sites and *discuss* Web sites. They may also impact on individuals' underlying illness representations. (An illness representation is a person's understanding of, usually, their own illness, which has in many cases been shown to have a major impact on self-management. (14))

The study of what makes a good information source and how we can identify such is well advanced. So, what makes a good OSG and how can we identify one? At present, it is hard to be prescriptive. There is a literature on what makes a good online group: Preece (4) talks about the dual importance of sociability (how the online group works in terms of its social interaction) and usability (ease of use and functionality of the enabling technology). These issues are pertinent to OSGs too, but they do not address issues around information quality or use. A group may be lively and easy to use, but contain misinformation.

I suggest that the OSGs that should raise most concern are those with illness representations very at odds with orthodox medicine as happens with, for example, certain groups for functional disorders (like CFS and fibromyalgia) or alternative medicine. Another example are groups that promote or sanction behaviours that are more usually seen as psychopathological. Suicide groups have attracted much media attention (e.g. 15-16). A pro-anorexia group (17) like Project Shapeshift <www.plagueangel.net/psboard> may meet all the right criteria for sociability and usability, but we would see its ethos, to promote anorexia nervosa 'as a lifestyle and a choice', to be harmful. However, such groups may not be as bad as they seem. Anecdotally, some 'pro-suicide' online groups are helpful to those with suicidal ideation and, in practice, actually discourage suicide.

Finding OSGs

OSGs appear valuable in terms of support and information; users report being better informed. However, they present a very different paradigm: instead of users accessing a (hopefully) reliable source of information presented in an ideal way, we have peer-to-peer communication, sharing information haphazardly, often based on personal experience, but offering information that can be more tailored and more practical. There can also be a group dynamic in how people interpret and share information that is different from individuals acting on their own. Within that context, with its various caveats, it does seem worth recommending OSGs to patients and carers. Unfortunately, finding OSGs is not a simple task. There is no single, central database and OSGs are spread over multiple technologies (WWW, email, Usenet, other bulletin board systems). It is possible to run an email list from a home computer, so some groups are only ever known of through word-of-mouth.

However, here are some suggestions for where to look. There are a number of major providers. I have mentioned Yahoo!Groups above:
<http://health.dir.groups.yahoo.com/dir/Health___Wellness/Support> lists support groups. Another provider, Topica, has a list of support groups at

<<http://lists.topica.com/dir/?cid=2460>>, while still others are DelphiForums <www.delphiforums.com>, MSN Groups <<http://groups.msn.com/>> and AOL Groups <<http://groups.aol.com/>>. All these have directory structures, generally with some sort of 'Health' category, and search facilities. I find a belt and braces approach is best as directories may be incomplete and directory placement user-defined, while finding the right search terms is difficult and the text on which searches are made may be short. CataList <www.lsoft.com/catalist.html> lists the 54,114 public LISTSERV email lists (as of 18/02/05); one then needs to perform a search.

Switching technology, if you are familiar with Usenet, browse the alt.support.* hierarchy or use Google's Web interface <<http://groups-beta.google.com/group/alt.support>>.

Many OSGs will have an associated Web site, others are Web-based fora. These will show up in Web searches. However, finding an OSG rather than any other Web site about a condition can be difficult as there is no consistent terminology for support groups. 'Support', 'group', 'chat' and 'discussion' are all worth trying as search terms. Voluntary organisations often offer some sort of online peer support, so their Web sites can be a good starting place.

There are a number of attempts at general directories of OSGs, but they include only a tiny proportion of existing groups. Condition-specific directories are better, although again rarely comprehensive. MoSt GeNe offers a directory of OSGs for genetic conditions, <www.mostgene.org/support>. The Congenital Heart Information Network offers a list of relevant OSGs at <www.tchin.org/support>. A University of Sydney study has a useful list of depression groups, <www2.fhs.usyd.edu.au/arow/isd/Resources/online_support_groups.htm>. Within cancer, ACOR <www.acor.org> is a provider of LISTSERV mailing lists for cancer-related groups with an extensive directory. I am not aware of any directory with a formal system for assessing the quality of OSGs.

Conclusion

While they have great potential, given the uncertainty about what makes a good OSG, it is best to forewarn patients and carers of their limitations. As with Web sites, look to see who sponsors the group, although with most privately run by individuals, this is not necessarily informative. Some OSGs have archives that can be viewed publicly, which can give you an idea of their content. However, do not be surprised if your patients are already using online support groups!

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[all accessed 18/02/05]

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