

# The Lived Experience of Young People who have Alopecia:

## PATIENTS AND RELATIVES



WHY CONDUCT THIS STUDY?

# PREVIOUS LITERATURE

- Impact of alopecia on adults
- Impact of chemotherapy induced alopecia on adolescents
- Impact of disease on family members

# IMPACT OF ALOPECIA ON ADULTS

Tucker (2009)

A systematic review of 19 studies (adult samples) concluded that:

“It is apparent that alopecia areata causes dramatic and devastating emotions in patients, which can negatively impact their self-esteem, body image, and/or self-confidence,” (Tucker, 2009, p. 142).

# IMPACT OF ALOPECIA ON ADOLESCENTS

## Rafique and Hunt (2015)

Coping behaviours of adolescents aged (15-19).

- loss of self
- concerns for the future
- negative emotions and thoughts.

# IMPACT OF DISEASE ON FAMILIES

Golics et al. (2013)

Most chronic diseases have significant effects on family members:

- Psychological and emotional functioning
- Disruption of leisure activities
- Effects on interpersonal relationships
- Impact on financial resources.

# WHY CONDUCT THIS STUDY?

---

The **AIM** of this research is to explore alopecia related experiences from the perspectives of close relatives and adolescents with alopecia.

# STAGE ONE

---



THE LIVED EXPERIENCE OF  
**RELATIVES** OF  
ADOLESCENTS WHO HAVE  
ALOPECIA



# METHODOLOGY

---



Going back to the very first time X lost their hair - could you tell me what happened?

What has been the impact of X's alopecia on you? Can you describe a recent occasion where this has occurred?

What has been the impact of X's alopecia on other people close to you?

I'd like you to think about when X attended school during a period in which the alopecia was most prominent. Could you describe how you felt during this time?

What support have you received?

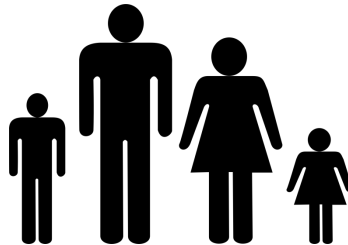
Has anyone spoken to you about your own needs of having a family member with alopecia? What would you consider your needs to be?

## Loss (self and social)

*'I did feel terribly upset - rather like my daughter had died and now there was a different child living with us. It gave her a new identity and I felt really confused. She was absolutely Sarah BUT somehow she wasn't'*  
-Alison

## Impact on family

*'I have two other children but Adam has become the focus as he's very emotional so house is in a constant state of high alert/emotion.'*  
-Rachel



## Concerns (Physical and Future)

*'Joey is looking forward to his new school but I worry he has no idea what he might come up against and expect. I feel like I am throwing him to the wolves and he will be fair game for the bullies'*  
-Monica

## Negative emotions/ thoughts

*'I have thought and thought about this and I don't want to have to admit that I was distraught, but I was distraught. She looked so forlorn, and she looked so unwell/ poorly, I was distraught.'*  
-Jessica

# STAGE TWO

---



THE LIVED EXPERIENCE OF  
**ADOLESCENTS** WHO HAVE  
ALOPECIA

# DISSEMINATION OF RESULTS

## ADOLESCENTS WITH ALOPECIA

### THE LIVED EXPERIENCE OF RELATIVES OF YOUNG PEOPLE WHO HAVE ALOPECIA

**Lead Author: Joanna Smith & Claire Taylor**  
University of Huddersfield, University of Huddersfield, University of Leeds

**BACKGROUND INFORMATION**

Alopecia areata is a dermatological condition in which individuals lose some or all of their hair. Although it is most common on the scalp, alopecia can affect other parts of the body where hair would usually grow.

Alopecia is a chronic inflammatory condition and can occur at any age but is most prevalent for individuals aged 15-29 (NHS, 2015).

**WHY CONDUCT THIS STUDY?**

Little is known about what it is like for young people to have alopecia and how it might affect them and their families or other relatives. The aim of this study was to explore the lived experience of relatives of young people with alopecia and their relatives.

**PREVIOUS RESEARCH**

According to Thompson et al. (2022), there is a need to explore the impact of alopecia on young people and their families or other relatives. There is limited research on young people with alopecia generally, and studies which explore the experience of alopecia tend to focus more on body image concerns rather than investigating alopecia as an independent measure/phenomenon.

Equally, studies of relatives of young people with alopecia are limited. In particular, studies which explore the experience of relatives and their relatives are limited. In particular, studies which explore the experience of relatives and their relatives are limited.

**METHODOLOGY**

Participants were recruited through an advertisement placed on the Alopecia UK website.

The interviewer sent the participants one question a week over the course of six weeks via email, in which individual and personal 'probe' questions are sent based on their initial response.

The transcripts will be analyzed using Interpretive Phenomenological Analysis (Smith, Flowers and Larkin, 2009).

**RESULTS**

**Relatives' Experiences**

Participants described how they felt about their relative's alopecia and how it affected their family. Some participants described how they felt about their relative's alopecia and how it affected their family.

**Supportive Experiences**

Participants described how they felt about their relative's alopecia and how it affected their family. Some participants described how they felt about their relative's alopecia and how it affected their family.

**Conclusion**

Findings provide an understanding of what it is like for a relative of a young person with alopecia. The study also identified the need for further research on young people with alopecia and their relatives.

## THE LIVED EXPERIENCE OF RELATIVES OF YOUNG PEOPLE WHO HAVE ALOPECIA

**Lead Author: Joanna Smith & Claire Taylor**

**Q?** Key questions for stage one (relatives' experiences)

Going back to the very first time X lost their hair - could you tell me what happened?

What has been the impact of X's alopecia on you? Can you describe a recent occasion where this has occurred?

What has been the impact of X's alopecia on other people close to you?

Is there any time you think about the time your relative first started losing their hair during a period in which the alopecia was most prominent? Could you describe how you felt during this time?

What support have you received?

Has anyone spoken to you about your own needs of having a family member with alopecia? What would you consider your needs to be?

### PREVIOUS RESEARCH

According to Thompson et al. (2015), there is a need to explore the impact of hair loss on a younger population. There is limited research on young people with alopecia generally, and studies which explore the experience of alopecia tend to focus more on body image concerns rather than investigating alopecia as an independent measure/phenomenon.

Tucker (2008) systematic review of 10 studies (adult samples) concluded that "it is apparent that alopecia areata causes dramatic and devastating emotions in patients, which can negatively impact their self-esteem, body image, and/or self-confidence" (Tucker, 2008, p. 142).

### WHY CONDUCT THIS STUDY?

Little is known what it is like for young people to have alopecia, such as what it means to them and how it could affect them. The aim of this research is to explore alopecia related experiences from the perspectives of close relatives.

### METHODLOGY

Participants were recruited through an advertisement placed on the Alopecia UK website.

The interviewer sent the participants one question a week over the course of six weeks via email, in which individual and personal 'probe' questions are sent based on their initial response.

The transcripts will be analyzed using Interpretive Phenomenological Analysis (Smith, Flowers and Larkin, 2009).

### RESULTS

Children started to make fun of him and would run around the playground and take his hat off him. This left him feeling very upset and he had several conversations about 'why me?' and 'I wish I wasn't here' and 'no-one will ever want to love me'.

"She worried that people would think she was a boy. In many ways it was like a loss of self - and she can't be a thinking widow, she has always been quite a feisty woman, but the alopecia pushed her for a while."

"It's made me feel very guilty & hopeless. That I can't do it or give him the answers he wants. I have two other children but Adam has become the focus as he's very emotional so focuses in a constant state of high alert/emotion."

"No words can describe how frightened and sad I was when Nathan lost his hair. To see my son afraid, bewildered and devastated when he could see all his hair was falling out broke my heart... I became really depressed for a long time."

THANK YOU FOR LISTENING

---