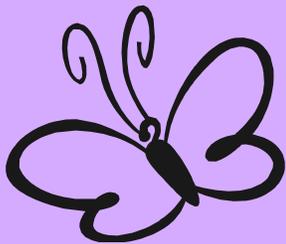


Self-Harm Self Help/Support Groups



User led research on individual's experience of attending a self-harm self-help/support group and the support needs of such groups.

Angela Smith & Jill Clarke

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The full report can be obtained from the Mental Health Foundation Website, www.mentalhealth.org.uk or by e-mailing a.smith433@ntlworld.com or jillclarke@rock.com . A summary report of the research can be obtained from the Mental Health Foundation by telephoning 020 7802 0300 or by writing to the Mental Health Foundation, 83 Victoria Street, London SW1H 0HW.

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Introduction

There has been very little research conducted into self-help groups in general in the UK and self-help/support groups in particular, for people who self-harm. To our knowledge, this is the only research carried out by members of such a group.

There are currently 34 self-help/support groups for people who self-harm in the UK, although not all groups are meeting (Bristol Crisis Service for Women [BCSW] 2002). Many groups are set up but may only function for a very short time before closing. I wondered why this was the case, especially as in my work with the National Self-harm Network (NSHN), we got numerous enquiries from the people wishing to attend or set up groups. For this reason, when the opportunity arose to do user led research funded by the Strategies for Living Project I decided to apply.

When the research proposal was sent to the MHF there was one researcher. After being encouraged to find others to help with the research, I was very grateful that Jill Clarke came on board to share the whole process of carrying out the research. It lightened the load enormously and we found that our skills complimented each other.

We are extremely grateful to the Mental Health Foundation [MHF] for giving us the opportunity, training and support through their 'Strategies for Living' (SFL) programme to do this. SFL have been carrying out and supporting user-led research for six years and have been funded by the National Lottery Board (now Community Fund).

Aims

For many, self-harm is a strategy for living with otherwise intolerable distress. We wanted to find out if and how groups worked in helping people through this, our aims were to:-

- To look at the positive and negative effects of attending a self-harm self-help/support group.
- To look at the similarities and differences between groups.
- To look at the support needs of groups and whether these needs are being met.
- To identify what would help to sustain groups e.g. network, conferences, workshops, newsletters etc.

Literature Review

What is self-harm?

All humans self-harm in one form or another. "Self-harm can be defined as any act which is detrimental to an individual's health" (Self-harm Alliance 2001). However some self-harming activities are more acceptable than others. For example kicking or punching a door in anger; the individual knows it will hurt but does it anyway as they are aware it will diffuse their anger and make them feel better. Another example might be that working long hours, in this culture is seen positively, however this does lead to detrimental effects on one's health (Arnold 1997).

More commonly, the term is used to mean direct harm to the body, such as cutting or burning oneself without intent to die. We will be using this term throughout this report.

Self-harm can be seen as an act taken in order to preserve life (BCSW 2000, Kindmond and Bent 2000, Reeve 2000, Clarke and Whittaker 1998). This may seem illogical, as harming one's body is detrimental to one's physical health and can put the individual's life in danger. However, if individuals are in extreme emotional distress, and are aware harming themselves will reduce this; they are sacrificing physical well-being to improve their mental well-being. Hence ultimately limiting the damage to self (Clarke 2003). The individual is showing great courage and determination to survive their emotional turmoil. These qualities can be harnessed to relieve the individual's emotional distress. As stated by the National Self-Harm Network (1998 p.1) "self-injury [harm] is frequently the least possible amount of damage that an individual needs to do in order to continue to fight for and preserve his or her life".

What is self-help?

There has been little research conducted into self-help groups in the United Kingdom. The self-help movement is more advanced in the USA and more recognised by the medical professions as being valuable in supplementing and extending the health and mental health care system (Self-Help Network 2002).

The philosophy of self-help is one of equality and empowerment. Members are all seen as equal, with everyone having a valuable contribution to make. Self-help groups are run by and 'owned' by their members and have no reliance on professionals. As the members own the group, it reflects what **they** feel is needed and members can control the focus, structure and process of the group. Self-help groups offer mutual support which enables people to explore their feelings around self-harm, they provide a safe environment through acceptance, for people to look at their coping mechanisms and what lies behind them. Groups provide an opportunity for people to gain trust and friendship and in turn a better understanding of

their self-harm. Individuals are helped and enabled by sharing common experiences and knowledge, by being helped by others and helping others, and the forming of friendships which leads to raised self-esteem and worth (Faulkner and Layzell 2000, Hyndman 1996, Wilson 1993). A study of people who had experienced acute long term mental ill health by Young and Williams (1987) found that people who attended a network of self-help groups needed fewer medical services.

Benefits people have received from self-help groups include: -

- Feeling less isolated and alone
- Empowerment
- Acceptance
- Increased self-esteem and confidence
- Friendship
- Emotional and social support
- Provide information and education
- A sense of control, regaining personal power
- Discovery of coping mechanisms
- Hope
- Increased life satisfaction
(SHN 2002, Hyde 2001, Adamsen and Rasmussen 2001, Kurtz 1997)

Self-help groups can sometimes be the only option for people. The help received from statutory services is often seen as judgemental and unhelpful (Pembroke 1996). Many people feel disappointed because when they do seek help they are not offered the help they need or do not fit the criteria for the help on offer (Corcoran 2003, Wilson 1995b, Gunn 1984). This can lead individuals to turn to others with similar experiences for support (Bywaters and Rolfe 2002, Harris 2000). Many personal stories from people who have direct experience of self-harm commented on how helpful contact with others who self-harmed was and how it was a turning point in their road to recovery (Clarke 2003).

Definitions and defining features of groups

Mutually supportive self-help groups.

Groups are run by and for their members. They have no leader and all members of the group are equally responsible for its smooth running. As the members own the group it reflects what they feel is needed. Individuals support each other by listening and empathising, whilst members explore their feelings or issues of concern to them. All members have direct experience of self-harm.

Support groups run by one or more paid facilitators.

These groups are run by one or more people, who may or may not have direct experience of self-harm (usually the latter). Their job is to help participants voice their feelings and ensure the smooth running of the

group. They are paid for this service. They are unlikely to share their personal experience of life or their views.

Support groups run by unpaid facilitators.

These groups are run by one or more facilitators who usually have direct experience of self-harm. Their role is very similar to that of paid facilitators but they are more likely to share personal life experiences with members of the group.

Support groups do not meet all the criteria of self-help groups, but they provide support through similar shared characteristics. With support groups there is likely to be differences in power between members of the group and the facilitator (Oka and Borkman 2000). There are both advantages and disadvantages to this. With a designated individual(s) in charge there is a named person who is responsible to ensure the smooth running of the group and funding of the group. Some people feel safer knowing there is a leader present and research has shown that professionals are happier to support and refer people to groups with a facilitator (Salzer, Pappaport and Segre 2001). However, this can lead to group members being less equal and less empowered, with looking to the facilitator(s) for answers and support.

Methods Used

It was decided to employ two research methods to the study to find out as much information as possible. Using questionnaires would mean we would be able to reach a wide range of people and get several opinions. However we recognised that this would not lead to the in-depth information which we felt the research question needed, so we also decided to conduct in-depth interviews with a number of individuals.

We designed the questionnaire using both our experiences of attending a self-harm self-help group and the reading we did around our topic of investigation. The questionnaire consisted of two parts. Section A was for people who were currently attending a self-harm self-help/support group, section B was for people who had previously attended a self-harm self-help/support group. Both of these sections contained the same questions with section B having an added question relating to the reasons for leaving the group. The questions on the whole were multiple choices with tick box responses, wherever possible respondents were given the opportunity to expand on their answers. (Questionnaire attached as appendix).

Recruiting participants

To find participants, flyers were sent out to members of the National Self-Harm Network (NSHN) inviting individuals to take part and, in addition, flyers were sent to all the existing self-help/support groups that we were aware of outside the NSHN. Advertisements about the research were also placed in mental health magazines. Potential respondents were asked to contact either of the researchers for more information and a questionnaire. We felt this process was important as it meant people were actively seeking to participate rather than feeling obliged to. It also had the added financial benefit of saving money on postage as questionnaires were only sent to those who showed an active interest in taking part. Forty five questionnaires were sent out; quite a few were sent in multiples to groups. Thirty four were returned completed; this gave us a response rate of 75.5%.

At the back of the questionnaire, individuals were asked if they would be willing to take part in the second stage of the study: semi structured interviews.

Once we had received the majority of the questionnaires back, a list was compiled of all those willing to be interviewed for the study. We selected a range of people for this part of the study. It was important to us to get a mixture of people of different ages and who were still attending a group and those who were no longer doing so. We also wanted to interview people from different geographical locations. It became apparent at this stage, that face to face interviews would not be possible with all the participants selected for interview. This was due to both financial constraints and geographical distance. We resolved this by conducting some of the interviews over the telephone.

Both the face to face interviews and telephone interviews took similar formats with the same topic guide used. The topic guide had again been developed by us based on our personal experience along with important issues that emerged from early analysis of the questionnaires. The topic guide contained several areas which we wished to cover but also allowed for the participant to guide the direction of the interview.

The interviews were recorded to ensure an accurate record of participant's experiences. For the telephone interviews a hands free phone was used to enable the recording of the interview. The interview recordings were then transcribed verbatim and coded to develop themes and sub-themes.

Ethics

The topic of research is a sensitive subject area, so steps were taken where possible, to ensure participants well-being and to help them feel a valued part of the research.

As stated earlier, flyers were sent out to potential participants and not actual questionnaires as we didn't want people to feel pressurised to fill them in. The questionnaires were anonymous. As much information as possible was placed with the questionnaire so participants felt fully informed about the purpose of the research.

Those individuals who agreed to be interviewed were sent a detailed information sheet (see appendix) which outlined the purpose of the research and what would be involved. For those interviews, which took place face to face a consent form was signed, for those, which were conducted over the telephone; verbal consent was sought from participants. Participants were given the opportunity to ask questions at the interview. It was made clear that participants had the right to withdraw their consent at any point in the study. To ensure this was the case all participants were given the opportunity to have a copy of their transcript. They were then able to withdraw sections or the whole transcript if they wished. All participants were happy with their transcript and nothing was removed or changed. However one person enlarged upon the information given at interview. Two participants were given a copy of the final draft research report to read, comment and suggest changes. Both were happy with the content of the report and felt it accurately reflected what they were saying.

To help ensure individuals well-being participants were offered time at the end of the interview to discuss any difficult issues that had arisen. Each participant was also given a leaflet (appendix), which contained a number of helplines, and organisations that could be contacted for further support and information. Face-to face interviewees were given a small gift and £10, whilst telephone interviewees were given a thank you gift of £10.

It was also important confidentiality and anonymity was maintained (Carpenter 2003a, Polit and Hungler 2001). Measures were therefore put in place to ensure only the researchers had access to personal information (e.g. names and addresses). Interview tapes and transcripts were kept in a

secure place and were coded so they could only be identified by the researcher where necessary. Any quotes taken from the transcripts and used within this report have been chosen to ensure individuals cannot be identified.

Four of the interviewees were members of the group the researches attend. This may have influenced what was said. However eight of the interviewees were unknown to the researchers. The findings from all interviews were similar which shows there is unlikely to have been bias.

Research Findings

This section describes the findings from the 12 in-depth interviews and 34 questionnaires. The analysis identified many issues raised by people setting up and/or attending self-help/support groups for people who self-harm. Ten themes were identified, these were:-

- Meaning of self-harm
- Locating a group/setting up a group
- Group characteristics
- Group process
- Benefits and Gains
- Difficulties for groups
- Difficulties for individuals
- Other support
- Leaving the group/group closure
- How others view self-harm

Where respondents own words are used (*which appear in italics*) some names and places have been altered to protect individuals identity.

Personal and demographic characteristics

We had wanted males and females who attended or had attended groups to participate, however, our respondents were all female. Most of the participants attended a female only group but 13 participants attended a mixed gender group.

- 22 of the 34 respondents currently attended a self-harm self-help group.
- 11 of the respondents had attended a self-harm self-help/support group in the past but were not attending a group currently.
- One woman who self-harmed currently attended a mental health self-help group for support with her self-harm but the group was not dedicated to solely self-harm.

The respondents had been attending a self-harm self-help group for a variety of lengths of time (this also includes the time in groups for those who are no longer attending):

- 7 women had been attending for less than 3 months.
- 10 between 3-6 months.
- 1 between 6 months and a year
- 16 had been attending for over a year.

The majority of respondents were therefore well experienced in attending these groups.

Of the 11 who used to attend a group:

- 5 respondents had left the group in the last 12 months.
- 6 had left over a year ago.

Of the respondents selected as interviewees:

- 6 were attending a group at the time
- 6 had previously attended a group but since left.

Meaning of Self-harm

A broad definition

All of the participants felt that self-harm involved doing something damaging or detrimental to themselves. This, however damaging, was often seen as a coping mechanism, a way of surviving intense emotional pain.

"It's quite destructive isn't it really, it's not exactly a positive thing to do to yourself but I don't know what I would have done without it to be quite honest."

"Self-harm means lots of things to me. Most of them are bad though but I suppose but sometimes I do truly believe that it is a valid response to a situation as anything."

All the participants felt that the behaviours which can be termed as self-harm are much broader than the stereotypical view of cutting, burning and swallowing harmful substances etc.

"I had this kind of view that initially that self-harm was cutting, biting and scratching and then I realised that there was a whole spectrum out there."

"I think if you damage yourself in any way then that's self-harm."

Survival not suicide

All the participants stressed that self-harm was different to suicide and felt that it has the opposite intention, that of survival. Many felt they would be in a worse position in life than they were at present, if they had not been able to self-harm.

"I don't see it as a prelude to suicide; I see it as a survival thing."

"I feel that if I didn't self-harm then I probably still wouldn't be here, it has been a survival tactic you know."

"At times I have done it as a way of looking after myself. That sounds twisted I know but I had a few really awful years of utterly hating myself and deliberately putting myself in dangerous/nasty situations that would make me more miserable. By cutting myself [...] I could sort of nurse myself better, or my wounds, at any rate it provided the only valid reason to look after myself, albeit in a limited manner."

A way of expression

All the participants felt that self-harm helped them to express their emotions and cope with feelings which they found difficult to articulate to others.

"I think for me it's a way to relieve frustrations that I have. I think it's a way of coping really more than anything. I just find that sometimes I just get overwhelmed with feelings and emotions and I don't know what to do with them, I don't know how to express myself so that somebody else can understand."

"I think a lot of times I have done it as a way of grounding myself, focussing my brain by making me concentrate on one thing."

"Self-harm also provides a way of articulating an emotion that I perhaps can't verbalise."

Two of the participants felt that self-harm enabled them to have some control over the emotional pain they felt which helped them to cope with the pain inflicted by others.

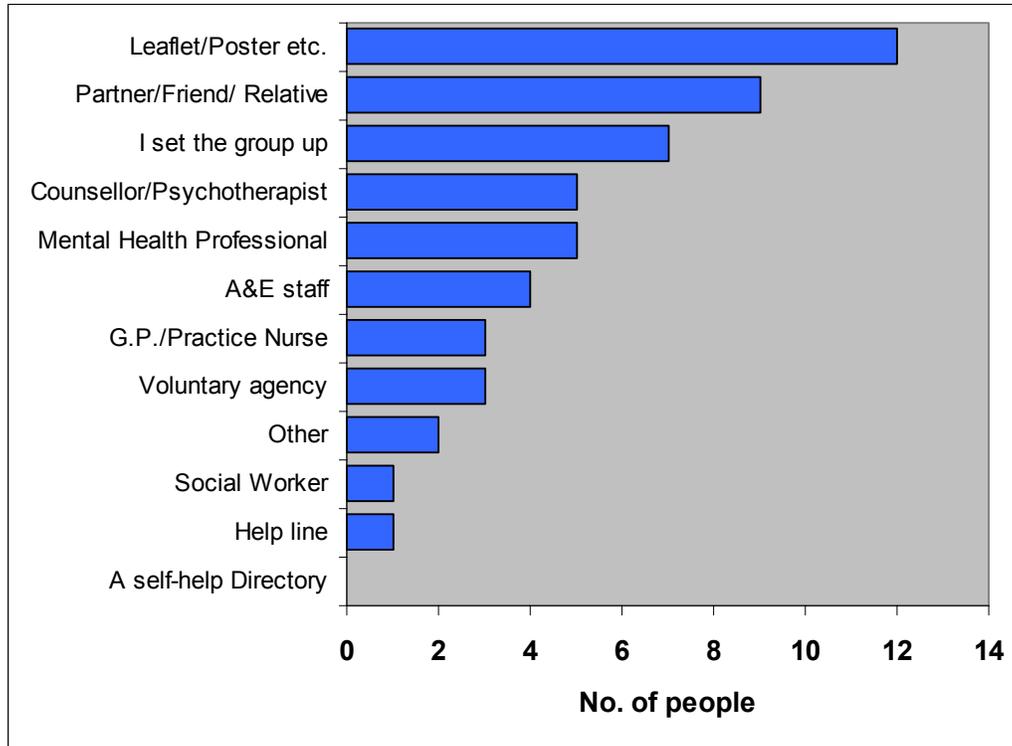
"In some ways it gave me control over the pain I felt, rather than having it inflicted on me by someone else, somehow inflicting harm on myself as I say, got me through the other afflictions [...] it was just helping me through life in general."

Locating or setting up a group

Most people found out about their group through chance and were not actively seeking to find one. However many of the women were seeking some kind of help.

"I've been searching for help for years, but just couldn't seem to find anyone to help, the psychiatric services have been no use at all, the little help they have offered me has only been for a few weeks and then they decide they cannot do anything for me and just leave me on my own again and then I found the group. It was the only help I could find but it wasn't for the want of trying"

The graph below shows the responses to the question 'How did you find out about the group?'



Graph 1:- How did you find out about the group?

N.B. Respondents often ticked more than one box in this section. When 'Other' was ticked we asked people to give us details. These were defined as the internet, information from NHS Direct and from a friend who worked for a health authority.

Making Contact

Initial contact was made in one of three ways: by phone, letter or email. Mostly people met someone from the group to find out more information before deciding that they would like to attend the group.

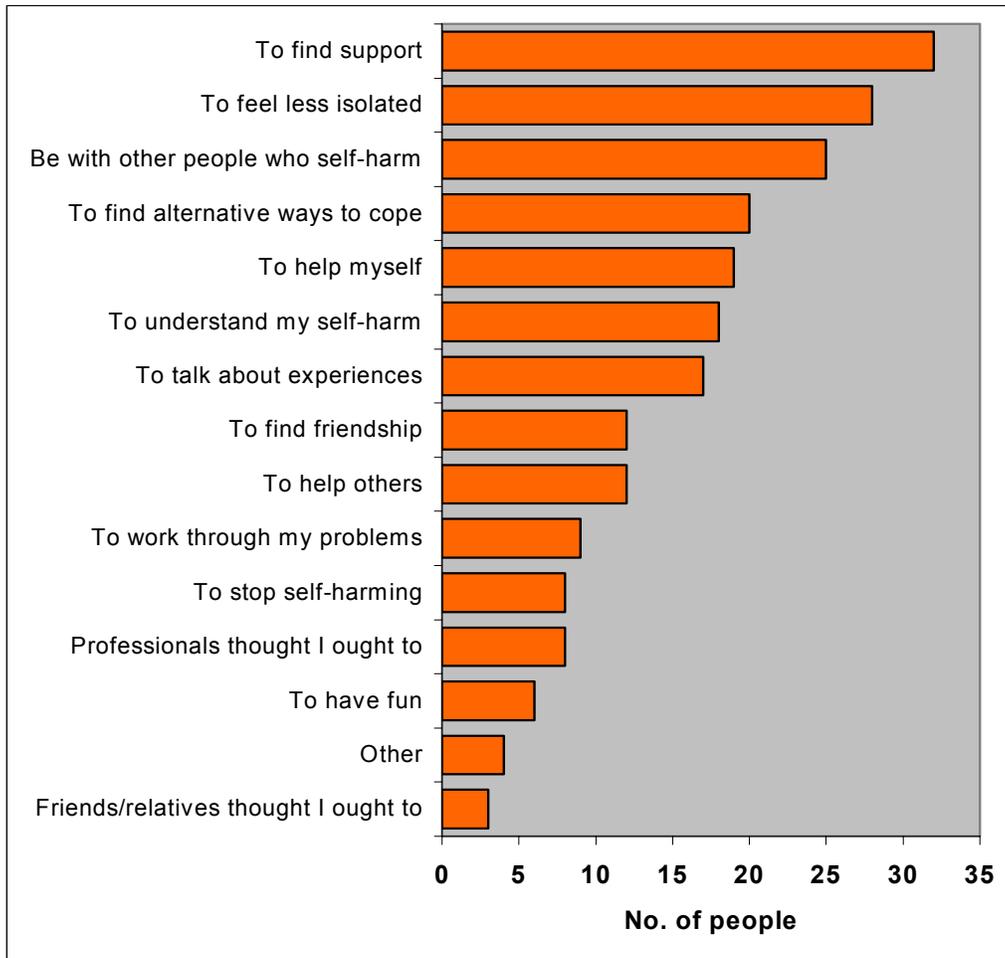
"I phoned up and spoke to her about it (the group) and she told me a bit about it, and she told me a bit about herself and asked me a bit about myself and arranged to meet.[...] So she could tell me a bit more about the group face to face and she could get to know me and see if I was a suitable candidate really."

Two of the respondents were involved in setting up their group, one stated;

"I thought, well if I don't set up a group you know, then I have no form of help. So partly it was for selfish reasons I was motivated to establish a group because there was nothing and partly because I'd been in psychiatric wards and I realised there was a lot of people who did self-harm and there was no

support. I knew there was nothing available to them and I thought I'd give it a go setting one up, so I did."

The women identified a number of reasons why they attended the group these can be seen in the graph below.



Graph 2:- Why did you decide to go to the group?

N.B. Most respondents ticked more than one box and some ticked most of them. One of the respondents who ticked 'other' went on to explain what this meant...

"To find out about other organisations and get factual information and book titles about self-harm and as part of feeling less alone. Also to feel it was less of a 'crazy' thing to do and not a 'bad' thing to do."

Two of the interviewees felt that they were unprepared for what to expect from the group which caused some distress.

"They were certainly wearing short sleeves. That was a bit of a shock to me when I first walked in, but I didn't really, wasn't really prepared for that."

Group Characteristics

Some of the groups had one or more facilitators whose job it was to meet new members and oversee the smooth running of the group. Most groups were mutually supportive. Commonalities within groups were identified. These were:-

The lower age limit for members was 16 and there was no upper age limit set. Those who participated were between the ages of 18 and 59.

13 respondents were from mixed gender groups although there were predominantly women-only groups.

Groups tended to have between 6 and 12 members however, one group had 47 members and another had 4.

All the groups met weekly for two to two and a half hours; however one group met for one hour and another from 10 am to 4pm. Most of the groups were open to accept new members all of the time. However, one group ran for 15 weeks at a time and had a loose programme for that period. All of the groups met at premises owned/rented by voluntary sector organisations.

Groundrules/ Aims

All of the groups had groundrules such as respecting confidentiality, respecting each other and trying to be non-judgemental. Over half of the groups had a 'no self-harm on the premises ground rule.' These rules were mostly set up at the start of new groups but some evolved over time. Groups tended to discuss what groundrules needed to be in place in order for the group to feel safe.

"We all sort of sat down and discussed groundrules and things that would sort of make us feel safe and enable us to be open within the group really."

From our research we found that funded groups tend to have more formalised aims for their groups. Interviewees were often not aware of the aims of the group as such, but were aware of the groundrules.

Group Process

Groups tended to have three distinct phases of each meeting. Groups would begin with a period of settling in and everyone welcoming each other. Some groups would spend the next phase doing activities such as creative writing or exploring their feelings around self-harm. In some groups, each member would be given the opportunity to talk about their week, the things that had happened and feelings provoked. However there was no pressure in groups for people to talk. Over two-thirds of respondents felt safe in their group to talk.

"I felt great. I felt really good because of what I had released; to talk to someone that knew what you were going through."

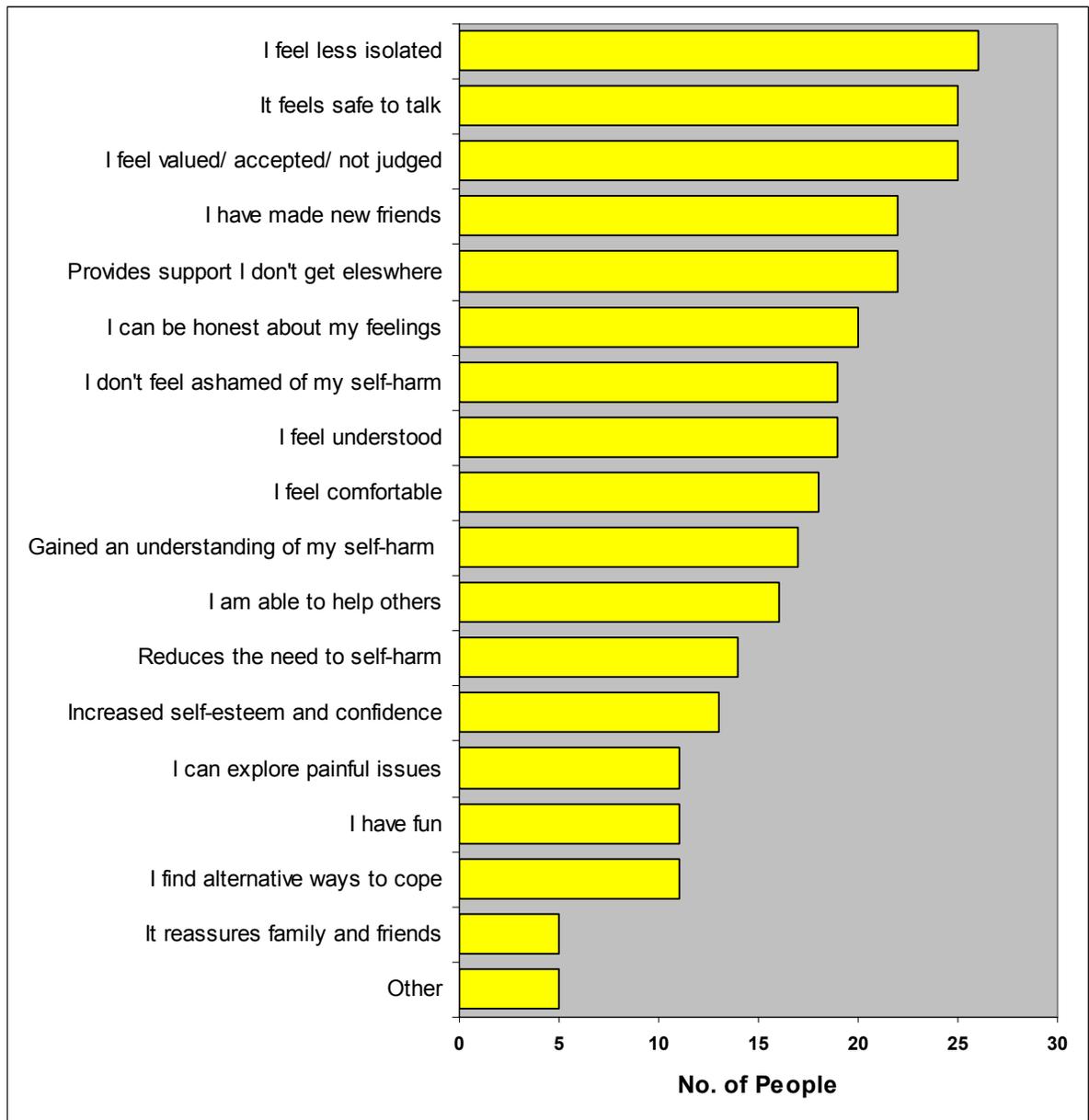
However, one interviewee felt that they were not given an opportunity to talk about issues around self-harm and their feelings as the group was more activity based, which did not suit her. Another woman felt unable to talk due to feeling she was very different to others in the group. All but two of the groups had a break in the middle and one woman felt more able to talk during this time, as she felt safer discussing neutral subjects.

The third phase of most of the groups would involve looking at positives to end the group with. Group members felt this was a good idea as it prevented them from leaving the group feeling too negative and focussed them on looking to the week ahead.

"I always really like ending on a positive note you know because it's all too easy going away feeling all too gloomy and I think even if you just said, I'm looking forward to going home to bed now, it makes you think about what you were going to do in the week ahead."

Benefits and Gains

There were many benefits gained by all participants. In the graph below the results from the questionnaire are shown.



Graph 3: - What benefits have you got from the group?

N.B. Some respondents ticked more than one box. One person who ticked 'other' went on to say...

"Because it felt okay to read and talk more about self-harm. [...] I found good books and found SHOUT¹ pen pals. [...] I went on to do a radio interview and some user training."

¹ Self-Harm Overcome by Understanding and Tolerance - newsletter no longer in existence

Reduced isolation

Many of the women stated that when they started self-harming they were not aware that other people also self-harmed and that it was a relief to realise they were not alone. Over two-thirds of people in the study stated that they felt less isolated because they had attended the group. The women really valued the sharing of common experiences and felt that this helped them to better understand themselves and each other.

"I guess the feeling that I wasn't alone, because initially there was a feeling of isolation, oh no-one else does this and I must be the only person in the world who does it because I've never come across it, so it was nice to know that I wasn't alone."

"I think one of the positive things that really stands out for me, is that it broke down the sense of shame and isolation around self-harm."

"It made me feel as though I wasn't such a freak."

Acceptance

Over two-thirds of the respondents felt valued, accepted and not judged by others in their group. This was considered to be of vital importance in order to feel safe within the group.

"To feel accepted, not judged or asked stupid questions; to feel safe."

"Somewhere where you can be a self-harmer..."

Making Friends

Making friends was one of the benefits of attending a self-harm self-help/support group. Some women felt it was nice to socialise with friends they had made in the group away from the group situation.

"It is good to be sociable with people who understand, not necessarily dwelling on self-harm; having a laugh, a coffee or a shopping trip."

"It felt like we had time to get to know other aspects of each others lives and share good times as well as bad times. It made me feel more 'normal' and acceptable."

Helping others

Many people were able to offer support to others, which often boosted their self-esteem; they were not recipients of a service but were active members of a group that they had a stake in. They were enabled to show their strength and ability in helping others.

"You will find that one person will recognise straight away that somebody is low and they will go and talk to that person so, in a way, they are self-helping one another."

"It gives me a sense of purpose, doing something usefully that I am actually useful in listening to other people."

Effect on Self-esteem

All but two of the women felt the group had a positive impact on their emotional and mental well-being. Before attending the group the women felt their opinions of themselves were low. By being accepted by the group and not being judged increased their self-esteem and made them feel more like worthwhile people. The women felt that this gave them the self-confidence to talk about their problems and acquire support from the group.

"It supports me in terms of it made me feel better about my self; it gave me a boost mentally and emotionally."

"My self-esteem increased because the group made me feel like a more worthwhile person, [...] there were times when I felt despairing really and being able to go along to the group and sort of talk about things and gain support really kind of helped me feel like I was a valid person."

"My confidence sort of shot up."

New skills/abilities

Respondents highlighted that they had gained new skills and/or had their strengths and abilities illuminated. This had a positive affect on them. One person, who overall had found their group to be unhelpful and at times very negative, still described learning things from the group she attended which had enabled her to participate in a new group she now attends.

"I found I had other ways of coping, other skills that I didn't realise."

"It never occurred to me before I set up the group that writing poetry and doing art work was maybe another means of getting your feelings out, other than cutting your arms."

Gaining Information

Quite a few of the respondents stated that they had gained information about self-harm through their group.

"Information as well [...] knowing how to keep safe and perhaps picking up useful information, I think getting in touch with other organisations, to get support and information."

Effects on self-harm

Statutory services for people who self-harm are mostly geared towards helping them to reduce or stop self-harming, whilst self-help groups have less or no emphasis on this (Tantum and Whittaker 1992). However, for some individuals who attend groups this is an important aim.

Some of the women believed that their self-harm had lessened due to being a member of their self-help group. This was linked to acceptance and being able to explore painful issues without the fear of control being removed.

"I think the main thing that's helped me reduce my self-harming is the ability to talk about my feelings; I've never been able to talk to anyone before about my feelings. I've had help through psychiatric services but they don't seem to understand and judge and label you and there is always the fear that if you say the wrong thing that they're going to lock you up."

Two respondents felt initially that attending the group led to an increase in their self-harm, however it eventually decreased to less than before they attended. They felt this would be an issue in all types of therapies and not just self-help groups.

"I think initially that my self-harm might have increased; the sort of frequency of it really and perhaps even the severity of it as well. I think that's because I was admitting that I had a problem and that I was talking to people and being open, or trying to be open about my feelings really and sort of laid bare"

"that's a problem you get when you talk about your problems anyway whether it's in a self-help group or more formal therapy"

Difficulties for groups

Funding

Lack of and difficulty in obtaining funding was one of the main challenges the groups faced. This impacted on the support and activities groups were able to offer. The groups most likely to receive funding were facilitated support/self-help groups, those without a designated facilitator tended to have more difficulty. Funding was difficult to obtain as groups were often required to prove the benefits of the group to outsiders (e.g. health professionals). Funding bodies would often view the success of the group by the reduction of self-harm (Tantum and Whittaker 1992). This was often at odds with the ethos of the group, as the groups aim was not to stop self-harming but to support each other in exploring their self-harm.

“The funding, that was difficult to this day because I got the one off sort of grant but then I had to prove that it was working and I was very nervous. I had to give speeches to various health professionals to prove that it was a valued, needed service.”

Training

Two of the respondents, who either attended a facilitated group or facilitated the group themselves, felt that they needed training in running groups. However, this issue was not raised by any of the respondents who attended non-facilitated self-help groups.

Pressure on leaders/facilitators

Some participants stated that facilitators and sometimes members of the group felt under enormous pressure just to be able to continue, due to having to spend a lot of time seeking funding. It was often down to one or two people who felt responsible for this. This sometimes led to members feeling guilty that they were not able to help with this due to time constraints or other factors in their lives.

The smooth running of some groups was often left to one or two people. This involved dealing with enquiries about the group, sending out information, meeting prospective members, gaining publicity for the group, allaying the fears of professionals, raising awareness about self-harm, sorting out the practicalities of the group; such as, where to meet and having to be at the group each week in order to let people into the building.

“people relied on me too much”

“the responsibility is too much sometimes”

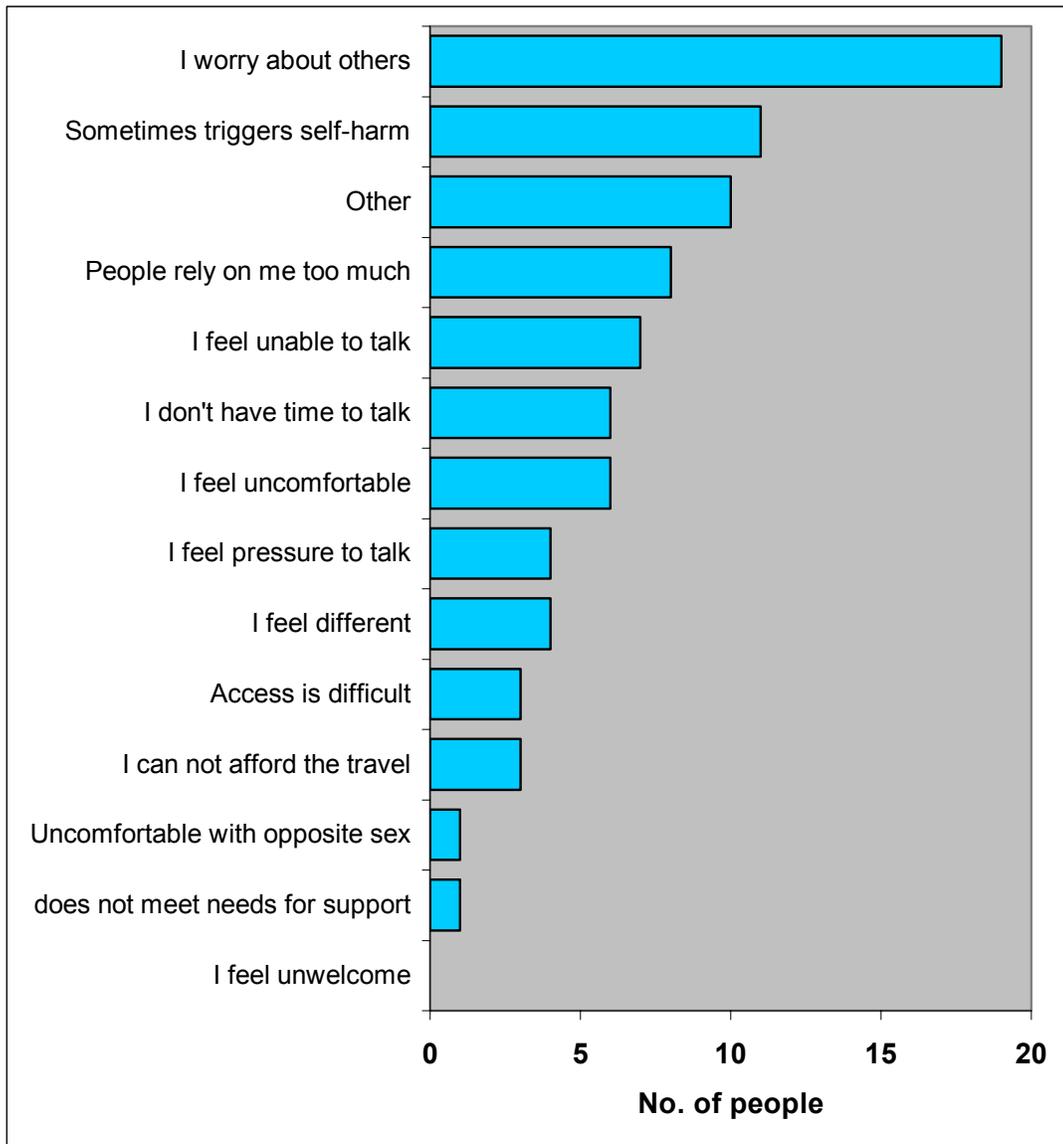
“I sometimes felt awkward and guilty that I wasn’t doing enough”

Another comment made by a participant was to do with time allocation.

“It felt hard for a facilitator to fairly choose who should have time to ‘work’ within the time. I felt it would have been good to have a user only group at times”

Difficulties for individuals

Some individuals experienced difficulties in relation to the group. Below the chart shows the findings from the questionnaires.



Graph 4: - Are/were there any difficulties in attending the group?

N.B. 'Other' comments have been absorbed elsewhere within this report.

Coping with others distress

Almost half of the women who took part in the research stated they sometimes worried about others in the group. Worry seemed to be invoked by two different scenarios: either an individual had been distressed during the meeting or a member had not turned up to the group for a while and had not been in touch. The women felt that this could have a negative affect on their well-being.

"I guess sometimes when people get really distressed and although you do as much as you can to help, they're going to go away and sort of, continue to be distressed [...] you do sort of take things away with you [...] I think that's sort of quite hard really [...] you're not feeling too great yourself but you're also worrying about how everyone else is or [...] you sort of think oh I should have done this and that and you start beating yourself up about it really, so it can have a bit of a negative effect sometimes."

"hearing certain things, especially other peoples bad experience at Accident and Emergency, or whilst in hospital, can freak me out".

Lack of support to individuals outside the group

Another problem highlighted was the lack of support group members received outside group times. This often led to people feeling responsible for others. Groups dealt with this in a variety of ways: some groups offered a helpline with one of the facilitators holding a mobile phone that people could ring if they needed support; another group set aside certain times when the facilitator would be available to take calls from group members.

"My chief concern is that there are a lot of people out there that have whole weekends and I know weekends are really hard for a lot of people where there's no contact."

Coping with their own distress

Whilst most respondents experienced a positive effect from attending the group, there were two women who felt that it had had a negative effect on their well-being.

The first woman felt she did not fit into the group as she was much younger and was the only group member who had not been in contact with the psychiatric services. When describing these difficulties she stated:-

"I was at least 10 years younger than all of them, which at the time felt huge. I felt completely insignificant and small in the face of those women who had frequently been sectioned, had ECT (Electro-Convulsive Therapy), been abused by a parent etc. which left me feeling guilty for my feelings [which led to] self-harm, I felt anything I said was unimportant in the face of their pain, I felt I had nothing to offer the group as I was feeling so useless. Therefore I didn't talk much (despite spending the whole week before the meeting preparing myself). This led to anger at myself for not opening up, which in turn led to more self-harm"

This woman reflected upon this experience and with her increased knowledge of herself is now able to participate more fully in a new group. When asked what she had learnt she said:-

" and so I think going to that other one,[first self-help group] kind of made me realise if you want to get anything from it [group] really you've got to open your self up a bit and put yourself on the line really. Cos otherwise there is no point going. It's just that I couldn't do it at the time"

It is important to recognise that a group situation does not suit everybody. Sometimes people are not ready for this.

The second woman who had a negative experience felt she could not relate to the other people in the group as she felt different, which is opposite to the feelings of acceptance that most people gained from the groups they attended.

"Well I didn't feel I fitted in very well. It's probably just that they weren't my kind of people because they weren't."

She was the only student in the group and all the other members seemed to have met each other in the local psychiatric hospital. Since leaving the group she has become a member of an internet support group which she finds helpful.

Some of the participants felt unsettled when new individuals attended the group.

"When new people come, people are more sort of coy, they don't want to obviously talk about problems when they don't know if someone's just come to try it out for a bit [...] and you never going to see them again you know, it can sort of, get a bit frightening really, sort of, becomes a bit unsafe, as you don't really want to talk about things with people that you don't really know."

Location of group

All of the groups were located in buildings belonging to, or rented by voluntary sector organisations. It was highlighted that there were, or had been problems with the buildings due to mobility issues.

"I actually had quite a few problems with the building as I have arthritis and my mobility is not brilliant."

One woman who travelled to the group from another town felt the group was difficult to get to geographically and this also stretched her financially. Whilst another woman who was visually impaired found it difficult to get to the group in another area when it was dark.

Groundrules

Group members, who felt a part of the process of developing the groundrules, were happy with them. However, one woman felt unsafe at the group due to the groundrule of 'no self-harm on the premises'. She felt that in order to explore painful issues, this rule would need to be removed. She felt unheard and judged by the group when she tried to raise her concerns about this.

"There was a bit of conflict when we discussed the groundrules. But nobody seemed to actually voice anything about the groundrules except me and I sort of said that the rule about no self-harm during the group was maybe a bit difficult and they kind of freaked at me. [...] It felt quite hostile and so after that, I mean I didn't self-harm during the group but when I went home I did quite badly. So you know that was why I felt this wasn't a very good rule to have necessarily and I just thought we could talk about it"

Some of the groups did not have this groundrule and would allow members to harm on the premises if needed. All of these groups had experienced no difficulties in this area.

Other support outside the group

Meeting outside the group

Over three quarters of people who filled in a questionnaire met or phoned group members outside 'group time.' The majority found this to be helpful.

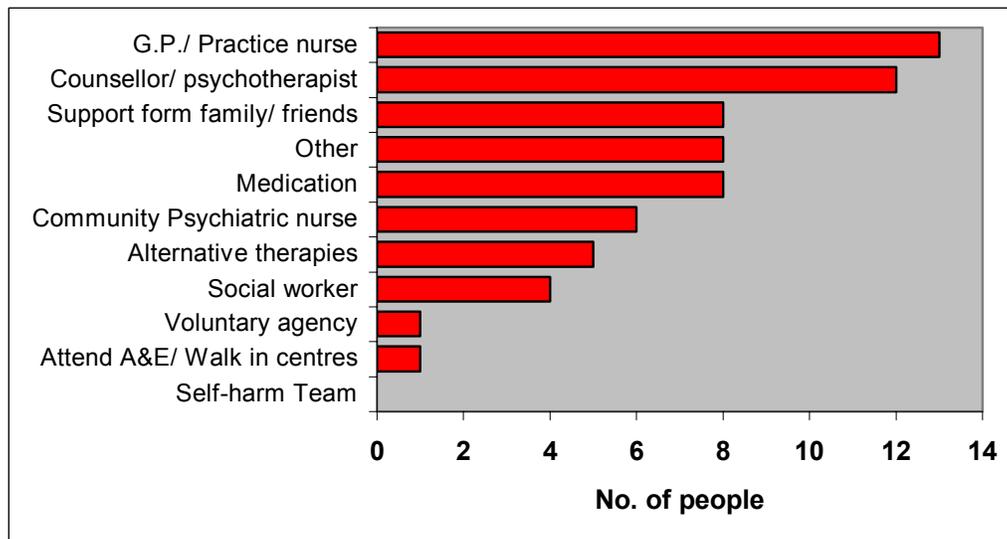
"It's nice to talk to someone who you know will not judge you."

Although people by and large found it helpful to phone or meet outside the group this carried pressures:

"I can get moral support if I'm feeling vulnerable and it helps my confidence to know someone else values me enough to call me when they are struggling but sometimes I feel responsible for the person who calls me, which can leave me feeling helpless."

Statutory services

The graph below shows what other help questionnaire respondents receive.



Graph 5: - What other help do you receive?

N.B. Respondents were asked to specify when they had ticked 'other'. These were:

- Newsletters, such as SPEAR² & SHOUT.
- Psychiatrist
- Boss
- Dialectical Behaviour Therapy
- Reiki
- Shiatsu
- Inpatient in a therapeutic community
- Rehabilitation workers

Some people had a mixture of support available to them outside the group. One woman in particular felt that going to the group and seeing a paid private counsellor complimented each other.

Many of the women felt that the help they received from services was unhelpful and on occasions, was detrimental to their health. They also stated that they had difficulty in finding the help which they wanted.

"I think the psychiatric services have really screwed me up[...] I think because he (psychiatrist) can't treat me with medication and stuff then he kind of really has given up to be honest."

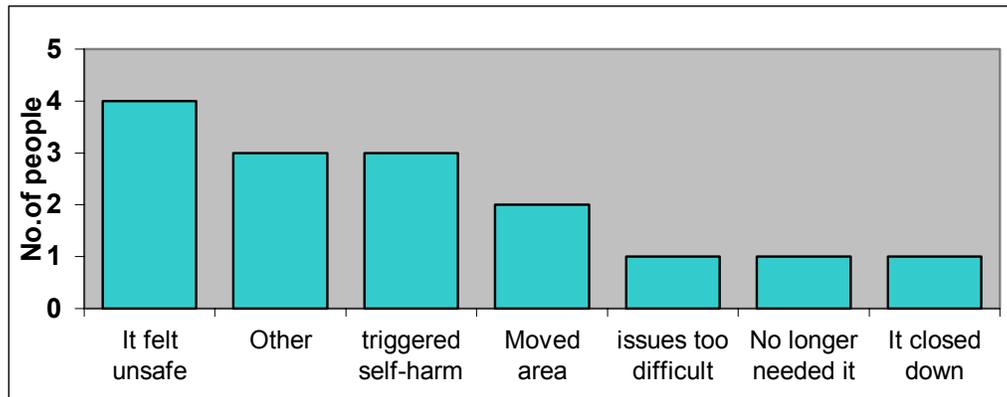
Many of the women felt that the psychiatric services were unsafe and only seemed concerned about whether or not they were going to commit suicide.

² Self Preservation Encouraging Active Response- self-harm information and training organisation.

"I don't really feel safe talking to him (psychiatrist)[...]. I wouldn't tell him anything, not that he asks anyway he just wants to know if I'm going to kill myself or not."

Leaving the group/group closure

Below you can see a break down of why individuals who no longer attend a group left the group they did attend. Some respondents ticked more than one answer.



Graph 6 : - Why did you leave the group?

N.B. Those who ticked 'other' did not enlarge upon their responses.

We asked respondents who had previously attended a self-harm self-help/support group if the group they belonged to was still in existence:-

- 5 respondents said yes the group was still running.
- 4 said that the group had closed.
- 2 were unsure.

Of those groups that no longer exist, only three respondents were aware of the reason for the group's closure. It is interesting to note that in all three instances the group ended as the key individual/ facilitator left.

The women who no longer attended a group were asked if they would still like to belong to a self-harm self-help group:-

- 4 respondents whose group had closed down felt they would still like to belong to a self-harm self-help group.
- 6 respondents were unsure
- 1 person did not answer.

Participants were then asked what were the 3 main things that would help them to attend a group. The three most important things for people were being safe to talk and being listened to, not being judged, and not having to travel too far. Other important things included a feeling of being understood, back up outside of group meetings, the group being single sex, funding and advertising.

How others view self-harm

Family & Friends

A third of the respondents highlighted that they gained support from their family, friends or partners. They stated that family and friends were helpful in trying to understand what self-harm meant to them. One respondent's mother attempted to cut herself in an effort to understand her daughters self-harm.

However, quite a few respondents felt unable to talk to family or friends about their self-harm. Some people said that this was because it upset their family, friend or partner or because it reflected badly on them. One woman whose friends got upset said:

"Because I think they don't like the thought of me doing that to myself [...], maybe it makes them feel like they're not being a proper friend or something and that they can't help me."

"He wouldn't talk to me for days because he said he was so horrified that I used self-harm as a method of coping."

The Public

When respondents were asked how they thought that the public view self-harm respondents said the following:

"The public and professionals have a bad attitude to self-harm."

"I think they're frightened by it because they don't often come up with it. You know, even though its becoming more common [...] people get a shock-tend to like walk away"

"the public see self-harm very negatively I would imagine and also they see it as attention-seeking, in-vogue, fashionable- oh dear shock, horror, keep away".

One interviewee, who had recently given a talk about self-harm, was stopped by a woman at the end who said, *"You don't look like a self-harmer!"* Another person said *"I guess it's mainly teenagers in the group."* When told that the group had people with a mixture of ages she said, *"Oh I thought it was something for young people."*

Professionals

Whilst there are some professionals who have a good understanding of self-harm there are many who believe it to be a bad thing, that should be stopped. This often leads to focussing on the behaviour rather than the pain behind it.

"The psychiatrist is very much of the opinion that I should stop doing it, [...] I don't know if they really, sort of, understand why we do it. They just sort of think we shouldn't do it."

She later highlighted a more helpful response from a professional.

"Well my support worker's a social worker [he...] understands that I need to do it, so he's sort of, more accepting than the psychiatrist."

One of the interviewees highlighted an unhelpful attitude when one group member tried to reply to an article posted on the internet.

"Rosie was trying to respond to an article on the internet that a doctor had written about self-harm. She responded and said she was involved in running a self-help group for self-harm. They (the organisation whose website it was) responded and said that they preferred to get professional opinions."

The following comments illustrate how respondents felt professionals viewed self-harm:

"I felt that the other help I've received through psychiatric services was judgemental, unhelpful and full of labels. I try not to go near them now if at all possible."

"I can talk about it but when I talk about it, I feel stupid; [...] She's [therapist] disgusted with me."

" People in A & E and sort of hospital people on the whole , have been kind of, not really horrible but not really nice like, Oh god, well we've got enough to do kind of thing, without you doing this to yourself!' But then there have been a few that have really, you know, outright hostile and kind of, you're wasting our time. But then there's also been a couple that have been really, really nice and have gone out of their way to be nice."

Discussion

Experience of carrying out the research

It was helpful working in a team of two researchers, as carrying out research alone can be very isolating. It was useful to bounce ideas off each other, which meant we could look at the subject in a broader way. It also worked well as we had different skills which complemented each other.

The project as a whole was both challenging and interesting. We were faced with tasks which we would otherwise not have faced, such as travelling to various cities within the UK and staying away from home, meeting and getting to know new people, participating in training and learning new skills. The most challenging and interesting aspect of the project was finding out about people's experiences of their group.

The work load was more than expected and with other commitments it was difficult to stick to original time frames. Everything seemed to take longer than we had anticipated i.e. developing and piloting the questionnaire, arranging interviews, the transcribing and analysis of interviews.

It was emotionally demanding, hearing other people's experiences at times evoked feeling within us. Although prepared for this through training it was still hard hitting at times. There were occasions when, due to personal circumstances we were not robust enough to carry out the work needed. This led to further anxiety and stress. However the support available from the Strategies for Living team and especially Sarah Wright at these times was excellent and they gave us the time and space to recover and gave encouragement and praise throughout the project.

It was disappointing to find out in the latter stages of the research, that the Mental Health Foundation would be unable to publish the reports. However, the full report will be available on their website and a printed summary will be available by post. Although £500 had been made available for each project towards the cost of publishing we felt this was insufficient. It is with great disappointment after all our hard work to find out that our report would not be as widely available as we had been led to believe. Strategies for Living have given support in ways to print and publicise our report but this has increased the workload upon us and led to further stress and pressure.

More positively, as a consequence of carrying out the research, we've been able to learn more about ourselves and the group we attend and learnt many skills along the way. It has been reassuring to find that there are groups out there that people find helpful and which enriches their lives.

Reflections on methods

Questionnaire

We decided to send out flyers inviting people to take part in our research, rather than unsolicited questionnaires because from experience in our group, questionnaires can trigger distress and people can feel obliged to fill them in.

Some of the questionnaires were sent out in the latter stages of the project and we were unable to give these people the opportunity to be interviewed if they wished.

The questionnaire was checked by the researchers and the Strategies for Living team. A pilot was conducted, which did result in changes being made. However, upon analysis we did discover that we had missed some questions from one of the sections. Also some questions would have benefited from a Don't know/ Other option. This led to some difficulties with the analysis.

The computer package SPSS³ used to analyse the questionnaire data was difficult to master but once we got to grips with this, it proved relatively straight forward.

Interviews

Initially we had intended to interview all willing participants face to face. However due to time, geographical location and financial restrictions this was not possible. After consultation with the Strategies for Living team and further information gathering, we decided to carry out interviews with the more distant participants over the telephone. We were worried about this because we felt we couldn't offer adequate support during or after the interview. To try to offer some support we produced a leaflet to be sent prior to the interview. However, the telephone interviews worked well, with all those we approached willing to be interviewed in this way. People were surprisingly open over the phone. However one woman returned her transcript with more in-depth information, it may have been that she had felt uneasy discussing this over the phone and in a face to face interview it may have been easier for her.

A benefit of telephone interviews was that we were able to write reminders to ourselves on points with which we wished to return to with the participant. This led to more in-depth information gained. This would not have been appropriate in the face-to-face interviews, as interviewees may have felt that we were not paying attention to what they were saying.

³ SPSS- Statistical Package for Social Sciences- a computer package used to analyse quantitative research data

Changing the methods we used, did also mean we had to change the information that was sent to participants, which resulted in further work for us.

We left most of the transcribing of the interviews till the late stages. This meant we were unable to learn as much as we could have done during the interview process about what themes were already emerging which could have informed the next interview.

Limitations

Although we had a high response rate to the questionnaire which we sent out (75.5%) we had a much lower response rate to the flyers we sent out. Approximately 200 flyers were sent to individuals and groups. The low response rate could be due to a number of factors. Flyers were sent out to all members of the National Self-Harm Network and it is probable that many of these individuals did not belong to a self-help/support group. Flyers were sent to all groups listed by Bristol Crisis Service for Women, however, it was later discovered that many of these groups had closed down or were temporarily closed. So the flyers would not have reached members of these groups.

It was very difficult to locate people who had previously attended a self-harm self-help/support group. This meant we were unable to find out why people had left or why groups had closed. It was important for the research that we had contact with these people to fulfil our aims.

We were not able to interview all those that had expressed an interest in taking a further part in the research. This was due to time constraints, difficulties in contacting people, and people being unwell at the time. We were able to gain a wealth of information from the 12 interviews we were able to conduct. However, new themes were still developing in the later interviews and we feel if we would have been able to do more, we would have found more information.

All respondents were female but 13 of the participants came from mixed gender groups. It would have been beneficial if we had been able to interview men who attend a self-harm self-help group as their experiences may have been different. It is possible that as we were both female researchers, males may have been put off taking part.

One of our aims was to look at differences and similarities between self-help and support groups. However, it was difficult to distinguish between self-help groups and support groups and individuals seemed to have different ideas about what the terms meant. We were maybe not clear enough in our own definitions which led to confusion during analysis and meant we were not able to fulfil this aim.

As with all research projects, we learnt things as we went along. We were given training and support throughout. However, if we repeated the research we would have done some things differently. For example we would have made more use of the internet in trying to contact people, and

been clearer in our minds about the definitions of what we were investigating.

There was the potential for us to be biased during the research as we have both gained much from attending a self-help group. This was minimised by training and supervision of the analysis by Sarah Wright (Strategies for Living-Research Supporter). However, the fact that we both had direct experience of self-harm and attended a self-help group may have made people feel safer to talk openly about their experiences. This also allowed us to gain access to groups who would not have participated in research conducted by health professional researchers. This has led to information which would not have otherwise been available to enrich understanding of the value of self-harm self-help/support groups.

Reflections on findings

Group Structure

It was striking how similar many of the groups were in structure and process. The structure of three phases in the group, with a period of settling in and welcome, a period of talking about individual's issues and ending on a positive note. This really seemed to work well and mimicked our experiences of attending a self-harm self-help group.

Groups seemed to work better when all members were involved in running the group and had an equal say as to what happened. Those groups that had a designated facilitator tended to rely on the facilitator to maintain the group and keep it running, although there were exceptions. This often led to facilitators feeling overwhelmed and burnt-out. This could result in the facilitator leaving the group and placing the continuation of the group in jeopardy. From the research it appears groups are more likely to continue if there is shared responsibility for the group or there is more than one facilitator, so the group can continue regardless of whether people leave or not.

Benefits and limitations of groups

The results showed that over two thirds of participants felt it was safe to talk within their group, felt valued, accepted, and not judged. The formation of groundrules was a vital aspect of this. It was important to members that they were involved in the development of the groundrules so they felt safe to attend the group and talk openly. The groundrules needed to be flexible so that they could be changed when new members arrived so they too felt safe. In some groups there were conflicts around what the groundrules should be. In this situation it's important that all members feel listened to so a compromise can be reached. This situation was particularly true for the 'no self-harm on premises' rule. One individual felt that with this rule in place, they would be unable to explore painful issues. They needed the safety net of being able to harm if they felt the need, in order to feel safe in the group. The woman who wanted to remove the 'no self-harm' rule felt she wouldn't need to self-harm on the premises but wanted to know she could, if desperate, without feeling she had been 'naughty'.

Some of the groups did not have this rule and would allow individuals to harm if needed and had experienced no difficulties in this area.

It was important that individuals were prepared for what to expect and what was expected of them from the group. This was best achieved if potential members could meet someone from the group before attending to find out more specific information. For example, one interviewee was not met before attending and when she arrived, she discovered that she was a lot younger than all the other members, she felt incredibly out of place; this led to further distress rather than being helpful. Another interviewee attended a group without an initial meeting to discover members wearing short sleeved tops so their scars could be seen. She felt shocked and felt that if she had been prepared for this, it would not have been such a distressing experience. It was important that individuals had information about the group characteristics and the group process so they could make an informed decision about whether to attend the group.

On the whole, people received what they were looking for from the group e.g. to feel less isolated, to understand why they self-harmed and receive support. However, half the people who wanted to find alternative ways to cope did not achieve this. People did however gain in other ways; more people benefited from helping others and had more fun than expected.

It is specifically important to note that only eight people went to try and stop self-harming but 14 people felt the group had reduced their need to self-harm. Gaining friendships was also a significant benefit for many people; this was not a primary reason for attending the group.

Sustaining groups

The research has highlighted a number of factors important in maintaining groups. Support is a major factor for the group in general, especially for key individuals and facilitators. Practical and emotional support is needed to keep groups going. Our research highlighted that individuals feel under personal pressure to look after others well-being in the group as support services are not available outside the group. Research has shown that individuals are more likely to harm at night and this is when services are not available (Warm, Murray & Fox 2002). Group members therefore felt pressure to support each other during these times, which in some instances led to further distress. This pressure was felt most by the people who set the group up or the group facilitator or leader.

Funding was another major pressure on group leaders and facilitators in particular. Obtaining funding was difficult and groups were unprepared for the amount of work that obtaining funding would take. To secure funding, many groups had to prove the effectiveness of the group; this could involve giving presentations to groups of professionals, which sometimes added to the pressure on group members. Groups often struggled with fundraising and this often led to individual's feeling inadequate and guilty that they did not have the time to dedicate to this. This could lead to power differences in the group with a specific individual being looked upon to undertake the task, even when the individual felt unable to do this.

Some groups found it beneficial to be able to undertake activities outside the group, for example one group went away for the weekend. Other groups incorporated activities inside group time. The groups felt it was important to have fun and look at each others abilities and strengths, as the group environment could lead to focussing on the negatives. Funding was often essential for these activities to take place and as highlighted above, obtaining this was difficult. However one group paid one pound a week to save up so these activities could take place. They felt this was important as it indicated they had group ownership and did not have to meet criteria set out by others to prove the group was beneficial.

Our research shows that all groups went through periods of difficulties. These included when new members came into the group, worries about others in the group and key individuals feeling burnt-out or leaving. Groups often felt isolated in dealing with these issues and had no one to call upon for confidential help. This could lead to detrimental effects for the group and individual members. Groups needed someone to talk to, which was not available in most cases. One group had access to a local self-help organisation that was able to offer support and advice during these times which the group found invaluable.

Conclusion

Self-help/ support groups offered more equality than professional services. Members felt more equal as they had a say in how the group ran and were able to set their own aims for what they wanted to get out of the group. An example of this is that only 8 people went to the group with the aim of stopping to self-harm; this would be more of a primary concern for professionals. Professionals tend to measure the success of therapy sessions or self-help groups by how many people have stopped or reduced their self-harming; this was not necessarily the aim of the group. However groups would often have to prove this to obtain funding (Tantam and Whittaker 1992).

The group was a safer place to talk openly and honestly about feelings without the fear of professional's response (e.g. sectioning). Many of the women felt that professional services were stigmatising and labelling however this was not present in the groups with the women feeling accepted, valued and not-judged. As stated earlier, friendship was one of the main benefits received however, this is not possible with professionals due to the boundaries of a professional working relationship.

It's clear from our research that self-harm self-help/ support groups provide a valuable, much needed resource for many individuals. People were able to gain help and support that they were not able to get elsewhere. They could be themselves and talk openly and be honest about how they were feeling. This was without the fear of judgement or consequences many had experienced with statutory services. By having contact with others who self-harm, people felt less isolated and accepted; they shared their common understanding. People were able to help others within the group which played a huge part in raising self-esteem, self-worth and confidence. People felt equal and were not recipients of a service but actively involved in the success of the group.

Despite the huge benefits people gain from attending a group, groups often struggle to survive. Main reasons for this are lack of funding and support. This can lead to individuals feeling burnt-out and groups closing. Funding needs to be made more easily available and support needs to be there to deal with the day-to-day running of the group and helping groups to deal with the difficulties which they face. The self-help group we belong to has been helped greatly by Self-Help Nottingham, an organisation specifically designed to help all types of self-help groups to set up and keep going. We believe that such organisations should be available to all groups in order for them to flourish and continue to help the large number of people they currently do. For self-harm this would be best met by an organisation specifically focused on self-harm as they have the specific expertise of the issues likely to arise.

Recommendations

- All groups should have access to someone who can help with supporting the group, not only with the practical things such as finding a meeting place and advertising the group but fundraising and support during difficult times on how to deal with the situation and how to continue as a group.
- Funding should be sought for a 'network of groups' so that support could be gained for each other during difficult times, this organisation could also help with setting up groups.
- For groups to be given the opportunity to meet up to gain ideas and support each other, and to offer mutual learning opportunities.
- For there to be more 'out of hours' services such as helplines like Bristol Crisis Service for Women, to provide support to individuals so that group members do not feel responsible for others well-being.
- For further research to be carried out in the area of self-help and self-harm, which should include mixed and men's groups.
- For research to be carried out into the differences and similarities between support groups and self-help groups for people who self-harm.
- For professionals to be more aware of the benefits of self-help and what it can offer, which they cannot. Also to inform people about their existence.

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Self-Harm Self-Help

DO or HAVE YOU ATTENDED A SELF-HELP/ SUPPORT GROUP FOR
PEOPLE WHO SELF-HARM?

IF SO WE NEED YOU!!!!!!

Could you spare 20 minutes to fill in a questionnaire about your experiences of attending a group? If you would be prepared to help, fill in your details below and return in the pre-paid envelope. For more information please contact:-

Angela Smith:- a.smith433@ntlworld.com Tel: 07905 635609
Jill Clarke:- jillclarke@rock.com

**User led research supported by the Mental Health
Foundation.**

-----Please cut here-----

Name: _____

Address: _____

SELF-HELP/ SUPPORT GROUPS FOR PEOPLE WHO SELF- HARM

Thank you for taking an interest in this research. It is being funded by the Mental Health Foundation's 'Strategies for living' project which supports user led research.

Angela Smith and Jill Clarke are carrying out the research. We attend a self-help group called 'Cutting Back' and would like to find out about other peoples experiences of attending similar self-help/ support groups by focusing on the following three areas:

- What individuals gain from groups?
- What works within groups?
- How can groups be sustained through difficult times?

The enclosed questionnaire should take approximately 20 minutes to complete. Please keep yourself safe and ignore any questions you do not want to answer.

The questionnaire will be kept confidential i.e. any names or addresses will be seen only by the two researchers. We will ensure anonymity when writing the final report.

We hope this research will provide information on what individuals and groups need to continue to be useful and to celebrate the achievements of groups.

Please return your questionnaire in the pre-paid envelope by _____

**THANK YOU FOR TAKING THE TIME TO
READ THIS.**

For more information contact:

Angela Smith:- a.smith433@ntlworld.com, Tel: 07905635609

Jill Clarke:- jillclarke@rock.com

Information about you

Please tick one box only unless otherwise stated.

1 Are you male or female?

Male

Female

2 What age group do you belong to?

Under 18

18-29

30-39

40-49

50-59

60 and over

3 Do you have direct experience of self-harm

Yes

No

4 Do you currently attend a self-help/support group for people who self-harm?

Yes **please go to part A**

No **please go to question 5**

5 Do you currently attend a self-help/ support group for people with mental health problems?

Yes **please go to part A**

No **please go to part B**

Part A – For people who currently attend a self-help/support group for people who self-harm.

Please tick one box only unless otherwise stated.

1a How did you find out about the self-help/support group?

Please tick all that apply

- | | |
|--|--------------------------|
| G.P./Practice nurse | <input type="checkbox"/> |
| Mental health professional | <input type="checkbox"/> |
| Counsellor/psychotherapist | <input type="checkbox"/> |
| Social worker | <input type="checkbox"/> |
| A&E staff | <input type="checkbox"/> |
| I was involved in setting the group up | <input type="checkbox"/> |
| A self-help directory | <input type="checkbox"/> |
| Leaflet/poster etc. | <input type="checkbox"/> |
| Partner/friend/relative | <input type="checkbox"/> |
| Help line | <input type="checkbox"/> |
| Voluntary agency e.g. Mind | <input type="checkbox"/> |
| Other- please specify _____ | |
-

2a Why did you decide to go to the group?

Please tick all that apply

- | | |
|---------------------------------------|--------------------------|
| To understand my self-harm | <input type="checkbox"/> |
| To find friendship | <input type="checkbox"/> |
| To talk about my experiences | <input type="checkbox"/> |
| To work through my problems | <input type="checkbox"/> |
| To stop self-harming | <input type="checkbox"/> |
| To find support | <input type="checkbox"/> |
| To find alternative ways to cope | <input type="checkbox"/> |
| To be with other people who self-harm | <input type="checkbox"/> |
| To have fun | <input type="checkbox"/> |
| To help others | <input type="checkbox"/> |
| To feel less isolated | <input type="checkbox"/> |
| Friends/relatives thought I ought to | <input type="checkbox"/> |
| Professionals thought I ought to | <input type="checkbox"/> |
| To help myself | <input type="checkbox"/> |
| Other Please specify: - _____ | |
-

3a How long have you been attending the group?

Less than 3 months

3-6 months

6months-1 year

More than a year

4a How often does the group meet?

Twice weekly

Weekly

Fortnightly

Monthly

Other please specify _____

5a Is the group for: -

Women only

Men only

Mixed

6a Is your group: -

Open (accepts new members all the time)

Closed (opens at intervals throughout the year for new members)

Closed (does not accept new people)

Don't know

7a Is your group: -

Survivor led **Please go to question 9a**

No leader support each other **Pease go to question 8a**

Professionally led/facilitated **Please go to question 9a**

Don't know **Please go to question 8a**

8a Do one or more individuals take a leading role in organising the group?

Yes

No

Don't know

Please go to question 10a

9a Is the person who facilitates your group: -

Someone who has experienced self-harm (unpaid)

Someone who has experienced self-harm (paid)

Someone from a voluntary organisation

Professional (e.g. Nurse, Psychologist, Occupational therapist)

Other- please specify _____

10a What benefits have you got from the group?

Please tick all that apply

I have made new friends

I have gained an understanding of my self harm

I feel less isolated

I can be honest about my feelings

I have fun

I can explore painful issues

It feels safe to talk

It helps me find alternative ways to cope

It's reduced the need to self harm

I don't feel ashamed of my self harm

Increased self esteem and confidence

I feel valued/accepted/not judged

Provides support which I don't get elsewhere

I feel understood

It reassures family and friends

I am able to help others

I feel comfortable

Other, Please specify: - _____

11a Are there any difficulties in attending the group?
Please tick all that apply, if you wish please explain further in the space provided.

I feel unable to talk	<input type="checkbox"/>	_____
I worry about others	<input type="checkbox"/>	_____
I sometimes feel it triggers self-harm	<input type="checkbox"/>	_____
I don't have enough time to talk	<input type="checkbox"/>	_____
I feel people in the group rely on me too much	<input type="checkbox"/>	_____
I feel uncomfortable	<input type="checkbox"/>	_____
I feel different	<input type="checkbox"/>	_____
I feel unwelcome	<input type="checkbox"/>	_____
Access is difficult (e.g. mobility)	<input type="checkbox"/>	_____
I can not afford travel	<input type="checkbox"/>	_____
I feel uncomfortable with members of the opposite sex	<input type="checkbox"/>	_____
It does not meet my requirements for support	<input type="checkbox"/>	_____
I feel pressure to talk at the group	<input type="checkbox"/>	_____
Other, Please specify: -		_____

12a Do you phone and/or meet group members in-between group sessions?

Yes **Please go to question 13a**
No **Please go to question 14**

13a Do you find phoning/ meeting group members: -

Helpful
Unhelpful

Please could you state in your own words what you find helpful/unhelpful.

14a Is there other help you receive for self-harm?

Please tick all that apply

- | | |
|------------------------------------|--------------------------|
| Attend A+E/Walk in centres | <input type="checkbox"/> |
| G.P./ Practice nurse | <input type="checkbox"/> |
| Community Psychiatric Nurse | <input type="checkbox"/> |
| Support from family/friends | <input type="checkbox"/> |
| Counsellor/psychotherapist | <input type="checkbox"/> |
| Self-harm Team | <input type="checkbox"/> |
| Medication | <input type="checkbox"/> |
| Social worker | <input type="checkbox"/> |
| Voluntary agency e.g. Mind | <input type="checkbox"/> |
| Alternative therapies e.g. massage | <input type="checkbox"/> |
| Other _____ | |
| _____ | |
| _____ | |

Please feel free to add anything you think we have missed in this questionnaire, or any comments you have about its contents or the research, add additional sheets if required. Thank you.

Thank you for completing this part of the Questionnaire; **please go to part C**

5b Why did you decide to go to the group?

Please tick all that apply

- | | |
|--------------------------------------|--------------------------|
| To understand my self-harm | <input type="checkbox"/> |
| To find friendship | <input type="checkbox"/> |
| To talk about my experiences | <input type="checkbox"/> |
| To work through my problems | <input type="checkbox"/> |
| To stop self-harming | <input type="checkbox"/> |
| To find support | <input type="checkbox"/> |
| To find alternative ways to cope | <input type="checkbox"/> |
| To have fun | <input type="checkbox"/> |
| To be with others who self-harm | <input type="checkbox"/> |
| To help others | <input type="checkbox"/> |
| To feel less isolated | <input type="checkbox"/> |
| Friends/relatives thought I ought to | <input type="checkbox"/> |
| Professionals thought I ought to | <input type="checkbox"/> |
| To help myself | <input type="checkbox"/> |
| Other Please specify: - | |

6b How long did you attend the group?

- | | |
|--------------------|--------------------------|
| Less than 3 months | <input type="checkbox"/> |
| 3-5 months | <input type="checkbox"/> |
| 6months-1 year | <input type="checkbox"/> |
| More than a year | <input type="checkbox"/> |

7b How often did the group meet?

- | | |
|----------------------|--------------------------|
| Twice weekly | <input type="checkbox"/> |
| Weekly | <input type="checkbox"/> |
| Fortnightly | <input type="checkbox"/> |
| Monthly | <input type="checkbox"/> |
| Other please specify | _____ |

13b Is the group still in existence?

- Yes
- No
- Don't know

14b What benefits did you get from the group?

Please tick all that apply

- I have made new friends
- I have gained an understanding of my self harm
- I feel less isolated
- I can be honest about my feelings
- I have fun
- I can explore painful issues
- It feels safe to talk
- It helps me find alternative ways to cope
- It's reduced the need to self harm
- I don't feel ashamed of my self harm
- Increased self esteem and confidence
- I feel valued/accepted/not judged
- Provides support which I don't get elsewhere
- I feel understood
- It reassures family and friends
- I am able to help others
- I feel comfortable
- Able to mix with members of the opposite sex
- Other, Please specify: - _____

15b Were there any difficulties in attending the group?
Please tick all that apply, if you wish please explain further in the space provided

- I feel unable to talk freely
- I worry about others
- I sometimes feel it triggers self-harm /it may trigger self harm
- I don't have enough time to talk
- I feel people in the group rely on me too much
- I feel uncomfortable
- I feel different
- I feel unwelcome
- Access is difficult (e.g. mobility)
- I can not afford travel
- I feel uncomfortable with members of the opposite sex
- I feel pressure to talk at the group
- Other, Please specify: - _____

16b Did you phone/meet group members in-between group sessions?

- Yes **Please go to question 17b**
- No **Please go to question 19b**

17b Did you find phoning/ meeting group members: -

- Helpful
- Unhelpful

Please could you state in your own words what you found helpful/unhelpful.

18b Do you still meet people who were members of the group?

Yes

No

19b Why did you leave the group?

It closed down **Please go to question 20b**

I felt unsafe

I found the issues too difficult

It triggered feelings of self-harm **Please go to question 21b**

Moved area

No longer needed the group

Other- Please specify _____

20b Why did the group close down?

Please tick all that apply and explain further if you wish

Not enough people were interested _____

Funding ran out _____

Key individual left (person who organised the meetings) _____

Facilitator left _____

Lost meeting place _____

It felt unsafe _____

People had moved on _____

Group had served its purpose _____

Issues were difficult to resolve _____

It triggered self-harm _____

Other- please specify _____

21b Would you still like to belong to a self-help group for

people who self-harm?

Yes 1

No 1

Don't know 1

22b What are the three main things that would help you to attend a self-harm self-help group?

Please feel free to add anything you feel we have missed in this questionnaire, or any comments you have about its contents or the research, please attach additional sheets if needed. Thank you.

Thank you for completing this part of the questionnaire; **please go to part C.**

Part C

We would both like to thank you for completing this questionnaire; the answers you have provided are a valuable part of the research project and we appreciate your participation very much.

We will gladly send information on our research findings to anyone who has taken the time to fill in a questionnaire. If you would like us to do this, please fill in your details below and we will send this out to you in late 2003.

Part of this research project involves conducting interviews and possibly, discussion groups at a later date and we are looking for people to take part in these. If you may be interested in helping us further and would like more information, please fill in your details below and tick the relevant box.

Name: _____

Address: _____

Telephone Number: _____

- **I would like further information regarding participation in interviews and focus groups**
- **I would like to receive a copy of the report when finished**
- **I would like further information about self-harm**

Please return your questionnaire in the pre-paid envelope provided.

THANK YOU

This page will be removed and stored securely to ensure your confidentiality is maintained.

Self-Help/Support Groups for People Who Self-Harm

Funded and supported by the Mental Health Foundation's Strategies for Living Project

Researchers: - Angela Smith & Jill Clarke

Information Sheet

Thank you for taking the time to fill out one of our questionnaires and asking for more information about interviews/focus groups. We are now ready to begin conducting interviews and would like to invite you to take part. We hope that by conducting interviews we will be able to gain more in-depth information about self-help/support groups for people who self-harm. We will aim to focus on the following areas in the interview: -

- What individuals gain from groups
- What works within groups
- How groups can be sustained through difficult times

Information about the Interview

Either Angela Smith or Jill Clarke will conduct the interview. We are both members of a Nottingham based self-help group for people who self-harm. Each interview will take approximately one to one and a half hours. We will try to arrange the interview at a time and a place where you feel comfortable. During the interview you will be asked questions about your experiences of attending your group. We would like to tape the interview. This is so we have an accurate record of what was said and means we will be able to concentrate on what you are saying during the interview. After the interview the tapes will be transcribed. If you would like we will send you a copy of the transcript. This is so you can read through and agree with what has been said. If you are unhappy with anything in the transcript you will be able to withdraw anything you do not want us to use.

It's important that you keep yourself safe during and after the interview. We will provide time afterwards for a drink and a general chat and give you a list of organisations that provide support. We hope to make the experience as positive as possible. We will of course pay out of pocket expenses, such as travel, we would also like to give you £10 as a small token to thank you for your valuable contribution.

Consent Forms

If you decide to be interviewed we will arrange a time and a place. At the interview you will have the opportunity to ask any questions you may have about the research. Once you feel satisfied you have enough information you will be asked to sign a consent form. We have included a copy of this with this information sheet for you to have a look at. The consent form is for your protection and makes it clear what you are agreeing to.

Your rights to drop out

You need not answer any questions you feel uncomfortable with during the interview and are free to withdraw from the research at anytime without giving a reason. This will not affect your entitlement to the payment of expenses or the £10 as a thank you.

Confidentiality and Anonymity

Only the two researchers and anyone who you wish to tell will know you are taking part in the research. All the information that you give us will be kept confidential and anonymous. This information will be coded and kept in a safe place. Access to the information will only be for the researchers and the Strategies for Living team and any employees that we contract (such as a typist to transcribe tapes). Our contract binds us to confidentiality. This means we will not share any personal details (such as name, telephone number) with anyone unless we have your permission. Any quotations which are used in the final report will be anonymous and any identifying names or places will be changed to protect you unless otherwise instructed.

Reporting the results/Ownership

We will write a report of our research findings which will be published in late 2003 by the Mental Health Foundation. Ownership of the research will rest with the two researchers. We may later wish to use the information you provided to write an article for newspapers or magazines or enlarge on the research.

Further Information

If you require further information about this information sheet or any part of the research please feel free to contact either of the researchers and they will be willing to help.

Angela Smith:- E-mail:- a.smith433@ntlworld.com Tel No.:- 07905635609
Jill Clarke:- E-mail:- jillclarke@rock.com

Thank you for reading this

CONSENT FORM FOR PARTICIPATION IN RESEARCH PROJECT

SELF- HARM SELF-HELP/SUPPORT GROUPS

I (name) _____

Of (address)

consent to take part in the above investigation. I have been given the information sheet, which I have read and understand, and any questions I wished to ask have been answered to my satisfaction.

I understand that I am free to refuse to answer any questions I do not wish to and that I can withdraw from the study at any time without giving a reason for doing so and that my decision will be respected.

I agree to be tape recorded for the purpose of the investigation and understand that I will be given the opportunity to read my transcript and to change, add, or withdraw any comments I have made.

I am happy for quotations from my interview to be used in the final report and any other publications by the researchers. I understand that these will be used anonymously (unless otherwise instructed).

SIGNED (interviewee)_____

SIGNED (researcher)_____

PRINT (researcher)_____

One copy to be retained by the interviewee.

Contacts:

Angela Smith: - a.smith433@ntlworld.com Tel: 07905635609

Jill Clarke: - jillclarke@rock.com

Topic Guide

Introduction

- Hello
- Thanks
- Introduction of ourselves as researchers for MHF
- Introduction of ourselves as group members
- Time 1-1½ hours
- Tape recorded
- Time out/ able to withdraw at any point/ keep self safe/ not to answer questions you feel uncomfortable with
- Confidentiality, Angie, Jill, Sarah
- Questions about project
- Questions about us at end

Them and the Group

- Age
- Ethnicity
- Describe a bit about themselves
- What self-harm means to them
 - Coping mechanism
 - Survival
- How did you find out about the group
- How made contact => what happened next
- Characteristics of group
 - Age mix
 - Ethnic mix
 - Numbers
 - Open/closed
 - Gender mix
 - Facilitators
 - History
 - How often
 - Length
 - aims/ groundrules
- Process/ Content of meetings
- Contact outside group
 - Phone/meet
 - helpful/unhelpful
 - Why

Gain from the group

- What do you get from going to the group
- What do you feel you offer the group
- Support

**NOT JUST- BUT
WHY/HOW**

Other Support

- Do you/have you received any other help
- How does this compare to the group
- What other contacts do you have with others who self-harm (NSHN, BCSW, SHA)

Difficulties

- Self-harm
 - Professionals
 - Public
 - Friends and family
- GROUP
 - Safety
 - Worry
 - Distress
 - Over dominance
 - Personality clashes
 - Practical
 - Money
 - venue
- How did you/ the group deal with these
- What would have helped
- What would help/ make it easier for the group to keep going

Closing

- Thank you
- Gift/ Money
- Questions
- ANYTHING ELSE they want to say
- Questions about us/research
- Leaflet with useful contacts

- **Threshold**

14 St Georges Place

Brighton

BN1 4GB

A women's Mental Health initiative. They have a free self-harm fact sheet for mental health service users.

Tel:- 0845 3000 911

- **Mental Health Foundation**

83 Victoria Street

London

SW1H HW

Tel:- 020 7802 0300

A national mental health charity who have information on mental health problems.

- **MINDlink**

MIND

Granta House

15-19 Broadway

Stratford

London

E15 4BQ

Contact the above address for details of your local MIND association.

- **Supportline—**

A help line providing confidential emotional support for children and adults on any issue.

Includes support for depression, eating disorders, self-harm and survivors of abuse.

Help line No. 0208 5549004 (flexible hours, next-opening time will be announced on the answering machine)

- **42nd Street**

2nd Floor, Swan Building

20 Swan Building

Manchester

M14 5JW

A community project based in Manchester for young people (15- 25). They offer support on a wide range of mental health issues and have a specific self-harm and suicide worker.

Help line No. 0161 832 0170 (Monday, Tuesday and Friday 9:30-5:00, Wednesday and Thursday 1:15-5:00)

- **National Self-Harm Network**

Po Box 7264

Nottingham

NG1 6WJ

A survivor led organisation, which campaigns for the rights and understanding of people who self-injure.

- **Bristol Crisis Service for Women (BCSW)**

PO Box 654

Bristol

BS99 1XH

Supports self-help groups, offers training and publishes a wide range of literature.

Help line No. 0117 9251119 (open Friday and Saturday evenings 9pm– 12:30am and Sunday 6pm-9pm)

- **Self-Harm Alliance**

Help line No. 01242 578820 (open

Wednesdays– Sundays 7pm-8pm)

- **Samaritans**

Help line No. 08457 90 90 90 (24 hour crisis help line)

INFORMATION LEAFLET

We would both like to thank you for taking part in our research. We understand that after talking to us, you may want to talk to someone or gain more information. Inside you will find a list of helpful organisations which you may find of interest.

Thank
You