

Investigating the beneficial experiences of online peer support for those affected by alopecia: an interpretative phenomenological analysis using online interviews*

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Summary

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The work was completed independently. Alopecia UK provided support in reviewing the proposed methods and in accessing potential participants.

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Background Those affected by alopecia are at risk of experiencing a range of psychosocial consequences. Alopecia UK provides online peer support via facilitated Facebook pages. Online peer support has been found to provide a variety of benefits in other long-term conditions, such as providing information and emotional support.

Objectives This study sought to gain an experiential account as to how online support provides benefit to people living with alopecia.

Methods A purposive sample of 12 participants was recruited directly from Alopecia UK's Facebook group. A total of 11 were diagnosed with alopecia and one participant was a family member of someone with alopecia. The qualitative approach of Interpretative Phenomenological Analysis was used to guide data collection and analysis. Participants took part in online synchronous interviews, which drew on review of participant-selected screenshots of online activity.

Results Four themes were identified, including 'gradual healing', 'image concern', 'belonging' and 'new identity and self-acceptance'. The participants made use of the group through expressing emotion, finding practical advice, and also as a place to connect and share experiences. Participants also reported that the online support facilitated the return of social confidence.

Conclusions This study provides a detailed understanding as to how online peer support groups can be beneficial. Online groups have the potential to create a feeling of belonging, which can develop a sense of being accepted and understood and as such can be important in maintaining psychological well-being. The findings indicate that online groups have the potential to be used as a platform for assisting people in developing both effective coping styles and feeling understood, and such platforms warrant further investment by healthcare professionals.

What's already known about this topic?

- Alopecia may be associated with psychosocial distress due to both the individual impact and the reactions of others.
- Online peer support is known to be a beneficial method of providing psychosocial support for people living with a range of health conditions.

What does this study add?

- An in-depth view of the benefits experienced through belonging to an online peer support group for those diagnosed with alopecia, in addressing the psychosocial effects experienced with the condition.
- This research highlights the need for further investigation of the utility of supporting the development of online peer support for people living with skin conditions.

- Online peer support groups could be highly effective to use in combination with existing psychological therapies to connect others with shared experience.

What are the clinical implications of this work?

- People living with alopecia can benefit from peer support, and healthcare professionals should ensure that patients know where they can gain access to both psychological support and peer support.

Alopecia areata is an autoimmune condition thought to be caused by genetic and environmental influences,¹ and is characterized by loss of hair, and can also result in the experience of significant psychosocial consequences.² These include anxiety, depression and feelings of isolation.^{3,4} Many people living with the condition report feeling confused and having a sense of disappointment due to the lack of a cure and the uncertainty associated with prognosis.^{5,6} The psychosocial impact can also affect parents and partners.⁷

Peer support could be highly effective for those affected by long-term health conditions such as alopecia. Peer support can be defined by when people with similar experiences provide knowledge, emotional and practical guidance to one another.⁸ Knowing that there are similar others out there can reduce the anxiety felt by individuals.^{9,10} Those with visual differences have been found to normalize their experience through connecting with peers, decreasing loneliness and increasing hope and confidence.^{9,10}

In recent years, accessing peer support online has become a popular method for those seeking advice on the management of both physical and psychological consequences of long-term health conditions.^{11–13} Many people have access to online communities through mobile phones and social media, and reports suggest positive effects in coping with various health issues through such mediums which can encourage daily self-care.^{12–14} The benefits of online peer support have been found to outweigh the risks,¹⁵ and sharing health experiences in online groups has been considered one of the most beneficial aspects of the online world.¹⁵

Online support platforms might offer protection from social stigma and better opportunities for self-expression, and it has been argued that as such they can facilitate feelings of empowerment.^{15–17} Online peer support has been found to boost general well-being and decrease loneliness in conditions as wide ranging as long-term mental health disorders, cleft-lip and HIV/AIDS,^{15,17–19} yet little is known about the benefits of online peer support for people living with skin conditions and most of the existing research has used descriptive qualitative approaches such as content analysis.

There is no known research examining the provision of online support for alopecia, and the aim of this study is to investigate the 'closed' Facebook peer support group provided by the U.K. charity Alopecia UK. The group strives to act as a safe place for members to connect and share experiences

through publishing posts. Prospective members are required to answer a set of questions before being allowed to join (Table 1) and are expected to follow a clear set of group rules once accepted (File S1; see Supporting Information), any member who is considered to be breaking the group rules is denied access to the group, and any posts deemed unsuitable are deleted. These decisions are made by administration staff within the charity who approve of any posts prior to them being published, to ensure the culture remains welcoming and friendly.

Facebook groups have been investigated with positive results indicating that they provide opportunities to share and gain knowledge, emotional support, as well as achieve goals.^{18,19} Understanding the experiences of users of such support groups can help in the development of psychosocial interventions in an area where resources are known to be limited. Given that existing research indicates that online peer support can be beneficial, the present study sought to investigate how such a platform is experienced as being beneficial for those using it.

Interpretative Phenomenological Analysis (IPA)²⁰ was specifically designed as a qualitative approach that enables researchers to gain detailed first-hand accounts that can explore how certain phenomena are experienced, and as such it seemed ideally suited to the aims of the present study. In this study we sought to examine how participants benefited from the online peer support set up by Alopecia UK. IPA has been used previously to explore the lived experiences of those with alopecia, from a journey with diagnosis and treatment, and the development of

Table 1 Questions asked by Alopecia UK administration staff prior to acceptance into Alopecia UK Facebook group

- This group is to support those with Alopecia or supporting family/friend. Please can you confirm your connection to alopecia?
- This group is specifically for those living in the United Kingdom (there is a worldwide alopecia group on Facebook – search 'Alopecia Areata'). Please can you confirm you live in the UK?
- Our rules help to keep the group helpful & supportive. Please can you confirm you agree to review the rules (found in the pinned post at the top of the group) & understand there is strictly no advertising?

coping strategies.^{5,21} It has also been used as an approach to gain nuanced insights into other skin conditions.^{21–23}

Methods

Participants

In line with guidelines for IPA,^{20,24} a small purposive sample of 12 participants was recruited directly from the Alopecia UK Facebook peer support group. An advert was published to the group page asking for volunteers who felt they had benefited from being part of the group. All participants were female and aged between 30 and 59 years. All members were welcome to take part including those diagnosed with alopecia ($n = 11$), as well as family members and partners of those diagnosed with alopecia ($n = 1$). All members could take part as the group was created not purely for those diagnosed, but for those affected by alopecia. Although a variety of individuals could take part, the sample remained purposive in that all participants were members of the support group and identified as having benefited from being part of the group. Ethical approval was gained from the University of Sheffield.

Procedure

All communication with participants was conducted online either by email or through Facebook messenger. Participants were first asked to provide some quantitative measures prior to their interview for contextual information, including their sex, age, relationship status, age of diagnosis and whether they were undergoing treatment for their alopecia (Table 2). The first author then conducted semi-structured synchronous interviews with the participants individually, all on Facebook messenger.

Table 2 Individual participant demographic details

Pseudonym	Age (years)	Relationship status	Age diagnosed (years)	Undergoing treatment for alopecia
Carla	30–39	Married	21–29	No
Merida	30–39	Married	30–39	No
Alice	50–59	Married	21–29	No
Olivia	50–59	Married	30–39	Yes
Penny	30–39	Married	30–39	No
Evie	50–59	Divorced	30–39	No
Poppy	40–49	Married	30–39	No
Claire	50–59	Married	17 or younger	No
Lily	50–59	Married	50–59	No
Isabelle	50–59	Married	50–59	No
Amber	n/a	n/a	n/a	n/a
Leah (parent)	40–49	Married	17 or younger ^a	No ^b

n/a, data not provided. ^aAge of Leah's daughter when she was diagnosed; ^bLeah's daughter is not receiving treatment

The interview schedule consisted of open-ended questions and prompts, which allowed for a detailed and reflective account of each participant's experiences of the Alopecia UK Facebook group.^{20,25} The interview began with general questions regarding participant experiences in the group, followed by questions on more specific experiences. Prompts included asking participants to explain in more detail when an interesting statement was made. The semi-structured interview questions can be found in Table 3. All interviews lasted over 1 h and provided comprehensive accounts of use of the online peer support group.

Prior to participating in the interview, the participants were sent instructions to provide a 'screenshot' of chosen critical incident/s (File S2; see Supporting Information). This part of the method was based on the Critical Incident Technique and photo elicitation techniques, which are methods that have been used previously to facilitate participant reflection ahead of taking part in interviews.^{26–28} In this study the request to take screenshots was made prior to the interviews to encourage participants to reflect on moments when the use of online peer support had been perceived as positive. The chosen screenshots acted as critical incidents and participants were asked to provide their screenshots when questions turned to specific experiences within the group. Out of the 12 participants, 11 provided screenshots.

The data from each interview including the screenshots were saved into a password-protected document for analysis.

Data analysis

In order to demonstrate reflexivity, the first author made notes on any arising thoughts and feelings following each interview, to identify any preconceptions. These notes were used to assist in each stage of analysis, as well as being made available as

Table 3 Interview questions

Questions on general experiences	
1	How did you hear about the Alopecia UK Facebook group?
2	What made you decide to join the group?
3	What has been helpful about the group?
4	Have you noticed any changes in how you feel about your hair loss since joining the group? Please describe these changes
5	Have you noticed any changes in how you manage your hair loss? Prompt – Have you tried different treatments or used wigs?
6	Have you noticed any changes in yourself since being part of the group? Please describe these changes
Questions on specific experiences	
1	Can you tell me about a time when you found the group particularly helpful?
2	Can you describe the post?
3	How were you feeling at the time of this post?
4	What was it about this particular post that was so helpful?
5	Did you notice a change in how you managed your hair loss after this particular post?
6	Would you like to add anything else regarding your experiences within the group?

part of the audit process, which was used to test the credibility of the findings. This audit was conducted by the second author during the final stage of analysis and involved inspection of each stage of the data analysis to ensure all data was coded and the development of the results was warrantable.²⁵

The analysis focused on the positive experiences had by the participants themselves. For the participant who was a parent this still remained the case, as the focus was the beneficial experience had by the parent and not by their child.

The analysis method was guided by a rigorous step-by-step process,²⁵ with each transcript being read through a number of times (screenshots included) for familiarity and for early themes to be noted. Early themes were then put to one side and line-by-line analysis was conducted which enabled descriptive phenomenological codes to be generated. Such codes were generated for all individual participants, prior to comparisons being made between participants, which ultimately led to the development of the final set of interpretative themes, which, in keeping with the IPA approach, sought to maintain the individual contributions to the analysis.

Results

A total of 12 members of the Alopecia UK Facebook group were interviewed for this research, including 11 participants who were diagnosed with alopecia, and one participant who was a parent to someone diagnosed with alopecia (see Table 1). A total of four themes were identified within the data. Although the sample consisted of those who are diagnosed with alopecia, and a member who was a parent to someone with alopecia, themes were generated by considering the benefits of being part of the online group as a whole. Each theme is discussed below and supported by representative quotes. Further quotes for each theme can be found in File S3 (see Supporting Information), along with supporting screenshots. Pseudonyms have been used to protect the identity of the participants. The participant with the pseudonym 'Leah' is the only participant who was a parent to someone diagnosed with alopecia; this has been indicated in brackets next to any quotes referred to. All themes held true for those diagnosed as well as for Leah, with the exception of 'Gradual Healing', to which she did not contribute.

Gradual healing

Participants described many ways in which being part of the group had facilitated them in coming to terms with their alopecia. This journey was reported as typically not being linear, with the psychosocial adjustment process appearing to be gradual. Instrumental in this process was having the forum as a place to express emotion.

Expressing emotion

In the interview with Amber, she explained that alopecia can lead you to a 'dark place' due to the impact it can have on daily

life. Being part of the group was reported as having been beneficial in getting individuals out of such places where they had formerly been trapped. Indeed, most participants described the forum clearly as a place to let go of their feelings about the condition:

Lily: 'I realised that posting on my page about the Alopecia was the best way to deal with it rather than having to keep going over it all the time'

Image concern

Participants highlighted that concerns about their body image were frequent topics of discussion on the forum. Typically, concerns centred upon feelings of being 'less feminine' (Lily) and consequently less attractive. Evie described having initial concerns about her body image as being 'alien', demonstrating the marked sense of loss. The participants described this loss in the past tense and spoke about how peer support had often not only provided them with a forum to share such concerns but also a platform to learn about practical 'tips' on managing appearance concerns via use of clothing and wigs.

Practical support and knowledge

Participants all described benefitting from gaining (and sharing) practical advice:

Merida: 'The knowledge. The tips and hints. Practical stuff. How do you keep it on? Glue or tape? Lace or hard front? Treat or don't treat?'

Penny described a technique for wearing a wig that she discovered as a 'lifesaver', which is telling as to how important such things are to those with alopecia. Looking for ways to reduce cost or techniques that look more natural were often reported as being of benefit. Participants also described benefitting from sharing knowledge about alopecia. Interestingly, they also reported hearing about research as reassuring that their condition remained of concern to the medical profession:

Evie: 'Hearing about research and taking part in anything that will help in the future'

Tips on coping

Being part of the group was reported as assisting members in making important decisions surrounding the ways in which they coped:

Poppy: 'Seeing how other people manage their alopecia has made me confident to do what is right for me'

The group also appeared to acknowledge that there were individual differences and choices available in coping, which allowed each participant to feel accepted in their approach to

adjusting to the change in their body image. For example, for Amber, shaving her remaining hair was reported as a relief, as if there was a need to do this in order to let go of emotional ties:

Amber: 'Yea before it was make sure u cover cover cover now it's like eh, sometimes I forget and think oh well I'm out now who cares'

Many reported how inspiring those were who could 'brave the bald look' (Olivia); however, those who chose to cover up were no less supported:

Olivia: 'It's nice when ladies post pictures of new wigs. I decided to try a different style from seeing a post, and i love it. I posted a picture wearing a new wig and i got so many positive comments which was nice'

Olivia was not as content as others, but there is hope that she will be through seeing others cope well:

Olivia: 'Maybe one day i would be able to wear a different wig everyday and not worry what people think!'

It was clear that some of the participants were looking to the group for positive outcomes in future. Many of the participants state that prior to joining, they had not been in contact with anyone with alopecia, which may have left them at a loss for ideas about creating positive changes, but within the forum these ideas become easily available. Positive changes occur gradually through interacting within the online group.

Belonging

Some of the participants described the group as being like a 'family' (Amber) as well as using the affectionate term for those in the group as 'alopecians' (Alice). The group appeared to create a sense of belonging and does so through connecting and through common experiences.

Connecting

Participants described feeling less alone in their experience of alopecia through connecting with similar others. There are feelings of isolation in terms of the physical experience of alopecia, as well as the proximity to others with alopecia:

Claire: 'Its very isolating. . . alopecia is very good at telling you "you can't", so you don't'

Loneliness was also described as being reduced and participants clearly reported the forum as facilitating their ability to make friends and attend events:

Poppy: 'That's how I found my friend she private messaged me not knowing who I was (different name) and I recognised her name I thought there was no one like me around here'

The language used here again, suggests that having alopecia contributes to having a sense of being different to others ('like me'). From going through the journey with alopecia

themselves, participants described wanting to give back some advice and some clearly had developed a sense of wanting to connect with others and act as a role model:

Merida: 'It's easy to let this knock your confidence and your self-image. You need to put effort into making the best of it. Maybe even set an example'

Shared experience

Participants reported getting to share their treatment history and day-to-day experiences of life with alopecia within the group. Relief was reported as being found through the establishment of common experience, which engendered a sense of normality:

Evie: 'It feels more normal now I see others who look like me whereas before this group the only bald person I saw was me at home alone in front of a mirror'

Thoughts of isolation and negative comparison come through in Evie's quote above, and it is clear that she felt different following engaging with peers on the forum. From gaining a feeling of normality and sharing experiences, an understanding appears to develop between people on the forum, a sense that those using it 'get it' (Claire). The shame and embarrassment attached to alopecia appeared to be reduced through this sense of understanding:

Alice: 'I don't feel shame anymore, not so much like a freak'

Lily: 'In the beginning I couldn't go out, wouldn't look in the mirror, became withdrawn and was probably very depressed. Since joining the group I have realised that it's ok to be different and that the sky won't fall in just because I've lost my hair'

Difficult situations were reported as becoming easier to deal with, as participants come to realize that these are not negative or uncommon experiences to be ashamed of, but common experiences that are part of making the adjustment to life with alopecia. Some reported that seeing others thrive was a great source of inspiration for this:

Merida: 'The first one [screenshot] is really inspiring that we can just go about our lives and no one is really paying that much attention which is basically what you're worried about'

New identity and self-acceptance

New identities were reported as being formed through accepting the changes that came with the alopecia or by returning to a lost version of oneself. Changes appeared to occur both at an internal or psychological level and also at a social level for the participants.

Internal changes

Positive internal changes largely occurred through a growing sense of acceptance of the condition. Claire neatly describes

this by referring to 'calling a truce' with her alopecia, almost as if she was formerly at war with it. Acceptance appeared to facilitate the development of compassion and tolerance:

Leah (parent): 'The group helped me to relax and see that she [daughter] possibly needed to wear more makeup to help maintain her identity'

Merida: 'Hair or no hair, we're still fabulous'

Even though Leah (parent) had not experienced alopecia herself, she had been able to understand the value of makeup for her daughter. Similarly, Claire suggests that the group had indirectly helped her husband:

Claire: 'I've met up with a few people who live nearby and my husband came with me to meet another couple, and it was nice for the men to talk about how it affected them us having it'

Social life and openness

Members described improved coping on a social level, enabling some to find the courage to attend events and return to daily life:

Merida: 'There's pretty much no fear. I'll go bald at the gym, playing football, walking about, going to the pub of an afternoon'

Learning to explain their condition to others and deal with negativity has been a valuable part of joining the group. For some participants the forum provided a safe place to practice how to talk about their alopecia to others:

Lily: 'I talk to the children about Alopecia and have introduced a wig box, which they love!'

Discussion

This study has offered an in-depth view of the benefits experienced by members of the Alopecia UK Facebook peer support group. The findings support existing research that has found that Facebook support groups can provide a place for participants to share advice on finding information, as well as providing a space for providing emotional support.^{18,19} The findings also extend that of previous findings by providing insight as to how online peer support is useful for people living with alopecia. The experience of alopecia can be associated with a loss of identity, loneliness and reduced self-esteem;^{2,5,6,21} the accounts here describe how peer support facilitates healthy adjustment to such issues via connecting with similar others within a shared community.

Within the first theme, participants describe the forum as being of assistance in many aspects of coping such as expressing emotion, as well as providing an ample source for gaining practical advice and tips as seen in the second theme. The online group makes it easy to display relatable stories that both normalize and build a common shared experience of life with alopecia, and this appears to provide a platform for reducing shame and stigma.¹²⁻¹⁹

Findings within studies of peer support for other dermatological conditions show that connecting with others encourages positive change and the restoration of confidence.^{9,10} Throughout the accounts, participants describe the peer support group as developing their ability to take a metacognitive position, through awareness of their experience with alopecia, allowing them to stand back from earlier self-critical thoughts associated with alopecia-related distress, and become more accepting of themselves with the condition. This mirrors many of the goals of cognitive behavioural psychological therapies, and suggests that peer support can engender an experience of affiliative emotions which may enable a switch in mentalities, from 'judgemental' to 'caregiving',²⁹⁻³¹ allowing participants to be more understanding towards themselves. Online peer support groups could therefore be an effective coping strategy to be used in combination with psychological therapies.

Some negative experiences were described within the current study, typically associated with the receipt of unhelpful comments and inaccurate advice.¹⁵ The findings suggest that healthcare professionals might wish to work alongside charities providing peer support so that such platforms can be developed to contain accurate information and also perhaps host psychological self-help techniques that could further boost the naturalistic mechanisms by which peer support provides its benefits. Clearly, this study purposively sampled people who reported having derived benefit from engaging in peer support, so further research needs to also examine negative experiences of people participating in online peer support forums. Gaining in-depth accounts of negative experiences will of course be important in further developing peer support programmes. Nevertheless, given that existing research demonstrates that significant benefits can be achieved by peer support, this study was justified in seeking to focus on gaining a greater understanding of personal accounts of mechanisms by which such benefits occur.

The transferability of the findings may be limited in part due to the investigation of a single charity source. The Alopecia UK Facebook group is moderated to ensure a certain culture is maintained; this could have an effect on how the group is experienced. It could be this factor that contributes to the beneficial experiences described here, and it may be the case that similar groups without such management may lack comparable benefits.

The fact that this was a small, in-depth, qualitative study with an all-female sample, could also impact the transferability of the results found here. The sample itself consisted of those who were diagnosed, and an individual who was a parent to someone diagnosed. A sample that included more family members might not produce the same findings. Each of these factors should be taken into account in future research, and there is also space to look at the experiences of younger people who might be using different forms of social media.

A final recommendation could be the use of face-to-face interviews for future research examining peer support. The use of online interviews suited the context of the current study; however, the reliance on written answers and prompts could

have lost a sense of rapport. This factor was taken into account with the use of informal conversation previous to the interview and the use of a photo within the researcher's profile.

There is very little research into alopecia, and the cause is still unknown along with any definitive treatments.^{1,3} What is understood is that alopecia can have a significant psychological impact and possibly directly affect an individual's sense of identity, and this in turn might explain the increased risk of experiencing anxiety, depression and social isolation.^{2,5,6} This study provides a unique insight into the benefits of online peer support, which is a highly applicable coping outlet for today's online culture.

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website:

File S1. Alopecia UK Facebook group rules and guidance.

File S2. Instructions sent to participants for creating screenshots.

File S3. Summary and supplementary information for each theme found within data: gradual healing, image concern, belonging, new identity and self-acceptance.