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Online discussion forums for young people who self-harm: user views[†]

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Aims and method   To explore what young people who self-harm think about online self-harm discussion forums. SharpTalk was set up to facilitate shared learning between health professionals and young people who self-harm. We extracted themes and illustrative statements from the online discussion and asked participants to rate statements.

Results   Of 77 young people who participated in the forum, 47 completed the questionnaire. They said they learned more about mental health issues from online discussion forums than from information sites, found it easier to talk about self-harm to strangers than to family or friends, and preferred to talk online than face-to-face or on the telephone. They valued the anonymity the forums provided and reported feeling more able to disclose and less likely to be judged online than in 'real life'.

Clinical implications   Mental health professionals should be aware of the value of anonymous online discussion forums for some young people who self-harm, so that they can talk about them and assess their use with their patients.

Declaration of interest   None.

Self-harm is a serious and growing health problem among young people.[1–4] Young people are known to be reluctant to consult health professionals for emotional and psychological issues,[5] but are prolific users of online discussion forums and chat rooms. The sheer volume of online communities and forums suggests that they must offer some benefit to their users, but evidence of their effectiveness in improving health outcomes is lacking.[6] There are concerns that some online forums, especially those relating to self-harm, present considerable risk to users.[7–9] Many health professionals may be unfamiliar with these sites and their potential benefits and risks. This paper presents the views of young people who took part in an experimental online discussion forum known as SharpTalk.

Method

Recruitment and baseline questionnaire

Announcements on existing online forums were used to recruit 77 young people aged 16–25 who had self-harmed or who have been affected by self-harm. Although the divide between adolescent and adult services in the UK is at age 18, we recruited across the typical age range of those who self-harm[10,11] rather than by this artificial, and at times unhelpful, service divide. (An Australian study of 4-week prevalence of self-injury found the highest prevalence

(2.4%) among 10- to 24-year-olds.[12]) Eighteen professionals and final-year students in health and social care disciplines were recruited by emails and advertisements in two universities, three National Health Service (NHS) trusts and on the national websites of relevant professional bodies. All participants were anonymous and known only by a chosen username. All completed an online baseline questionnaire requesting information on demographics, history and patterns of self-harm, and internet use.

Forums

The 95 participants were allocated to three discussion forums, each with 25–35 members. As on most discussion forums, participants could see who else was online and could send private messages. SharpTalk operated as both a support group and an online focus group. It was much smaller than most forums. Each forum had three 'rooms' for: support/ crisis posts, relevant discussion/debate and random chat. Six of the authors acted as moderators, whereas two were known as 'researchers' and introduced topics and facilitated discussions. Participants were also free to introduce discussion topics. The forums ran from 15 June to 20 September 2009. Although one of the intentions of the forums was to get discussion between the students/ professionals and the young people, there was little participation from students/professionals. As a result, the moderators had to take a more active offering support and advice. Given this more active involvement of study

[†]See commentary, pp. 368–370, this issue.

The Psychiatrist

researchers, and that SharpTalk forums were smaller than many online discussion forums, we wanted to identify young people's views on these issues, as well as on their use of discussion forums in general.

Follow-up survey

After 10 weeks, we extracted themes and illustrative statements from the online discussion and developed questionnaires for both young people who self-harmed and professionals. We report here sections of the young people's survey relating to their views about discussion forums, forum size and moderation. The questionnaire was developed using Limesurvey (an open source online survey package, www.limesurvey.org/download) and the survey was completed online. Questions were presented on screen one at a time and used a mix of rating, frequency and quantity scales (the questionnaire is available from authors on request). Participants were able to add qualifying comments. All participants were invited to complete the questionnaire.

Analysis

Because of small numbers we collapsed 5-point agreement–disagreement scales to 3-point scales, and 4-point frequency scales to 2-point scales. We differentiated between statements where there was no consensus ($<$30 of the 46 answering the same way, i.e. either saying yes or no to the rating system), consensus (31–38/46 answering the same way) and strong consensus (39–46 answering the same way). Thirty out of 46 is 65% consensus (95% CI 51–79) and 39/46 is 85% consensus (95% CI 75–95). We give illustrative quotes in tables below.

Results

Young people

The mean age of the young people who self-harmed was 19 years. Most were female ($n = 73$) and White ($n = 74$). All except two lived in the UK or Ireland. Only four were living alone, whereas the majority were living with parents or relatives, with a partner (with or without children) or in shared houses. Nearly three-quarters ($n = 53$) were students, some of whom were also working.

At the start of the study, 34 young people had self-harmed within the past 7 days and another 20 within the past month. Four had not self-harmed for more than a year. All 77 reported having used cutting as a method of self-harm. Some participants also harmed by biting ($n = 35$), burning ($n = 44$), overdosing ($n = 48$), not eating ($n = 50$), bingeing ($n = 34$), misusing alcohol or drugs ($n = 35$) and hitting themselves ($n = 20$). All but two used the internet daily; 70 (91%) used one or more social networking sites (e.g. Facebook, MySpace, Bebo).

Of the 77 young people who self-harmed 47 responded to the questionnaire, but 1 was excluded from further analysis as the username did not correspond to any of those used in the forum. Results are presented for 46 young people (60%). As expected, frequent users of SharpTalk were more likely to respond to the survey. Responders had a mean of 148 episodes on the forum (i.e. they logged on, read, and possibly posted) and non-responders had a mean of 24 episodes ($t = 4.0$; d.f. $= 75$; $P < 0.001$).

Agreement with statements

There was consensus on the advantages of big forums ('Good that there is always someone online') and small forums ('You get to know people individually'). Most users did not need someone else online in order to post (Table 1).

There was very strong agreement in thinking that it was easier to talk about self-harm online to a stranger than to family or friends (Table 2). These young people much preferred to talk online than on the telephone, felt less

Forum size	N	U	Y	Examples of qualifying comments
Strong consensus A good thing about big forums is that there is always someone online	1	4	41	(Y) 'I agree with this to an extent, as when you are posting something you want replies quickly (e.g. in the crisis room), and the support is more likely to be there. However, if there are many people posting messages, it is easy for your post to get "lost" among all the other postings, and receive fewer replies'
Consensus I generally don't post unless someone else is online	34	9	3	(N) 'I would rather post when there's few or no people online as it means there's no pressure to keep up a conversation or panic if someone doesn't instantly reply'
A small forum like SharpTalk is nicer as you get to know people individually and can give more personal responses	3	11	32	(Y) 'This is true, but I've found that on bigger forums you tend to make friends and these people will respond to your posts more personally'
No consensus Posting for support in a small forum like SharpTalk puts me more in the spotlight than I want to be	19	5	22	(N) 'When you post for help you post for help. You need to be noticed else you just get lost' (Y) 'I felt awkward posting because it was so small, and if one person were to be snide I would worry that everyone would side with them'

Table 1 Forum size: views of 46 young people who self-harm, ranked in order of consensus, with examples of qualifying comments

Y, agree; N, disagree; U, unsure.

judged online and were more open, and anonymity was an important factor in this. One added:

> 'It doesn't matter as much if a stranger judges you, but if it is your family or friends then you will feel bad and guilty. Family aren't good at talking about stuff like this because they care too much and sometimes you just don't want to hurt them. Plus you don't have to censor things you say to strangers or make things seem less important than they are.'

Participants thought that they had learnt more about mental health issues from online discussion forums than from information sites. Although there was no consensus on

whether being a member of a self-harm support forum makes people self-harm for longer, only four agreed with this statement. The benefit of forums for some individuals was clear (Table 2).

The young people in the study were competent internet users and found discussion forums useful, yet they did not think that online therapy could replace face-to-face therapy (Table 3). Although some people felt alone online, the majority did not. Most young people wanted to know that others had the same feelings.

Table 2 Online information and support: views of 46 young people who self-harm, ranked in order of consensus, with examples of qualifying comments[a]

Online information and support	N	U	Y	Examples of qualifying comments
Strong consensus It is easier to talk to an online stranger about self-harm than to your family or friends	1	0	45	(Y) 'It doesn't matter as much if a stranger judges you but if it is you family or friends then you will feel bad and guilty. Family aren't good at talking about stuff like this because they care too much and sometimes you just don't want to hurt them. Plus you don't have to censor things you say to strangers or make things seem less important than they are'
Consensus I think that online people are less likely to judge you	6	2	38	(N) 'But only if you go on the right forum. I've had bad experiences on support sites where people weren't even slightly understanding and made me feel stupid. But on SharpTalk we're all self-harmers so that is our link to each other and you can hardly judge someone for something you also do'
No consensus Being able to communicate online helps my self-esteem	12	20	14	(Y) 'Being able to help people is a wonderful thing. It's great to know you're able to help people even if you aren't hugely stable yourself' (U) 'I think my self-esteem gets a boost when someone answers me or listens but it's not a major shift or anything and could also go the wrong way if no one replies, etc' (N) 'May have been true when younger, not now'

Y, agree; N, disagree; U, unsure.
a. A full version of the table is available online.

Table 3 Online information and support (frequency response): views of 46 young people who self-harm, ranked in order of consensus, with examples of qualifying comments

Online information and support	N/S	F/M/A	Examples of qualifying comments
Strong consensus I post for support on more than one forum at the same time	45	1	(N/S) 'Only if it is a mega urgent problem and no one responded on the first support site'
Online therapy could replace face-to-face therapy	42	4	(N/S) 'I have seen several different pros and I reckon that there's a connection that can be maintained face to face that can't be online'
Consensus I feel alone online	38	8	(N/S) 'There's always someone there for you. Always. People understand and even if they don't know you and have never spoken to you, you'll find a lot who'll go out of their way to help you'
When I post for support I want to know that someone else has had the same feelings as me	15	31	(F/M/A) 'It does help to know that I'm not the only one, not a freak for having these thoughts or emotions'
No consensus I practise saying things in an online forum before saying them in real life	19	27	(N/S) 'Sometimes but not often, mostly as I never say much in real life anyway' (F) 'It's something I do regularly before talking to a pro. Kind of sound things out'
When I post for support I want people to suggest actions to take	27	19	(N/S) 'Sometimes I do – if I'm asking for help with a particular issue. If I'm in crisis or upset I just need people to talk to me' (F/M/A) 'I want both areas of support most of the time, both the practical and emotional. I do find it hard to accept the practical actions people may suggest however'
When I post for support I find distractions helpful	24	22	(N/S) 'Very infrequently do I find that distractions work for me'

N/S, never/sometimes; F/M/A, frequently/most of the time/always.

The Psychiatrist

Table 4 Moderation: views of 46 young people who self-harm, collapsed from 5-point agree–disagree scales, with examples of qualifying comments

Moderation	N	U	Y	Examples of qualifying comments
Strong consensus It is nice if the moderators get involved with people and offer support	1	4	41	(Y) 'It's great when the [moderators] don't isolate themselves from everyone else. I always feel more comfortable in a forum where it's not ''us and them'' '
Consensus There is no need for moderators on a self-harm forum	30	14	2	(N) 'I think moderation is useful to ensure that particularly graphic or ''triggering'' posts are labelled as such, or deleted if really necessary'
No consensus It is better if moderators are, or were, self-harmers themselves	7	21	18	(U) 'I think it can help as it can mean they have a greater understanding. However, people who haven't self-harmed can still empathise with some of the struggles that someone who self-harms has'

Y, agree; N, disagree; U, unsure.

The respondents agreed that self-harm forums should be moderated and that it was 'nice' if moderators got involved and offered support, as opposed to simply 'policing' the site (Table 4), but there was no agreement as to whether it helped for moderators to have lived experience of self-harm.

Discussion

The responses to our questionnaire in general suggest that the young people who self-harmed felt that they could find support and discuss online issues which they are not able to address with family or friends. Baker & Fortune[13] argued that interactive websites provide an accessible and effective alternative to conventional psychotherapeutic and pharmacological interventions for self-harm. Our findings confirm this. When we applied for ethical approval, concerns were raised about the anonymity of participants, specifically that we could not intervene in the event of a suicide threat. However, our findings illustrate the significance of anonymity to forum users, allowing them to talk openly about sensitive issues in a way that they could not otherwise do.

Admittedly, our results represent the views of only a small number (46) of young people who self-harm, and participants are self-selected from online communities, but there is very strong agreement for some views. Of course, the views reported in this project may not reflect those of all young people who self-harm. It has been shown that some interventions for self-harm may work for some subgroups but not others.[14,15] The data were gathered using an unvalidated questionnaire because there was no alternative measure with known psychometric properties available. However, our questionnaire had strong face validity and was completed by 60% of those registered with the forum.

Anonymous online discussion forums, if well-moderated, are valued by some young people who self-harm and may offer additional support that is not available elsewhere. However, the young people in our study did not think that online therapy could replace face-to-face therapy and further exploration of their views is needed. Mental health practitioners could benefit through increasing their familiarity with self-harm discussion forums and their potential utility in engaging with, and supporting, vulnerable and disaffected young people.

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Young people, self-harm and internet forums

Commentary on . . . Online discussion forums for young people who self-harm[†]

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Summary A generation of digital natives are living their lives in fundamentally different ways from previous generations. The rapid advance of the internet and mobile telephones, and the adoption of online social media, mean that substantial parts of the social lives of young people are played out in online settings. This has implications for how young people discuss and seek help for mental health problems. This commentary discusses the role of online forums for young people who self-harm. Practitioners need to understand the potential harms and benefits, and explore how benefits can be harnessed and harms minimised.

Declaration of interest J.P. is the part-time Clinical Director of NHS Choices.

Internet technologies hold the promise of engaging young people with mental health problems through routes which are familiar to them, as well as supporting leaner, greener, digital public services, with greater involvement of informed consumers and reduced use of 'real-world' resources. Such technologies are becoming ubiquitous as costs fall and e-literacy rises and ever more devices become networked.

A generation of 'digital natives'

Young people aged 16–24 years have been characterised as 'digital natives',[1] a term used to describe those who have grown up with the internet, mobile telephones and other technologies, and who are fundamentally different from previous generations in the way they communicate, seek information, engage, interact and entertain themselves. Increasingly, young people access the internet through mobile telephones and games consoles.[2] They have expectations that public services such as healthcare will be digital. The advent of Web 2.0 technology is transforming social relationships, which are now played out in online settings, whether public or private – 77% of those aged 16–24 years have at least one social network profile.[2] The default mode of communication for young people is becoming text-based. In a population of university students, Horgan & Sweeney[3] found that many (31%) had searched for mental health information online in the past and 68% reported that they would use the internet for mental health support, although there was still a preference for face-to-face support. The importance of internet technologies to young people was demonstrated in a survey of 16- to 24-year-olds conducted by Hulme for the UK charity YouthNet.[4] In the survey, 75% reported that they could not live without the

[†]See original paper, pp. 364–368, this issue.