

Scoping and development of an online peer support forum for burns survivors and individuals with traumatic scars.

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Knowing that other people face the same difficulties that I do – and finding out about how they've managed their burns – really has made it easier for me to live with burns.

INTRODUCTION

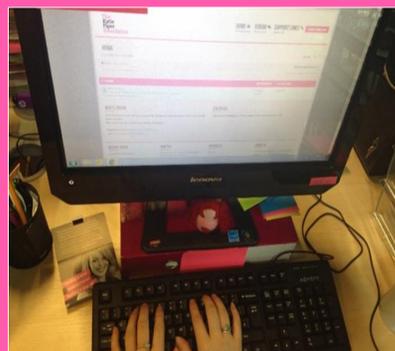
The Katie Piper Foundation (KPF) is a national charity for people with burns & scars. Evaluations of regional social events organised by the charity identified that attendees found it beneficial to meet others, but often struggled to travel to events. Feedback indicated that communicating with others in advance may have reduced attendees' anxiety. KPF noted that after events, attendees often connected on Facebook and Twitter; however this raises issues around safety & privacy. KPF concluded that an online peer support forum could be a cost effective, safe & accessible way to deliver peer support which is not limited by geographical location.

The aim of the KPF Forum is to create a safe & supportive environment where people with burns & traumatic scars can share experiences. There is relatively little academic literature on the development and management of online forums; this poster aims to outline the development of the KPF Forum & share learning, with the hope that this will be of use to others planning to develop online support in burns.

METHOD & RESULTS

Choosing & developing an online platform

In partnership with IT & social media specialists, we chose free (open source) forum software & adapted this to suit our our brand & functional requirements.



The usability & acceptability of the platform & content were tested by Peer Support Volunteers & suggested changes were made.

Certain functional requirements were identified through the scoping exercise, consultation process & risk assessment. Some requirements necessitated "custom building", for example:

- Filters to block personally identifiable information & 'hot words'
- A button for KPF/Forum moderators to close the forum & show an error/maintenance message in case of an emergency.

Other requirements could be met by simply switching on/off existing functions of the Forum, for example:

- Suspending the private messaging function between members
- Removing the function to upload photographs.



Security of information in terms of the platform & hosting solution is a high priority & this has caused technical challenges and delays during the development process.

Deciding how to manage and moderate the Forum

A scoping exercise involved contacting some of the national UK charities working with people with a range of mental health & long term physical health problems to examine the management & moderation strategies employed for online peer support. KPF then undertook a consultation process including:

- Experienced forum moderators/trainers in forum moderation
- Burns & scar specialists & clinical health psychologists
- People with personal experience of burns & traumatic scars.

A management strategy was produced, including a moderation model, escalation strategy (for managing risk & inappropriate use), & support links/structure were developed:

- To enable ease of use & flow of conversation a post moderation strategy has been chosen for the Forum pilot.
- Mon-Fri 9am-6pm the Forum will be managed by KPF. Volunteer moderators will cover 6pm -11pm with an "on-call manager" available for emergencies. Concerns regarding posts being made overnight, when moderators are not available, led to the decision that members will be unable to access the Forum, even to view posts, between 11pm-8am.
- Moderators have a professional background in mental health & were required to undergo training and interview/induction. Training was developed & delivered by Forum Intern/ Psychological Wellbeing Practitioner & KPF Psychological Advisor/ Clinical Health Psychologist.

Our vision is a world where scars do not limit a person's function, social inclusion or sense of well-being



DISCUSSION & CONCLUSION

Online peer support has potential benefit for people with burns & traumatic scars, but the risks need to be managed. A carefully constructed peer support programme allows constructive interactions in a controlled & moderated environment.

It provides more appropriate channels than mainstream social media through which patients can interact & gain support.

The Forum will be piloted for six months on an invitation-only basis. This pilot is a valuable opportunity to provide an insight into online peer support for people living with burns & traumatic scars.

A study of the KPF Forum pilot will be carried out to examine:

- The usability of an online peer support forum for people living with burns & traumatic scarring
- Forum members' experience of using the Forum using semi-structured interviews
- A retrospective content analysis to examine topics of interest to Forum members
- Any reported changes in perceived social support using pre-post questionnaires.

In the future we could expand this interactive online service to include patient information & clinical scar advice & to add a secure video-conferencing facility. We hope that the evaluation of the pilot, along with the material developed as part of this project, will be of interest & value to others aiming to develop online support in burns.

"Having a safe place to talk to other survivors online would have been fantastic for me. I could have had those very first conversations from the comfort of my own home, which would have been invaluable."