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What is 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 form 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.

Abstract

Background - Those affected by alopecia are at risk of experiencing a range of psychosocial consequences. Alopecia UK provide 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 1 participant was a family member of someone with alopecia. The qualitative approach used to guide data collection and analysis was Interpretative Phenomenological 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, that 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.

Key words: Alopecia, Peer influence, Social support, Qualitative research

Introduction

Alopecia areata is an autoimmune condition thought to be caused by genetic and environmental influences¹, and is characterised by loss of hair, and can also result in the experience of significant psychosocial consequences². 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 partners⁷.

Peer support could be highly effective for those affected by long term health conditions such as alopecia. Peer support can be defined as when people with similar experience provide knowledge, emotional, and practical guidance to one another⁸. 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 normalise their experience through connecting with peers, decreasing loneliness and increasing hope and confidence^{9,10}.

Over 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 conditions¹¹⁻¹³. 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-care¹²⁻¹⁴. The benefits of online peer support have been found to outweigh the risks¹⁵, and sharing health experiences here has been considered one of the most beneficial aspects of the online world¹⁵.

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 UK charity Alopecia UK. The group strives to act as a safe place for members to connect and share experience through publishing posts. Prospective members are required

to answer a set of questions before being allowed to join (Figure 1) and expected to follow a clear set of group rules once accepted (Supplementary File 1), 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 the 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 coping strategies^{5, 21}. It has also been used as an approach to gain nuanced insights into other skin conditions²¹⁻²³.

Method

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 30-59. 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 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 gender, age, relationship status, age of diagnosis, whether they were undergoing treatment for their alopecia (Table 1). The first author then conducted semi-structured synchronous interviews with the participants individually, all on Facebook messenger.

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 schedule can be found in Table 2 below. All interviews lasted over one hour and provided comprehensive accounts of use of the online peer support group .

Prior to participating in the interview, the participants were sent instructions (Supplementary File 2) to provide a 'screenshot' (Supplementary File 3) of chosen critical incident/s. This part of the method was based on the Critical Incident Technique (CIT) and photo elicitation techniques, which are methods that have been previously used to facilitate participant reflection ahead of taking part in interviews²⁶⁻³⁸. In this study the request to take screenshots was made prior to the interviews so as 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 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 so as to ensure all data was coded and the development of the results was warrantable²⁵.

The analysis focused on the positive experience 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 process²⁵, 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 that 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 1 participant who was a parent to someone diagnosed with alopecia. Further demographic information can be found in table 1 below. 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 within Supplementary File 3, 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' in 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 way 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. Previous to joining, many of the participants state not being in contact with anyone with alopecia, which may have left them at a loss with ideas for 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 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 realise 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 oneself. Changes appeared to occur both at an internal or psychological level and also as 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, Carla suggests the group had indirectly helped her husband:

Claire- *“Iv 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 often join in search of knowledge and 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 normalise and build a common shared experience of life with alopecia, and this appears to provide a platform for reducing shame and stigma¹²⁻¹⁹.

Findings within 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 advice¹⁵. The findings suggest that healthcare professionals might wish to work alongside charities providing peer support so that such platforms can be developed so as 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 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 source³⁴. 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 may 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 media³³.

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 rapport³⁴. 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, 35}. 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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Table 1: Individual participant demographic details .

Pseudonym	Age	Relationship Status	Age Diagnosed	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*	No**

n/a = data not provided

*Age of Leah's daughter when she was diagnosed

**Leah's daughter is not receiving treatment

Table 2 - Interview Schedule

Questions on general experiences	<ol style="list-style-type: none"> 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? <i>Prompt - Have you tried different treatments or used wigs?</i> 6. Have you noticed any changes in yourself since being part of the group? Please describe these changes
Questions on specific experiences	<ol style="list-style-type: none"> 1. Can you tell me about a time when you found the group particularly helpful? 2. Can you describe the post?

	<ol style="list-style-type: none"> 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?
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Figure 1 - Questions asked by Alopecia UK admin 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?

Supplementary File 1 - Alopecia UK Facebook Group Rules and Guidance

Alopecia UK is a registered charity. This group is for members living in the UK only. If you live outside the UK and are looking for support, you may wish to join the 'Alopecia Areata' Facebook Group which is a worldwide online community.

Further information about the charity can be found at www.alopecia.org.uk

General Rules and Guidance:

The aim of this group is to provide valuable peer support and share information about alopecia and Alopecia UK.

This is a 'closed' group. Anyone can find the group and see who is in it, but only current members can view the posts made within the group.

We also have three associated groups:

AUK Wigs, Headwear, Make Up & More Chat Group – for discussions about wigs and other products related to alopecia.

Alopecia UK Parents Chat – a private space for parents of children with alopecia to chat

AUK Men's Chat – a private space for men with alopecia to chat

Please DO NOT SHARE any member posts from this group. There is no 'share' setting within our closed group (apart from on external links) for the reason that posts are to remain in the group. Anyone found lifting any posts or photos from the group without permission from the post's owner will be deleted from the group with immediate effect.

Before your post is published in the group, it will need to be approved by one of our Admin team. The approval of posts improves the group experience for everyone, meaning any unsuitable posts are deleted prior to being seen by other group members. Admins work hard to approve posts in a timely manner but your post might take a short while to appear.

If your post does not appear in the group, please check whether it goes against any of the following rules:

Please keep all posts and threads relevant to the topic of alopecia (hair loss). If your post does not relate to alopecia, please consider whether the group is the place for the post or if it would be more appropriate for your own personal Facebook profile. We want the posts in the Alopecia UK group to remain on the topic of alopecia and support. We are trying to direct many of the post about wigs to the AUK Wigs, Headwear, Make Up & More Chat Group. If your post relates to questions about wigs, headwear, makeup and other products, please consider posting in the separate group which has been designed for more of the product chat.

NO SWEARING. Please refrain from swearing in posts. Please be aware that posts including swear words may not be approved. This can be a shame as sometimes the rest of the post is really good. Occasionally we will private message members asking for their pending post to be edited or reposted in order for it to be approved. But please remember, we are a small and busy Admin team. We won't always have time for this. To avoid your post being deleted, please keep your language clean. We recognise that you may need to vent but please make use of 'fluffing' or 'flipping'! (We know not everyone will agree with our firm stance on swearing but we do believe that keeping the group free from swearing makes it a much nicer place for everyone to be).

We do not allow posts highlighting petitions, campaigns or self-promoting businesses or webpages (see below for further details relating to business mentions/posts).

Any members found sending unsolicited messages (private messages without invitation) to other group members will be removed from the group.

Please do not recruit for media, casting, photography or research study opportunities in this group. If you are looking to recruit participants for any such project, you must get in touch with Alopecia UK: info@alopecia.org.uk Any recruitment adverts for participants posted without permission will be deleted.

Posts alluding to thoughts of suicide or self-harm might not be approved. Alopecia UK's Facebook group is not moderated by any professional counsellors and we are worried that anyone who may be in urgent need of help may not get the type of support they need from the replies in our group. If other mental health issues are also impacting on your life, please consider reaching out for support for these too. We want every member of this group to feel supported but we would ask you to consider if the Alopecia UK Facebook Group is the best place to get the support you might need. If we do not approve a post because we are concerned about the nature of it, an Alopecia UK admin will send you a private message signposting you to additional support organisations which can also be found here.

Posts that include links to fundraising pages for charities other than Alopecia UK or crowdfunding pages, including 'Go Fund Me' pages, will not be approved. If you are fundraising for Alopecia UK, we are happy for you to post a link to your fundraising page but it will only be approved the once. If you do wish to post about your fundraising efforts, please do a short post letting people know what you're doing. Please don't just post a link to your page without an introduction (it will just look spammy and most members will ignore).

Group members wishing to sell, swap or giveaway wigs/headwear are only permitted to do so in the AUK Wigs, Headwear, Make Up & More Chat Group, each Monday on

'Members' Market Mondays'. Any sales posts in the main group will not be approved.

Please note, 'Members' Market Mondays' are strictly for individuals and not business owners.

Posts promoting other Facebook groups will not be approved and comments including links to other Facebook groups may be deleted by admin.

Only Alopecia UK events or Alopecia UK support groups can be set up as Facebook events within our Facebook group.

Please consider carefully prior to posting 'jokes' & 'memes' in the group. Not everyone shares the same sense of humour and if admins believe a joke may cause offence to some group members, your post may not be approved.

If you share an alopecia news story or video in the group that has already appeared recently, the Admin team may choose not to approve your own post. Instead, they may tag you in the original post in the group – thus bumping it back up the page and also meaning there are not then lots of posts about the same news story in the group.

Posts that discuss, ask about or recommend shampoos and supplements which claim to stop hair loss or help hair growth will not be approved into the group, unless the manufacturers have provided clinical research to validate their claims. We appreciate that some people may feel these products have been beneficial for them and would then want to share with others. But we don't want to risk giving false hope to others who may try them and then feel they have wasted money.

Alopecia UK does not endorse the products or services of any one supplier. Any recommendations made in the group are not endorsed by Alopecia UK. Please see

below for further information prior to posting about products and suppliers.
Please be respectful to all members with your interactions within the group. Any offensive/rude/aggressive comments will be deleted and members may be removed. Alopecia UK reserves to the right to remove any content from the group that it deems Inappropriate.

Our public Facebook page can be found here: <https://www.facebook.com/AlopeciaUK>
Please visit our website: www.alopecia.org.uk to sign up to our mailing list.

Posts regarding businesses/products related to alopecia – Additional Info:
Businesses should not advertise any companies, products or services within this group.

Posts including adverts/external links to businesses will not be approved by an Admin. An exception to this rule is our weekly, 'Free to Promote Fridays' over in our AUK Wigs, Headwear, Make Up & More Chat Group. Each Friday in our separate wigs/products group, business owners are permitted to advertise their services to group members. Otherwise, business owners can answer queries and questions about products and services.

We're sure other members may be able to benefit from the expertise shared in the group*. But business owners should not send private messages to members with details of products and services, unless THEY request you to do so. The comments in which business owners share their expertise should not be used as an opportunity to tell the original poster that you have a business and can help. If an Admin believes a comment to be self-promotion by someone connected to a business, it will be deleted.

'Free to Promote Fridays' in the AUKWigs, Headwear, Make Up & More Chat Group is the only time that promotion of businesses can be done.

*This will be monitored and AUK reserves the right to amend the rules at any time and delete posts if they deem them inappropriate.

If any group members have a business relationship with any companies or brands, they should refrain from any promotion within the Alopecia UK groups and keep any such posts to their own social media pages.

If any group members receive a product free from a supplier or manufacturer, we would ask that you refrain from posting photos or discussing it in the group as this could be viewed as paid promotion.

Members should not create a post which appears to just be giving a shout out or thank you to a business or tagging a business owner in it after they have bought something from them. We know some people want to show their appreciation, but this is not appropriate for the group and is inadvertently advertising. If you want to thank a business owner, please thank them directly and not in the Alopecia UK Facebook Groups.

Where can businesses advertise?

Each Friday in the AUK Wigs, Headwear, Make Up & More Chat Group we have 'Free to Promote Fridays', allowing businesses to advertise their services to group members. You may also promote your business to those with alopecia through joining Alopecia UK's Suppliers Directory (an annual fee applies).

Issues & Complaints

Should you have any issues or complaints with the Alopecia UK Facebook Group please do approach a group admin and see if your issue can be resolved that way.

If your issue or complaint with the Alopecia UK Facebook Group cannot be resolved by an admin, or you have an issue or complaint about Alopecia UK generally, then please see the following web link for next steps: <http://www.alopeciaonline.org.uk/complaints.asp>

Supplementary File 2 - Instructions sent to participants for creating screenshots

Before your interview we would like you to find an example of your activity within the Alopecia UK Facebook group that was meaningful to you in a positive way. These can include posts with or without photos and either with or without comments. Please take care when doing this, allowing yourself some time

to reflect on your example and remember how you were feeling before and after publishing the post, as well as how it felt to receive any comments from others within the group.

Special permission given re screen shot posts in the Facebook Group:

You may be aware that the Alopecia UK Facebook Group Rules state that group members are not allowed to screenshot any posts and share elsewhere. We are giving special permission to participants of this study as you will be asked to screenshot posts that you have found helpful. We ask that you only share these for the purposes of the study and follow guidelines given regards deleting your conversation once it is complete. Sheffield University have been given guidelines to employ when using these screenshots and while they may quote wording from screenshots in their final paper they will not use any identifying data, names or imagery in their final report or any resulting published work.

(Jen Chambers, Charity Development Manager)

Once you have found your example/s we would like you to take a screenshot and send them over on Facebook messenger to be used during your interview. This can be done in several ways depending on what device you are using, instructions can be found for each device below. Once your example is visible on your screen, use one of the instructions below to take a screenshot.

You are also able to send screenshots from your phone, please email me if you need instructions on how to do this.

Windows PC or Laptop

You want the “Print Screen” key (or “PrtScn”) which is usually at the top right of your keyboard.

To take a screenshot try pressing one of:

- 1) “Alt” + “Printscreen”
- 2) “Fn” + “Printscreen”

3) Windows key + Printscreen



This will save a screenshot to the pictures folder on your computer, where you will be able to open the file and send over messenger.

Mac

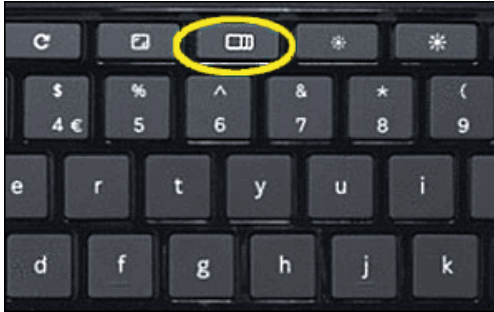
To get a screenshot on a Mac press:

“Command” + “Shift” + “3”

This will save your screenshot to your clipboard where you can open and send the file over messenger.

Chromebook

You want the “Switch Window” key, located on the top row between the “Full-screen” and “Brightness Down” keys.



Take a screenshot by pressing:

“Ctrl” + “Switch Window key”

This will save directly to your Chromebook’s download folder where you can open and send the file over messenger.

Supplementary File 3 - Tables with summary and supplementary information for each theme found within data.

Gradual Healing: Subordinate Themes, Supporting Quotes and Screenshots within Theme

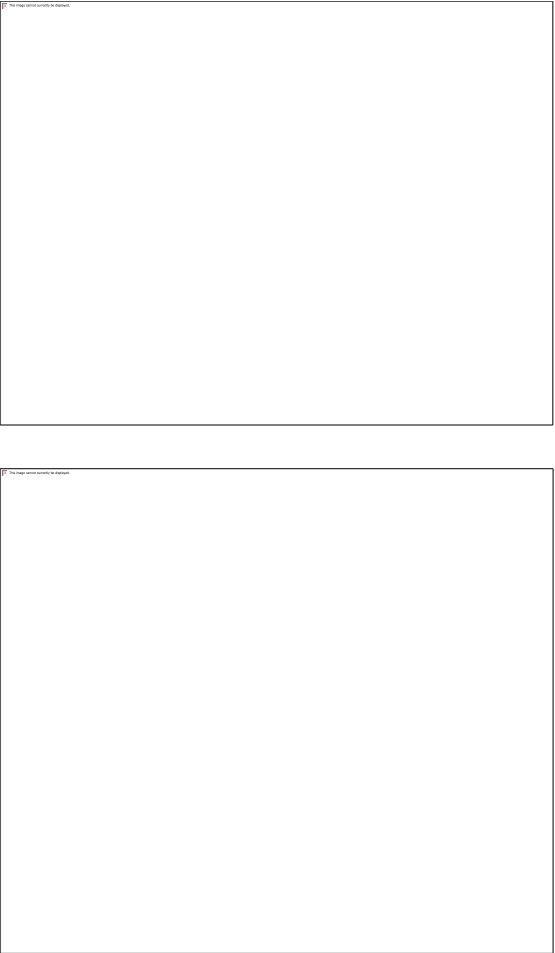
Subordinate	Description	Supporting Quotes	Screenshots
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Theme			
<p>Expressing emotions</p>	<p>Within this theme participants describe the use of the group for expressing emotions both good and bad. The group is a place to let go of feelings.</p>	<p>Poppy - “I think I would still be very depressed”</p> <p>Amber - “ I no that if I do have a bad day someone will be there and guide me or just be there”</p> <p>Merida - “It's a great resource to have.”</p> <p>Lily - “It’s a way of off loading at times instead of moaning to my hubby all the time!”</p> <p>Merida - “My husband (Who is amazing) was the only person I could talk to about it and I didn’t want to dump it all on him”</p> <p>Claire - “Every time I write a response it's a reminder to me of how far I’ve come, and how I’m doing OK.”</p>	<div data-bbox="1424 272 1861 628" style="border: 1px solid black; height: 223px; margin-bottom: 10px;"></div> <div data-bbox="1424 671 1861 754" style="border: 1px solid black; height: 52px; margin-bottom: 10px;"></div> <hr/> <p>Am feeling so great! My first time in public without anything to cover my head and feel so happy....it may have been only in the gym but it’s a start yes some people stared but you know what I don’t care, I have my family and friends who love me for who I am and I don’t care what anyone else thinks. Enjoy the weekend xo — 😊</p> <hr/>

		<p>Claire - “The history bubbles up to the surface every so often, and rather than keep it in, I shared it.”</p> <p>Merida - “I’d come to terms with what was happening but it helps to reinforce your attitude”</p>	<p>Having a bad few days and feeling very disheartened!! Recently been diagnosed with scarring alopecia & have lost considerable amount of hair on one side of my head. The last 2 weeks I am now losing handfuls of hair & it is very very thin in places, with more larger bald patches appearing. This week Hubby had to unblock the outside drain & pulled out the most enormous ball of my hair!!!! 😞😞</p> <p>Have started to lose eyebrows now & eye lashes have gotten thinner too 😞😞 hair on my arms has almost vanished too!!</p> <p>Am feeling really low & peeved off about it all!!!! 🙄🙄🙄🙄</p> <p>Have managed to keep it hidden with buffs up to now, but don't think I will be able to for much longer. It's the discomfort on my scalp that annoys me the most! Burning & itching sensation!! Bloody alopecia!!!!</p> <p>🙄🙄🙄🙄🙄🙄</p> <p>👍 Like 💬 Comment</p>
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Image concern: Subordinate themes, supporting quotes, and screenshots.

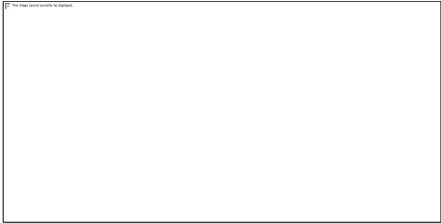
Subordinate Themes	Description	Supporting Quotes	Screenshots
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<p>Practical Support</p>	<p>Participants use the group to gain practical and up to date advice for coping with alopecia, including wig use and makeup techniques.</p>	<p>Evie - “I found out you could get 50% off eyelure eyelashes which has helped massively in feeling I can afford to try a new pair at £2.50 against £5.”</p> <p>Carla - “I’ve learnt a lot about good realistic wigs too that don’t cost an arm and a leg”</p> <p>Penny - “Yeah there was one a while ago about sealing the knots on wigs with concealer this is a lifesaver”</p> <p>Evie - “Yes at present but things change & again the group keeps me up to date with new ideas and more comfortable hair pieces”</p>	
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<p>Tips on coping</p>	<p>This theme highlights the individual choices available when coping with alopecia. Some chose to cover up whilst others choose to shave their hair. Whichever coping method is chosen there is always support found within the group.</p>	<p>Alice - "I am publicly bald now, and speaking to others on the group has inspired and encouraged me to do that "</p> <p>Leah - "I think once I started to see that there were lots of solutions, and practical things to do, I could focus more on practicalities rather than [daughter's] hair loss"</p> <p>Amber - "People putting up pictures/selfies of themselves bald or patchy or with wigs or scarves out in public, gives u a sense of feeling well they can do it y can't I"</p> <p>Amber - "So scared when I heard the sound from the shaver and watching what was left of my hair fall around me but I felt so so so much better and actually liked it.....I felt liberated"</p>	<p>Thank you so much to everyone for their lovely comments today on my first ever 'selfie'!! I'm touched by your kind remarks 😊😊😊 I have added another photo as so many of you said I needed to add a smile....</p>  <p>A whole year has gone by since I shaved the rest of my hair off supported by my lovely hubby!! Best thing I ever did!!! Taking control of a negative situation relieved the stress and anxiety. My life has changed so much since I joined this amazing group and I have made some wonderful friends along the way 😊 I have accepted how I look and now just get on with my life.</p> <p>Alopecia UK rocks 💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙💙</p> <p>Thank you all for the strength and support I have gained since joining this group xxxxxx</p>  <p>Iv done it I have shaved my head.....AND I feel so liberated. I can now hopefully watch my hair grow instead of watch it fall out.....I am channeling Demi Moore in GI JANE but with "duck lips selfie" 🦆 I am embracing it day by day</p>
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		<p>Olivia - “Maybe one day i would be able to wear a different wig everyday and not worry what people think!”</p> <p>Olivia - “Well i see people on there and they look so gorgeous with or without hair. I suppose i worry that if i told people of my alopecia they would think less of me. I don’t know why! It matters more what a person is like ie personality etc not how they look.”</p>	
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Belonging: Subordinate themes, supporting quotes, and screenshots.

Subordinate Themes	Description	Supporting quotes	<u>Screenshots</u>
Connecting	<p>Connecting with similar others reduces loneliness and allows group</p>	<p>Lily - “Scarring Alopecia is rare so it was even more important that I found someone else with the same type.”</p>	

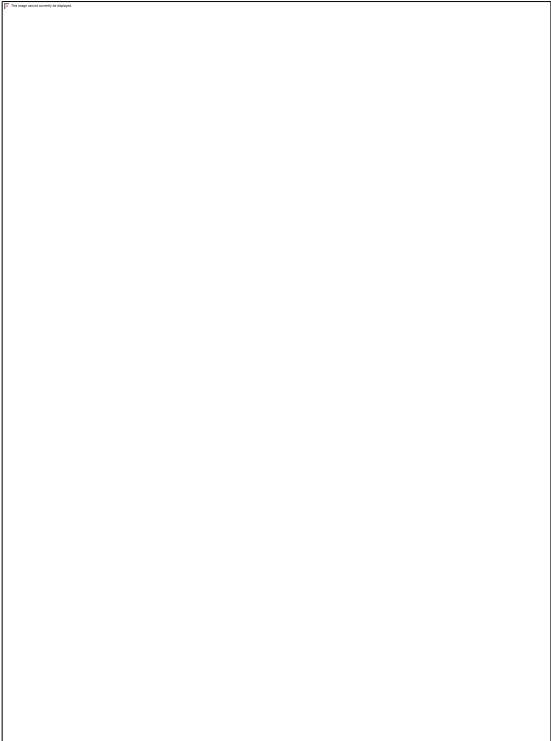
	<p>members to support each other.</p>	<p>Amber - “just getting the kind remarks made me feel even more happy and confident and felt like I did do the right thing and was glad that I did, I felt liberated.”</p> <p>Lily - “I did a charity raffle last September which was supported by AUK and they were amazing! They promoted it for me and helped me with resources etc. I felt very proud when they posted the story on their main charity page”</p> <p>Amber - “I wanted to post it and share it with the group and maybe inspire someone else who is thinking of the same thing”</p>	
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		<p>Claire - “helping others, helps me too.”</p> <p>Leah - “Just how brilliant the administrators are. [Administrator] was very helpful and supported me through the difficult times.”</p> <p>Carla - “Just that there is a well established community spirit of support”</p> <p>Lily - “When the comments and advice started coming I was overwhelmed by the support and kindness of everyone.”</p> <p>Poppy - “I felt like that post might help other people which also made me happy”</p>	
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<p>Shared Experience</p>	<p>Sharing experiences within the group creates a feeling of normality, appearing to reduce the shame associated with alopecia.</p>	<p>Evie - “helped me to see not the only one and not just me.....before this would blame myself but able to see actually it can happen to anyone and the fact that she’s able to tell others on the site just makes it less scary and so what if it does happen”</p> <p>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.”</p> <p>Amber - “The support group was different as you would get comments like I</p>	<p>Note to self- before jumping in a packed swimming pool and in front of your new boyfriends family, make sure to take your wig off😂😂 came back up to the surface and my wig was floating away from me😂😂</p> <p>👍👍👍 52 11 comments</p> <p>👍 Like 💬 Comment</p> <hr/> <p>Been a member for a while now and haven't posted anything. I thought I would let u in to my journey so far....From about 2015 I started loosing hair I had hair well past my shoulders and it really was my pride and joy being able to do all sorts of styles. I didn't realise at first what was happening, I was in denial. It got to the point where my pony tail was no thicker than the thickness of my baby finger 🙄. The doctor told me it was areata alopecia but what they didn't tell me was that the tablets they so desperately wanted me on for my exzema could cause hair loss! So for the next two years I battled with my hair falling out in patches and hair growing back WHICH I was VERY VERY thankful for but once it got to a certain length BAM hair all over my pillow chunks coming out when washing it patches reoccurring and lots lots of tears 😭.</p> <p>📅 👤 🏠 🔔 ☰</p>


		<p>no how u feel.....it was a different kind of support mentally and family and friends would b more physically like the hugs”</p>	<p>While talking to a friend the other day I mentioned how kids staring really hurts. Of course I get they are kids. But, when I’m walking through a park at lunch time and there is a camp of 50 kids having lunch...they all stop talking and eating and just stare. What a horrible feeling.</p> <p>   9</p> <p>11 comments</p> <hr/> <p> Like  Comment</p>
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New Identity and Self Acceptance: Subordinate themes, supporting quotes, and screenshots

Subordinate Themes	Description	Supporting Quotes	<u>Screenshots</u>
<p>Internal Changes</p>	<p>Participants describe acceptance with their alopecia, as well as developing compassion for others and themselves.</p>	<p>Evie - “ Now I can look at myself and think ok not what I would have chosen but it’s ok”</p> <p>Alice - “I have accepted that after 30 years nothing will make my hair grow back!”</p> <p>Amber - “Now I love my hair reminds me of GI JANE lol”</p> <p>Penny - “Yeah i don’t feel like i want it to come back i honestly prefer the way i am now. I couldn’t go through it coming back and having patches again”</p> <p>Carla - “Iv met up with a few people who live nearby and my husband came with me to meet</p>	

		<p>another couple, and it was nice for the men to talk about how it affected them us having it”</p> <p>Claire - “I feel more peaceful, I describe it as me and alopecia having called a truce, a respectful let’s not bother each other.”</p> <p>Merida - “I think I think more about judging people. You never know what’s going on with them. Like I try not to but when I do, I stop and think about how I would feel.”</p> <p>Evie - “That particular post I related to as I had been in similar position where wig has come off in public and you feel like you want to die at the time but by making light of it helps to not focus on it and puts it into perspective”</p>	<p>A whole year has gone by since I shaved the rest of my hair off supported by my lovely hubby!! Best thing I ever did!!! Taking control of a negative situation relieved the stress and anxiety. My life has changed so much since I joined this amazing group and I have made some wonderful friends along the way 😊 I have accepted how I look and now just get on with my life.</p> <p>Alopecia UK rocks </p> <p>Thank you all for the strength and support I have gained since joining this group xxxxxx</p> <hr/> <p>—</p> <p>feeling good. i have a life i love. i still miss my hair but would i trade it to lose any part of what i have the answer is no im happy and i am loved what more could u want.</p>
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		<p>Evie - "I was in the car with my daughter and said I wasn't going on a night out as it was a wig theme & that wasn't my thing & she laughed. If this had happened pre this group I would have felt low for weeks & embarrassed as her friend was in the car but I laughed with her at the irony of my comment"</p>	
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<p>Social Life and Openness</p>	<p>Within this theme participants describe better coping on a social level, returning to work, hobbies and being more open to others about their alopecia.</p>	<p>Carla - “I went to an alopecia uk big weekend and because i won a free head henna i didn't wear a wig all weekend there and went by myself to Birmingham to meet new ppl”</p> <p>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”</p> <p>Claire - “I believe more I have as much right as anyone else to be in a restaurant, to attend an event.”</p>	<p>Am feeling proud of myself today 😊 I have visited my first primary school to do a short talk about Alopecia in their reception class and it went really well. The children were amazing and loved Ella so much that they wanted her to stay! The little book 'Ben's first day' was a hit!</p> <p>Spreading Alopecia awareness 💙💙💙💙💙💙💙💙💙💙💙💙💙💙 — 😊 feeling proud.</p>  <p>Write a comment... GIF 😊</p> <p>📅 👤 🏠 🔔 ☰</p>
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		<p>Amber - “I even went back to work afterwards I felt ready to take on the world”</p> <p>Penny - “I don’t feel ashamed tell people like i used too”</p> <p>Alice - “I am able to express my feelings to others about how I’m feeling,which for me being able to verbalise has been invaluable”</p> <p>Lily - “The information about the support group should be put up in all dermatology departments”</p> <p>Lily - “I did this with the support and help from the group. It was a big thing to tell the world about it”</p>	<p>Am feeling so great! My first time in public without anything to cover my head and feel so happy....it may have been only in the gym but it’s a start yes some people stared but you know what I don’t care, I have my family and friends who love me for who I am and I don’t care what anyone else thinks. Enjoy the weekend xo — 😊 feeling fantastic.</p> <hr/>
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		<p>Penny - "I now model for that brand of wig get taken away to do a fashion show and promote their wigs they will often send me them to review for them"</p>	
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