School of Psychology
Ysgol Seicoleg

The Experiences of Individuals with Body Dysmorphic Disorder: A Systematic Review and Thematic Synthesis, and The Experience of Living with Hidradenitis Suppurativa for Affected Individuals and their Partners: An Interpretative Phenomenological Analysis

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Preface

The current thesis explores the experiences of individuals with the psychological condition body dysmorphic disorder (BDD) and then couples affected by the dermatological condition Hidradenitis Suppurativa (HS).

BDD is a distressing psychological condition where individuals are preoccupied with a perceived flaw in their appearance, often imagined or very slight and unnoticeable to others. The systematic review and thematic synthesis aimed to integrate the existing qualitative studies on the experiences for individuals with BDD. A systematic review protocol was developed and used to search for qualitative studies on BDD on six different databases. Guidelines for specifically conducting a systematic review were followed and 10 peer-reviewed journal articles were found that met the inclusion criteria. All 10 articles were quality assessed. Thematic synthesis was used to integrate the data from the findings. Three major themes and ten subthemes were created in the thematic synthesis. The first major theme 'self-objectification and the view of self' captures how participants viewed themselves in relation to the perceived flaw, the all-encompassing preoccupation of the perceived flaw and the shame and disgust which some participants experienced towards themselves. The second major theme 'control and protecting the self' details how participants with BDD felt out of control with their appearance but the safety behaviours and avoidance they engaged in were counterproductive as the behaviours became consuming and led the participants to have a more restricted life. The final major theme 'sociocultural influences and the impact of others in BDD' discusses the role of sociocultural factors in the development of BDD and how others may help or hinder individuals' experiences of BDD. The thematic synthesis contributes to the field by highlighting the role of shame and disgust in the lived experiences for people with BDD. In addition, the study supports the application of objectification theory in BDD but more research is needed on the experiences of males with differing sexual orientations and BDD. Services supporting people with BDD should ensure they are culturally appropriate, consider outreach initiatives and consider offering compassion focussed techniques alongside more established cognitive behavioural therapy. The thesis also suggests further areas of research in BDD.

The second part of the thesis focuses on the experiences of couples where one person in the relationship has HS. HS is a dermatological condition where individuals experience painful flares with abscesses and scarring often presenting in intimate areas of the body. The empirical study is the first one to interview couples about their experiences of HS. Six couples participated with all twelve individuals interviewed separately. The methodological approach used in this study was Interpretative Phenomenological Analysis (IPA) as it is appropriate when topics are particularly important to participants. In IPA, the researcher is making sense of the participant making sense of their experiences and so it is important for the author to be reflective throughout the lifecycle of the study as this could influence data interpretation. Interviews were held over the videoconferencing platform, MS Teams. The aim of the study was to explore the couples’ experiences of HS with a specific focus on flares, pain, intimacy, relational functioning and accessing healthcare. Three major themes emerged from the study. The first theme ‘being unheard: a frustrating journey to receiving care’ highlighted the difficult experiences that the couples often faced when trying to access healthcare for flares, often due to a lack of sensitivity or knowledge of HS from healthcare professionals. The second theme ‘relational burden and dyadic coping’ details the impact of HS on the couple, their relationship and how they work together to identify solutions or make adjustments to any difficulties that arise. The final theme ‘self-disgust and self-consciousness’ details the difficult emotions that people with HS experience such as shame and disgust. Whilst some of the patients with HS in the study could be very self-critical, the partners did not think of them or their HS symptoms in the same way. This study contributes to the field by highlighting the considerable impact of flares of HS for couples. To help improve the experience of accessing healthcare for flares, GPs and A&E staff should have further training on the emotional and psychological consequences of HS. Embedding psychological therapy in dermatology services may also help partners and patients cope with the experience of HS. Further research areas are also identified.

Theoretical overlap between the two studies include appearance concerns contributing to disgust towards the self and feelings of shame. The study exploring the experiences for people with BDD is more focused on appearance concerns and their impact whereas the study with couples impacted by HS explores how couples cope with the condition, including pain, losses, remaining close when unable to be intimate and experiences of accessing healthcare.

The Experiences of Individuals with Body Dysmorphic Disorder: A Systematic Review and Thematic Synthesis

To be submitted to Body Image (please see appendix one for full guidance)

Kathryn Thomson, Cardiff University

Word Count: 7,762 words

Highlights

- A thematic synthesis on 10 papers regarding the experiences of people with BDD
- Shame and disgust appear to play a role in living with BDD
- Objectification theory may help explain the experiences for individuals with BDD
- Social and cultural factors may influence the development and maintenance of BDD

Abstract

Introduction: Body Dysmorphic Disorder (BDD) is a distressing psychological condition where an individual is preoccupied by a perceived issue with their appearance. Qualitative studies provide a unique opportunity to investigate the lived experiences of people with BDD. The current systematic review aims to use thematic synthesis to integrate the findings from the extant studies.

Method: Searches were run on six databases to identify peer-reviewed journal articles of qualitative studies pertaining to the experiences of individuals with BDD. PRISMA guidance was followed and ten articles were identified for inclusion. The quality of each article was appraised. Thematic synthesis was then conducted to generate new and summative themes from the ten articles.

Results: Three superordinate themes were created; ‘self-objectification and the view of self’, ‘control and protecting the self’, and ‘sociocultural influences and the impact of others in BDD’.

Conclusion: Internal shame, external shame and self-disgust may contribute to experiences for people with BDD. Objectification theory may help explain the experiences for individuals with BDD. Services should ensure that they are culturally appropriate, consider outreach initiatives and consider offering compassion focused techniques alongside more established cognitive behavioural therapy. Areas for further research discussed.

Keywords

Body Dysmorphic Disorder; Qualitative research, Thematic synthesis, Lived experiences, Systematic Review

The Experiences of Individuals with Body Dysmorphic Disorder: A Systematic Review and Thematic Synthesis

Body Dysmorphic Disorder (BDD) is a psychological condition diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), requiring an individual to be preoccupied with a perceived flaw in their appearance (American Psychiatric Association, 2013). As the flaw is “imagined”, others do not see anything wrong with their appearance or if there is one, it is slight and the preoccupation and distress caused is very heightened in comparison (Veale, 2004a). An individual with BDD may have one or multiple perceived flaws (American Psychiatric Association, 2013). Furthermore, in BDD the area of concern may shift to another part of the body (Veale et al., 1996). BDD is also in the International Classification of Diseases, Eleventh Revision (ICD-11; World Health Organization, 2019). Unlike the DSM-5, the ICD-11 states that individuals with BDD can be preoccupied about “ugliness in general” rather than specific areas of concern and states that indviduals with BDD are likely to experience ideas of self-reference (World Health Organization, 2019, Essential (Required) Features section, para. 3). Individuals experiencing BDD may experience a significant amount of distress in relation to their appearance and may unduly view themselves to be disgusting, ugly or deformed (Feusner et al., 2008). This distress may reflect the suicidality experienced by people with BDD with approximately 80% of individuals experiencing suicidal ideation and between 24 to 28% having attempted suicide (Phillips, 2007). Furthermore, BDD is associated with significant functional impairment with more severe BDD associated with poorer psychosocial functioning (Phillips et al., 2008).

Similarly to other psychological conditions, BDD is placed at the end of the continuum for commonly held appearance concerns (Clarke et al., 2014; DeRosse & Karlsgodt, 2015; Ross & Gowers, 2011; Tebeka et al., 2021). However, if the appearance concerns are related to an obvious visible difference, a diagnosis of BDD cannot be made according to the DSM-5 and ICD-11 (American Psychiatric Association, 2013; World Health Organization, 2019). Concerns have been raised that a BDD diagnosis is therefore based on another person deciding how obvious the perceived flaw is as individuals with visible differences may have high levels of preoccupation, like those with BDD (Clarke et al., 2014). Furthermore, appearance-related distress can be experienced in any clinical severity of visible difference and may be more pronounced for those whose visible difference is classified as being more minor (Clarke et al., 2014). Nevertheless, individuals living with a visible difference may often experience stigma from members of the public in a variety of forms, such as “staring, audible comments, intrusive questions about the nature and causes of the difference, together with other negative or avoidant behaviours” (Rumsey & Harcourt, 2004, p.85). Therefore, an incorrectly given diagnosis of BDD, when someone has an obvious visible difference, may not capture the actual stigmatising experiences that the individual may frequently be subjected to.

Studies within the general population have found BDD to have a prevalence rate between 0.5%-3.2% (Minty & Minty, 2021). As individuals with BDD may not have insight that they have a psychological condition (Eisen et al., 2004), they may seek treatment to correct the perceived flaw, rather than access psychological support (McCausland et al., 2021). Likewise, feelings of embarrassment or shame about the perceived flaw may prevent individuals from help-seeking (Phillips, 2004). Therefore, the number of individuals experiencing BDD may be underrepresented (Minty & Minty, 2021).

Self-conscious emotions have been posited as playing a role in BDD. Shame has been recognised as being prominent in BDD (Weingarden et al., 2018). Shame is a primary emotion with the purpose of protecting the self from social exclusion by bringing into awareness any aspect of the self which could cause one to be rejected (Ryan, 2017). Shame can be separated into two types; external shame and internal shame. External shame is a self-conscious emotion that arises when a person feels they are being judged negatively by others (Matos et al., 2015). As individuals believe that their flaw is real and visible to others, they experience external shame when anticipating others will perceive them negatively due to it (Veale, 2004b). Internal shame is when one views themselves as being “inadequate, flawed or bad” (Gilbert & Procter, 2006, p.354). Individuals with BDD may experience internal shame due to their perceived flaw (Veale, 2002) and experience thoughts such as being worthless, inferior to others or inadequate (Veale, 2004b).

Disgust has received recent attention for its role in BDD (McKay & Lo Presti, 2015). The function of the emotion disgust is to protect the self by alerting oneself to any stimuli that could cause disease, infection or illness (Curtis et al., 2011). Previous literature has highlighted how individuals with BDD have higher levels of disgust directed towards the self compared to those in a control group without a psychological condition (Hickey et al., 2010). Powell et al. (2015) proposed that self-disgust is an emotion schema. In this model, when a part of the self evokes a disgust response, and this part of the self cannot be changed and is deemed to be important for how the individual views themselves, the individual experiences a prolonged or repetitive disgust response towards that aspect of the self and an emotion schema of self-disgust develops (Powell et al., 2015). Once this self-disgust schema has been formed, an individual will appraise and process information in line with this schema of them being disgusting (Powell et al., 2015). Subsequently, they may experience distressing psychological emotions and concepts, such as shame, self-hatred and self-criticism, and this may influence their behaviours (Powell et al., 2015).

There are a multitude of safety behaviours that people with BDD may engage in to cope with their perceived flaw. Veale (2004b) categorised these safety behaviours into three domains: avoidance or exiting situations where one feels overwhelmed, compulsive behaviours, and hiding the perceived flaw from others such as by camouflage. The functions of safety behaviours that individuals with BDD engage in are to alter, camouflage or correct the perceived flaw, to avoid thinking about it, to take away attention from the perceived flaw and to seek reassurance (Veale, 2004b). Whilst these safety behaviours may provide some initial relief, they are time-consuming and are counterproductive as they cause the individual to become more preoccupied and self-conscious of the perceived flaw (Veale, 2004b).

In addition to internal focussed theories, objectification theory may also be usefully deployed to explain some of the experiences of people with BDD. Objectification theory (Fredrickson & Roberts, 1997) originally evolved from a feminist position which hypothesises that women are subjected to frequent sexually objectifying messages embedded within male dominated culture and institutions. Fredrickson and Roberts (1997) opine that these ‘messages’ become internalised, and as a result, women may engage in body surveillance, make adverse self-comparisons and feel distress in relation to their bodies. As a result, women develop a tendency to view themselves as an object, placing excessive value on their appearance and may experience body shame if they do not feel they meet particular body standards (Fredrickson & Roberts, 1997). Due to men being subjected to sexualised and unrealistic beauty ideals through the media, it has been considered that objectification theory may extend to males (Heath et al., 2016). Research suggests that gay males may have higher levels of self-objectification than heterosexual males and that men do not have the same consequences of being sexually objectified by women (Calogero, 2012). Calogero (2012) called for further research to ascertain how “variability in the presence or absence of sexual objectification, and the attendant self-objectification, may lead men and women to develop particular self-body relationships” (p.579). To the best of the author’s knowledge, no studies have explored objectification theory in men with BDD, although some studies have explored symptoms of the BDD sub-type muscle dysmorphia and objectification theory in the general population. Objectification theory and drive for muscularity or muscle dissatisfaction, have been explored in males within the general population, however, the results have been mixed (Daniel & Bridges, 2010; Davids et al., 2019; Heath et al., 2016; Oehlhof et al., 2009;). Furthermore, a study exploring objectification theory in body builders felt that the theory applied to men but there was a lack of clarity in how body shame impacted this population group (Hallsworth et al., 2005).

Whilst not necessarily attributed to experiences of sexually objectifying messages, self-objectification has been incorporated into the Cognitive Model for BDD (Veale, 2004b) which highlights the role of ‘processing of self as an aesthetic object’ in the maintenance of BDD. The model proposes that self-objectification starts once “an external representation of the person’s appearance (e.g. looking in a mirror) activates a distorted mental image” (Veale, 2004b, p.115). Veale (2004b) explained that selective attention impacts the distorted image which influences how the person sees themselves and expects others to see them. It could be suggested that socially constructed ideal beauty standards contribute to people with BDD placing their self-worth on their appearance and becoming more pre-occupied with their body including the perceived flaw. As different cultures have different beauty standard ideals, there may be cross-cultural differences in where the perceived flaw is for individuals with BDD (Ayub et al., 2018).

Social learning theory (Bandura, 1977) has been suggested to play a role in the development of BDD. Through exposure to messages in the media, interactions with family and peers, bullying and sociocultural factors in early life, individuals vicariously learn the importance of looking a certain way in order to be successful and what an acceptable body is (Tiggemann, 2011). Similarities in objectification theory and social learning theory, when applied to body image, have been acknowledged in the literature (Heath et al., 2016).

Over recent years, a number of qualitative studies have started to explore the experiences for individuals with BDD. These studies are useful for understanding self-objectification within BDD, whether objectification theory is phenomenologically accurate when applied to the experiences for individuals with BDD and the impact of sociocultural factors in body ideals. Whilst qualitative research studies are important for gaining an understanding of the lived experiences for people with BDD and informing the refinement of our theoretical understanding of the condition and its treatment, to the best of the current author's knowledge, the existing qualitative studies have not yet been synthesised. Therefore, the aim of the current study is to complete a systematic review and synthesize the available published literature, which utilised a qualitative methodology, on the experiences for people with BDD.

Method

Protocol

A protocol for the systematic review was created and registered on PROSPERO (CRD42022345297). The basis for how the current review was written is the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Moher et al., 2009).

Search strategy

The framework PICo (Population, Phenomenon of Interest, Context: table 1) was applied to formulate the research question and identify search terms used in the thematic synthesis. PICo is a tool suitable for systematic reviews of qualitative research (Munn et al., 2018).

Table 1

PICo Applied to the Review Question

Characteristics of PICo	**PICo characteristics applied to review question**
Population	Individuals with BDD
Phenomenon of Interest	Qualitative lived experiences of BDD
Context	Any

After formulating the research question, the following search terms were then identified and used in the current systematic review: ("body dysmorphic disorder" OR "body dysmorphia" OR "dysmorphophobia" OR "dysmorphia") AND ("lived experience*" OR "qualitative" OR "qualitative method*" OR "interview*" OR "focus group*" OR "ipa" OR "phenomenological" OR "thematic" OR "template analysis" OR "framework analysis" OR "grounded theory" OR "view" OR "views" OR "experienc*" OR "opinion*" OR "attitude*" OR "perce*" OR "belie*"). To optimise the likelihood of identifying suitable literature, the search terms were run on six different databases: APA PsycINFO, CINAHL, Embase, MEDLINE, Scopus and Web of Science. During the searches, the only applied limit was 'peer reviewed journal'. This limit could only be applied on APA PsycINFO. There were no other limits used in the search strategy and titles published in any year could be identified.

Study selection

Studies were eligible for inclusion in the systematic review if they used a qualitative or mixed-methods approach to explore the experiences of people with BDD with extractable quotes from participants, were articles in a peer-reviewed journal and were written in English.

The exclusion criteria for the systematic review was quantitative studies, secondary research studies, conference proceedings, grey literature, book chapters, theses, qualitative studies where no specific methodology or structured process was followed and qualitative studies where quotes from participants were not provided. For homogeneity, studies focusing on the experiences of individuals with muscle dysmorphic disorder were not included, due to differences in their presentation. A study by Phillips (2007) found that when comparing men with BDD against those with muscle dysmorphia, men with muscle dysmorphia were more likely to have substance use difficulties, steroid abuse, have a poorer quality of life and more likely to have attempted suicide.

The current author completed the searches and identified the studies used in the review. Discussions were held with the research supervisor where there was a lack of clarity as to whether a study met criteria. All selected papers were discussed and agreed with the research supervisor. In addition, an independent researcher looked through a selection of records (n=5), which were accessed for eligibility at the full record stage, to ascertain whether the protocol was clear to follow and conclude whether a study was suitable. There were no discrepancies between which studies were included by the current author and independent researcher.

Ancestry and citation searches were run on all peer-reviewed journal articles identified as being suitable for the review. No additional suitable peer-reviewed journal articles on the experiences of people with BDD were identified during this process.

Two of the identified peer-reviewed journal articles selected for the review were from the same study. Each article analysed the data using a different qualitative methodology and therefore the results section differed. As a result of the difference in findings, it was decided to include both in the systematic review and meta-synthesis.

Quality assessment

To assess the quality of the research used in the current review, the Critical Appraisal Skills Programme (CASP) qualitative checklist was used by the current author (CASP, 2018). The checklist does not produce a scoring system but intends to encourage the reviewer to reflect on the quality and utility of the qualitative studies (CASP, 2018). On the CASP, the rating options for each item of the checklist is ‘yes’, ‘can’t tell’ and ‘no’. When rating studies on the CASP, the ‘can’t tell’ section was used when an item was partially met but it could not be ascertained from the information available whether it met the criteria or not.

As outlined in the review protocol, no studies were to be excluded from the review due to poor quality. To ascertain whether any poorer quality studies influenced the findings from the thematic synthesis, after the descriptive and analytical themes were developed, these studies were extracted, to see if they contributed solely to the development of any themes within the review.

To help assure inter-rater reliability, an independent researcher completed the CASP qualitative checklist for a selection of studies in the review (n=2) to check that there was consistency between their ratings and those of the author of the review. Any discrepancies between the ratings of the author and independent researcher were discussed and resolved in supervision. Furthermore, the author discussed with the research supervisor CASP ratings where there was uncertainty about what an item was rated as on the CASP.

Data extraction

The following information was extracted from each of the peer-reviewed articles used in the current review: author(s), year of publication, aims of the study, country, participant characteristics, recruitment strategy, data collection, methodology for data analysis and key findings. Please see table 2 for the information extracted from each paper.

Data synthesis

The methodology selected to synthesise the findings from the studies identified in the systematic review was thematic synthesis (Thomas & Harden, 2008). Thematic synthesis was chosen as it has a clear and transparent process for synthesising qualitative data in addition to having an interpretative element which produces themes beyond what is reported in the initial studies (Thomas & Harden, 2008).

Adhering to the guidance of thematic synthesis, the entire findings or results section of each peer-reviewed journal underwent line-by-line coding. Line-by-line coding was done with the use of the NVivo 12 software (QSR International Pty Ltd, 2018)(please see appendix two for examples of using NVivo). After the first study was coded, these codes were used to create a bank and when coding subsequent papers either a code in the bank was used or a new one was created. This process resulted in 337 initial codes being created. A structure was used to cluster these codes in a hierarchical way, resulting in 37 descriptive themes being developed (please see appendix three). To refine these themes further, another structure was made (please see appendix four). Finally, analytical themes were created by applying the author’s interpretations to these.

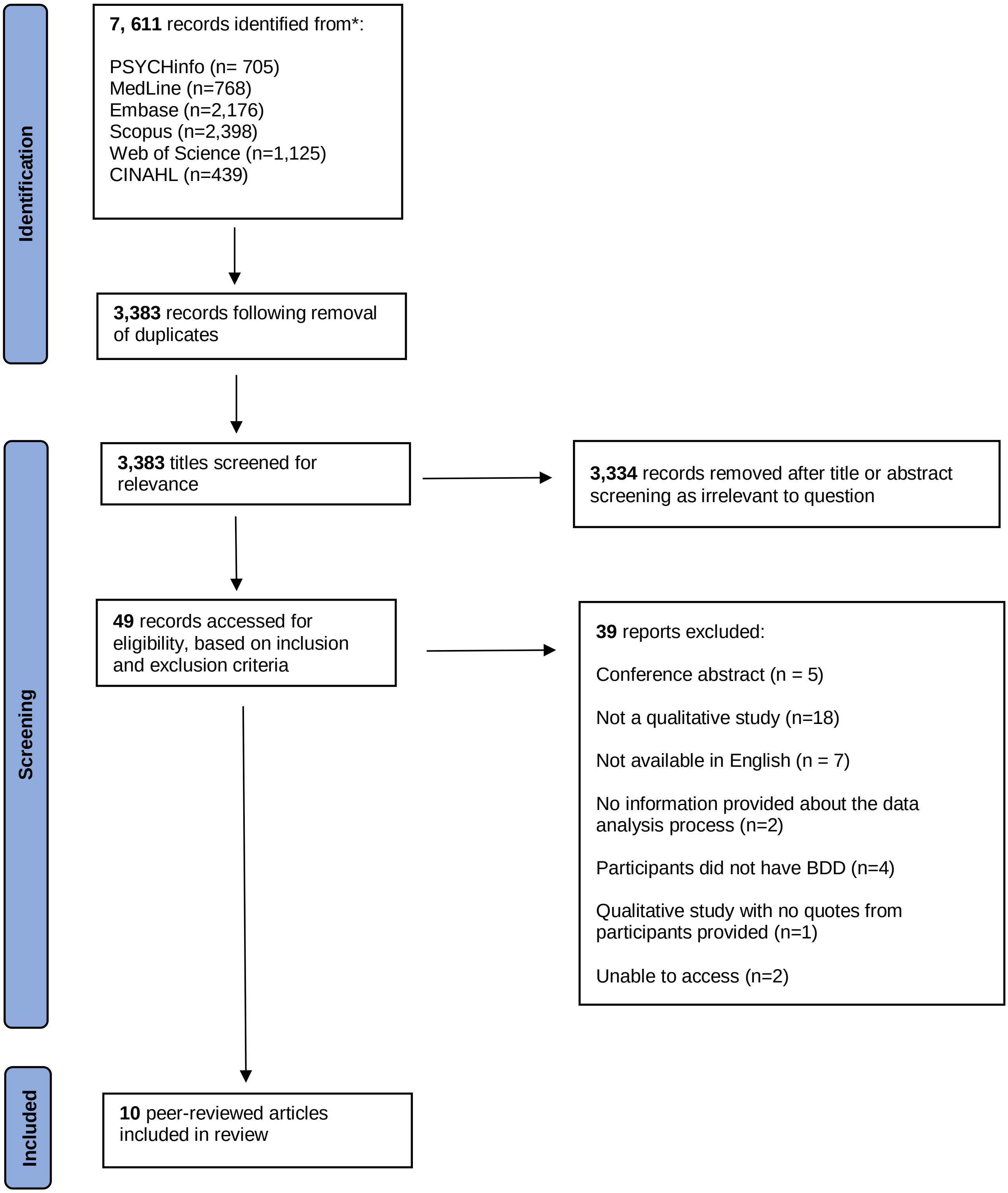
Results

Summary of included papers

Following removal of duplicates, the searches found 3,383 records. For information on the process of how studies in the review were selected, please see figure 1.

Figure 1

PRISMA Diagram showing Systematic Review Process for Identifying Qualitative Studies on BDD



Ten peer-reviewed journal articles were identified in the systematic review which met the inclusion criteria. All studies were published between 2010 and 2022. Two of these studies used the same participants and interview data but analysed the information using different qualitative approaches. Therefore, there were 76 participants who were either receiving psychological support for BDD, had a diagnosis, identified as experiencing it or were screened by the research team as meeting criteria for BDD. One study interviewed clinicians and parents in addition to young people with BDD, however, only the data from the young people with BDD was extracted and included in the current review and thematic synthesis. All studies were conducted in the following Western countries: Australia, England, Sweden and USA. However, two studies recruited participants from other countries and as a result one participant lived in India and another in an unidentified country in North West Europe. The ages of the participants across the included studies ranged from 15-60 years old. Co-morbid psychological conditions were only reported in three of the journal articles. For more information on the included studies in the current review and thematic synthesis, please see table 2.

Table 2

Data Extracted from Each Study

Author(s)(year) Country	**Aims of study**	**Participants**	**Recruitment**	**Data collection and methodology**	**Key findings or themes in article**
Brohede et al. (2016) Sweden	To explore patients' experiences of BDD	15 participants • 6 males and 9 females • aged 19-48, mean age = 30 • either under a clinic for BDD or met BDD screening criteria • comorbidity included: social anxiety disorder (n=1), BPD (n=1) and Asperger's & GAD (n=1)	Either approached following previous involvement with another study or recruited via a specialist clinic	Data collection: Interview (either face-to-face or via telephone) Methodology: Interpretative Description	Overarching theme of: 'feeling imprisoned - struggling to become free and no longer feel abnormal' Key themes: 'being absorbed in time-consuming procedures', 'facing tension between one's own ideal and the perceived reality', 'becoming the disorder', 'being restricted in life', 'attempting to reduce one's problems' and 'striving to receive care'

Craythorne et al. (2020)* England	A methodological piece to display the artwork and account of a participant from a wider study exploring individual experiences of coping with BDD	1 participant • female • aged 27 • identified as living with BDD • lives in North West Europe	Online recruitment and advertisement in a newsletter for a relevant organisation	Data collection: Artwork and semi-structured interview (via telephone) Methodology: Boden and Eatough's Framework for Analysis of Drawings and IPA	Article focuses on the theme of 'the fragmented self' and 'towards a reconciliation of the self and body' Two additional themes not reported but in wider study: 'the integration of BDD in one's lifeworld' and 'detachment and distancing of perceived self'
Jassi et al. (2020)** England	To explore whether family accommodation occurs in BDD and, if so, how	5 participants • 3 females and 2 males • aged 15-18 • under the care of a BDD specialist clinic	Via a specialist clinic for young people	Data collection: Semi-structured interview Methodology: Thematic Analysis	Key themes: 'involvement in rituals, reassurance seeking and funding for products/procedures', 'facilitating avoidance', 'minimise distress and reduce risk/suicidality' and ‘family accommodation as a support'
Morgan-Sowada and Gamboni (2021) USA	To explore the lived experiences of gay men with BDD	10 participants • all males who identify as being gay • aged 18-60 • responded yes to screening questions for BDD and therefore viewed by research team	Online recruitment	Data Collection: Online pre-interview survey and telephone interview Methodology: Hermeneutic Phenomenology	Key themes: 'degrading and abject influence of BDD', 'culpability of gay culture', 'intersection of BDD and gay culture as a barrier to intimacy' , 'toxic masculinity's impact on gay men with BDD’

		as self-diagnosed with BDD • live in USA • 6 Caucasian, 3 Latino and 1 mixed race participant		approach with Thematic Analysis	
Oakes et al. (2017) Australia	To explore the lived experiences in relation to BDD behaviours	8 participants • 5 females and 3 males • aged 27- 46 • reported a BDD diagnosis • 7 had comorbid conditions at some point in their lifetime (depression, OCD, social anxiety, bipolar disorder, PTSD, BPD and agoraphobia) • country of residence: UK (n=4), USA (n=2), Australia (n=1) and India (n=1)	Online recruitment, advertised via psychology clinics and local psychologists. Participants from a previous study were also approached	Data collection: Semi-structured interview via Skype (audio only) Methodology: Inductive Thematic Analysis	Key themes: 'routine and repetition', 'safety through control' and 'natural and automatic'
Schnackenberg (2021) England	To develop a constructivist grounded theory for the experiences of young people with BDD	10 participants • 8 females and 2 males • aged 16-25 • self-identify or have been diagnosed with BDD	Via a specialist clinic (for young people with eating disorders) and online via relevant organisations	Data collection: Semi-structured interview, also asked to bring an object or artwork to discuss	Key themes: 'appearance based identity is informed by and informs relationships in young people's experiences of BDD', 'characteristics of BDD are expressions of

	including within educational settings	• 9 White-British, 1 Caribbean participant • 2 attending school, 2 attending university, 4 in work and 2 neither employed or in education		Methodology: Constructivist Grounded Theory	shame and low self-worth', 'educational experiences trigger and are affected by BDD'
Silver & Farrants (2016)* England	To educate health care professionals on mirror gazing in BDD, from a wider study on exploring experiences of people with BDD	10 participants • 7 females and 3 males • aged from late teens to mid-30s • all identified having BDD • duration of BDD ranged from 4 to 25 years	Online advertisement, discussed at a self-help group and word of mouth	Data collection: Semi-structured interview; participants were asked to take photographs and bring in existing ones representing their BDD experience, to record any reflections or feelings this process brought up in a notebook and bring both of these to the interview Methodology: IPA with photo elicitation	The article focuses on the findings from the constituent theme 'omnipotent mirrors trap the self' which falls under superordinate theme of 'the imprisoned self' Key themes from the wider study: 'the self as an aesthetic object'; 'striving for the 'good enough' self'; 'the confused self' and 'the imprisoned self'

Silver & Reavey (2010)*** England	To examine in people with BDD narratives of the self across different times in their lives	11 participants • 7 males and 4 female • aged 20-39 • diagnosed with BDD or identified as having BDD • 9 White British and 2 Asian British • 3 middle class, 4 lower middle class, 4 working class	Self-help group, via a national OCD clinic, and word of mouth	Data collection: Participants were asked to bring in photos from different time points in their life, semi-structured interview, artwork then produced Methodology - Narrative Analytical Approach	Themes not explicitly stated in text; around wanting to looking like younger self who was pure and untainted prior to having BDD and discussion of loss in relation to aging
Silver et al. (2010)*** England	To identify how people with BDD view themselves and live their lives	11 participants • 7 females and 4 males • aged 20 - 39 • have BDD • comorbidity allowed as long as BDD was the primary diagnosis • other diagnoses obtained from six of the participants who attended the clinic - OCD (n 5), social anxiety disorder (SAD) (n 4), depression (n 2), obsessive compulsive personality disorder (OCPD) (n 1), Gilles de la Tourette syndrome (n 1), and trichotillomania (n 1)	Either through a specialist clinic or a self-help group	Data collection: Semi-structured interview and artwork produced; participants were asked to bring photographs from different time periods Methodology: Thematic Analysis (including discussion of the drawings and photographs)	Key Themes: ‘increased threat perception resulting in disordered interpersonal relationships’, ‘wish for regularity and symmetry in appearance versus beauty’, ‘idealisation of childhood self’, ‘the duty to look good’ and ‘focus on specific “defective” features rather than “ugliness”’

		• for 8 participants, BDD had started in adolescence • for 6 participants, case-note review revealed clinicians' assessment of BDD severity ranging from mild to moderately severe			
Stechler & Henton (2022) England	To explore how women with BDD view their experiences of physical intimacy in their current romantic relationships	6 participants • all females • aged 21-33 • identify as having BDD, 4 of whom report being diagnosed • currently in a physically intimate relationship • length of relationship ranged from 8 months to seven years • all identify as being heterosexual	Online advertisement	Data collection: Semi-structured interview (face-to-face) Methodology: IPA	Key themes: 'the shame in being seen', 'disgust and detachment during intimacy' and 'a flawed self, unworthy of relationships'

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* studies reported on narrowed focus of a wider study

** other participants, without BDD, also included as part of the study

*** same study and participants, different qualitative analytical approaches used and discussed

Quality appraisal results

From using the CASP, the studies generally appeared to be of a high quality. This may be reflective of the inclusion criteria only allowing peer-reviewed journals articles to be part of the review. Most of the studies met the different criteria in the CASP. Under the ‘reflexivity and relationship between researcher and participants’ criteria, only 3 studies met criteria, 5 did not meet criteria and for 2 it could not be ascertained from the information provided. Under the ‘rigorous data analysis’ criteria, 6 met criteria and 4 could not be ascertained. The reasons for this item not being fully met included a lack of reflexivity in IPA studies, data saturation not being completed in a grounded theory study, limited quotes to support the themes and a lack of clarity pertaining to how themes were identified. All but one study met the criteria for the item ‘clear statement of findings’. Please see appendix five for more information about the results on the CASP for each study.

Thematic synthesis

The thematic synthesis of the 10 studies resulted in three superordinate themes; ‘self-objectification and the view of self’, ‘control and protecting the self’ and ‘sociocultural influences and the impact of others in BDD’. Ten subthemes were identified which fell under these superordinate themes. Please see table 3 for information on which themes were within each study. There is overlap between some of the themes which may reflect the intersecting experiences for people with BDD.

Table 3

List of Superordinate and Subthemes within Each Study

	Brohede et al. (2016)	Craythorne et al. (2020)	Jassi et al. (2020)	Morgan-Sowada & Gamboni (2021)	Oakes et al. (2017)	Schnackenberg (2021)	Silver & Farrants (2016)	Silver & Reavey (2010)	Silver et al. (2010)	Stechler & Henton (2022)
Self-objectification and the view of self										
Disgusting, ugly, deformed and not correct	x			x	x	x	x	x	x	x
Self-worth, identity and success through appearance	x			x		x	x	x	x	x

Self-focus, obsessive thoughts and pre-occupied with the perceived flaw	x	x		x		x		x		x
The fragmented self		x			x					
Reality of the perceived flaw	x	x		x			x	x		x
Control and protecting the self										
Behaviours in BDD	x	x	x	x	x	x	x			x
Increase sense of threat, fitting in and judgement from others	x			x	x	x	x		x	x
Consequences of BDD	x	x	x	x	x	x	x	x	x	x

Sociocultural influences and the impact of others in BDD							
Social and cultural factors in BDD			x	x	x	x	x
The role of others in BDD	x	x	x	x	x	x	

Self-objectification and the view of self

The superordinate theme ‘self-objectification and the view of self’ encompasses how individuals with BDD see themselves. Nine of the studies had at least one theme that fell under this superordinate theme.

Disgusting, ugly, deformed and not correct. Eight of the studies spoke of how participants in their study felt disgusted by their appearance, that they were ugly, deformed or that their perceived flaw did not look correct or as it should (Brohede et al., 2016; Morgan-Sowada & Gamboni, 2021; Oakes et al., 2017; Schnackenberg, 2021; Silver & Farrants, 2016; Silver & Reavey, 2010; Silver et al., 2010; Stechler & Henton, 2022).

Some of the studies included data of participants feeling that they did not look human, but a monster or another creature. A participant in the study by Silver & Farrants (2016) explained “I look like a monster I just don’t feel sort of human” (p.2651). Some of the participants explained that BDD is not about looking beautiful or being vain, but rather not being ugly, as explained by a participant in the study by Brohede et al. (2016) who said “I never had an ambition to be the most beautiful – I would just like not to be grotesque” (p.194). Another participant, from the study by Schnackenberg (2021) explained “they think it’s something to do with vanity or narcissism or something but, oh, gosh, that couldn’t be further from the truth, I don’t think” (p.210).

Two studies mentioned that apart from the perceived flaw, some of the participants were content with their appearance and only saw the perceived flaw as unattractive (Silver et al., 2010; Silver & Reavey, 2010).

Self-worth, identity and success through appearance. Seven of the studies spoke of how some participants based their self-worth or identity on their appearance or perceived flaw (Brohede et al., 2016; Morgan-Sowada & Gamboni, 2021; Schnackenberg, 2021; Silver

& Farrants, 2016; Silver et al., 2010; Stechler & Henton, 2022). Some of the studies explored the experiences that individuals with BDD have between their current and ideal self. A few participants spoke of how meeting their appearance ideals would equate to a perfect or successful life, as demonstrated by a participant in the study by Brohede et al. (2016) who said "I am always admiring beautiful people, like, it's as if I looked like them, my life would be, like, perfect, and I would be able to live a normal life" (p.194).

Two studies reported that participants viewed their childhood self as their ideal self, and viewed this version of themselves as innocent, pure and attractive (Silver et al., 2010; Silver & Reavy, 2010). As these positive feelings about the self were before the person had BDD, it may reflect how participants see themselves as dirty, unattractive and sinful in relation to their current appearance.

Self-focus, obsessive thoughts and pre-occupied with the perceived flaw. Six of the studies spoke of the self-focus, preoccupation and obsessive thoughts which participants had regarding the perceived flaw and their appearance (Brohede et al., 2016; Craythorne et al., 2020; Morgan-Sowada & Gamboni, 2021; Schnackenberg, 2021; Silver & Reavey, 2010; Stechler & Henton, 2022). The pre-occupation with the perceived flaw can be all-encompassing, as shown by a participant in the study by Morgan-Sowada & Gamboni, 2021) who described how "I was constantly judging and critiquing my body. I was constantly preoccupied with my appearance…the way I looked" (p.7).

The pre-occupation with the perceived flaw can result in a critical inner dialogue whereby the individual with BDD berates themselves and scrutinises their bodies. Pre-occupation was identified as interfering with intimacy:

> I guess kind of ruins it when you're trying to be intimate. Like the body dysmorphia has its little . . . [sigh] thing to everything, its input to everything, [. . .] it doesn't give you peace. It just kind of pecks at you. (Stechler & Henton, 2022, p.7)

The fragmented self. The subtheme 'the fragmented self' is the only one within the systematic review and thematic synthesis where no studies which met full criteria on the CASP fell under.

A few studies spoke of how participants may view their body in a fragmented way. Craythorne et al. (2020) spoke of how a participant saw themselves as a collection of different body parts and struggled to see their self as a whole person, explaining "I'm not really able to… look at my body in a kind of – integrated way or something" (p.23).

Similarly, when engaging in appearance-related behaviours, such as mirror-checking, participants may seek out specific body parts to check, as a participant described "then I look at my individual body parts, for example how big my stomach might look, how big my arms might look, how broad my shoulders might look" (Oakes et al., 2017, p.436).

Reality of the perceived flaw. Six studies provided data around the reality of the perceived flaw (Brohede et al., 2016; Craythorne et al., 2020; Morgan-Sowada & Gamboni, 2021; Silver & Farrants, 2016; Silver & Reavey, 2010; Stechler & Henton, 2022). The perceived flaws tended to not be acknowledged by others (Brohede et al., 2016). Some participants in the studies queried whether, or acknowledged that, they were exaggerating their perceived flaws. Some participants recognised that others did not see them the way they saw themselves, which could create confusion:

> Um, people see, seem to see this thing, this person which isn't me. It's like my body is like Dorian's Gray's body, then when I look in a picture, I mean in the mirror, or something reflective I then see the true person. But, then what if the thing, which I

> see, is true isn't true, and what people see in me is the true thing? That's what gets to me (Silver & Farrants, 2016, p.2652)

Some participants felt that they had the correct image of themselves and were essentially waiting for others to see it too as demonstrated by Stechler and Henton (2022) who quoted a participant that said "what if he saw me for who I, how I really was, like . . . what if one day he just woke up and seeing all the flaws that I saw" (p.8).

Control and protecting the self

Individuals with BDD often felt out of control with their appearance and feared being judged and ultimately rejected by others. Individuals would try to protect themselves and regain control through appearance-related behaviours, however, these came with consequences. All studies within the review had at least one subtheme which fell under the superordinate theme 'control and protecting the self'.

Behaviours in BDD. Eight of the studies spoke of the behaviours that individuals with BDD engaged in (Brohede et al., 2016; Craythorne et al., 2020; Jassi et al., 2020; Morgan-Sowada & Gamboni, 2021; Oakes et al., 2017; Schnackenberg, 2021; Silver & Farrants, 2016; Stechler & Henton, 2022). These included avoidance from others and being more housebound, camouflage (including wearing make-up), reassurance seeking, comparing themselves to others, covering or avoiding mirrors, avoiding being photographed or seeing themselves in photos, checking their appearance in mirrors, engaging in routines, rituals and trying to change or alter the perceived flaw. The avoidance and use of safety behaviours helped relieve some of the distress for participants and helped them to feel more in control of their symptoms. However, relief provided from the safety behaviours tended to be short-lived and these behaviours could be incredibly time consuming.

An exception to the soothing function of these behaviours was in one participant who compared mirror-gazing to a form of self-harm, purposefully using a mirror to scrutinise her appearance:

> On the bad days when you are using a mirror, it, it really is a form of self-harm. It’s kind of like, because you are looking at it, you know you know what your faults are going to be, and they are about how disgusting that you are, um and then you just get, you get really sort of like sad as well, because it’s like fuck what am I going to do? (Silver & Farrants, 2016, p.2650)

Increased sense of threat, judgements from others and the need to fit in. Individuals with BDD appeared to have an increased sense of threat and feared being judged from others, as described by a participant who was “scanning the area and sort of listening to what other kids were saying, and if they were talking about me, or assuming that if they laughed, they were laughing at me” (Schnackenberg, 2021, p.207).

The use of avoidance and safety behaviours helped the individuals with BDD feel more protected. One participant in the study by Brohede et al. (2016) explained “I admit that I have to live, but I refuse to go out into life, I don’t want to participate in it because people will just say that I am ugly and disgusting” (p.194).

It seemed as though avoidance and safety behaviours were used to help protect themselves from judgement and the external shame they were experiencing. The use of avoidance and safety behaviours seemed to reflect an innate need to belong and fit in. Schackenberg (2021) explained how important this was to their participants: “the task of “belonging” in adolescent identity formation came through strongly in every interview. Some participants spoke about social pressure within their peer group being linked to their experience of BDD, including the need to fit in within education settings” (p.207).

Consequences of BDD. Every study within the current review and thematic synthesis detailed the consequences of BDD. Despite the use of avoidance and safety seeking behaviours to gain control, ultimately the condition took control of the participants' lives, some of whom felt imprisoned and helpless by the condition. Brohede et al. (2016) explained that for their participants "living with BDD was described as a constant struggle, comparable to constantly carrying a weight or being in a prison and never being free" (p.193).

BDD behaviours were time consuming, participants felt compelled to do them and coupled with the distress of BDD, led many participants to lead a more restricted life. This included missing or dropping out of school, missing work or being unable to, not entering romantic relationships, not enjoying hobbies or interests and not socialising with others. Silver and Farrants (2016) explained that for one of their participants "despite having 'buckets of love to give' she is unable to have a romantic relationship as it would 'interrupt' her mirror gazing and 'interrupt' her thoughts, which would be 'overwhelming' and 'claustrophobic'. Jane thinks that by not having relationships she is 'missing out on this whole world of things', making her feel 'very very sad' and 'very very fucking lonely'." (p.2654).

Relationships with families, friends and intimate ones were also impacted as a result of the BDD and its behaviours. Jassi et al. (2020) explained that in their study with young people who had BDD, family rows would occur. Brohede et al. (2016) described one participant's mother being distressed by the condition.

People with BDD would become increasingly isolated as a result of the condition, including not wanting to be seen. Some studies spoke of the impact of people with BDD excluding friends and feeling unable to socialise with them. Morgan-Sowada and Gamboni, (2021, p.8) quoted a participant who explained "I live 98 percent [of the time] at home. I don’t want anyone to see me… It’s lonely”. Another of their participants stated “my interests and hobbies no longer bring me joy, and I have been increasingly lonely because I self-isolate” (Morgan-Sowada & Gamboni, 2021, p.8).

For those in romantic relationships, some participants felt unworthy for their partners and as a result, intimacy could be associated with disgust, detachment and anxiety due to seeing their body and it being seen by their partner (Stechler & Henton, 2022). An exception to this was a participant in the study by Stechler & Henton (2022) who felt her partner had habituated to her perceived flaws: “I don’t really have a problem with that [. . .] we’ve been together for so long [. . .] I’m so comfortable with him that all my flaws [. . .] I’ve already drawn so much attention to them [. . .]” (p.7).

Sociocultural influences and the impact of others in BDD

The final superordinate theme focuses on wider sociocultural influences and roles of others in BDD. Seven of the ten studies had subthemes which fell under this superordinate theme.

Social and cultural factors in BDD. Five of the studies acknowledged the role of sociocultural factors in the experiences for individuals with BDD. These included cultural expectations to look a certain way, feeling society judges people for their looks and how family experiences contributed to individuals with BDD placing emphasis on their appearance:

> My mum’s side of the family, they tend to be, they are quite vain people, and I feel like I have a lot to live up to. When I did used to go to family dos, people used to say how the children and the kids in the family, how good looking they all are, and how we look very similar, and I feel like I am damaging that somehow, by not being one

> of these attractive kids that they have brought up, whereas I used to be the most attractive, I feel like a sort of black sheep now. (Silver & Reavey, 2010, p.1645)

Differences in how genders should look was discussed by participants in three studies, where participants spoke of how men and women should look a certain way. For example, one female participant in the study by Silver and Farrants (2016) described herself as having masculine features alongside other derogatory comments towards themselves. Morgan-Sowada and Gamboni (2021) discussed how gay men were impacted by messages of toxic masculinity with conflicting messages about needing to look perfect to fit unrealistic cultural body standards. However, they could not look too perfect as this was associated with femininity.

Morgan-Sowada and Gamboni (2021) highlighted how gay men may body shame to cope with the unrealistic body standards within the gay community and shame placed on their own body. The study details that when gay men with BDD avoid gay spaces due to feeling unsafe and fear of being judged, they are also losing a community where their sexuality is accepted and celebrated (Morgan-Sowada & Gamboni, 2021).

The role of others in BDD. Six studies provided data pertaining to the role of others in BDD (Brohede et al., 2016; Jassi et al., 2020; Schnackenberg, 2021; Silver & Reavey, 2010; Silver et al., 2010). Three studies spoke of individuals being supported for the BDD, two of these studies were with participants who were young people and one study was with adults. This support came from teachers in educational settings, family and close friends.

One study spoke of how family members may be complicit in the BDD behaviours, due to fear of distressing their child or their symptoms worsening:

> If we had somewhere to go and if I couldn't go, before they would have forced me in the car and stuff, now they let me relax, wait a bit, see if I feel better. If I don't, I just don't go and one of them stays behind with me. (Jassi et al., 2020, p.325)

Shame of discussing BDD with others and being rejected as a result was identified as a barrier to confiding in others about BDD (Brohede et al., 2016). Similarly, a few studies mentioned how participants had poor experiences when disclosing they have BDD. Brohede et al. (2016) stated that some "friends would consider the participants to be superficial, ridiculous, or even crazy and had said 'get over yourself'" (p.195) and that some of the participants' partners were not understanding or lost patience. Schnackenberg (2021) discussed how BDD and its behaviours were not always understood by teachers and resulted in the young person being punished such as having a detention and believed this contributed to feelings of shame. One participant in the study described how teachers "saw it as me not trying . . . 'he's just bunking the lessons' . . . they started to be a bit mean to me . . . it must have seemed like I was just, you know, at home, just messing around." (Schnackenberg, 2021, p.209).

Comments from other people about their appearance were identified as starting the pre-occupation with the perceived flaw for some participants, as described by a participant in the study by Silver and Reavey (2010) ""look at you, you've got quite a big nose", and that's when it snapped." (p.1645).

However, a shame-inducing misconception about BDD for young people was assuming that it always resulted from being bullied (Schnackenberg, 2021).

Experiences of accessing healthcare for BDD was discussed in one study. Brohede et al. (2016) discussed how participants had lost faith when accessing support for BDD due to a lack of knowledge and a lack of services set up to support them. However, a diagnosis for

BDD elicited hope for some participants that the BDD was treatable in addition to working with professionals familiar with BDD (Brohede et al., 2016).

Discussion

The purpose of the current systematic review and thematic synthesis was to identify, appraise and integrate the available published literature of qualitative studies regarding the experiences for individuals with BDD. Ten peer-reviewed journal articles on the experiences of individuals with BDD were identified as part of the systematic review. Three superordinate themes were produced as part of the thematic synthesis: ‘self-objectification and the view of self’, ‘control and protecting the self’ and ‘sociocultural influences and the impact of others in BDD’.

The participants who contributed in the studies used in the thematic synthesis showed pre-occupation with the perceived flaw and self-objectification. In line with objectification theory (Fredrickson & Roberts, 1997), self-worth was viewed in relation to the perceived flaw and their appearance. Similarly, seeing the self in a fragmented manner and as a collection of body parts may be a result of the self-objectification. The views that participants held towards themselves and their perceived flaw highlighted disgust they felt towards the self and internal shame. These experiences complement research which has recognised the role of shame (Weingarden et al., 2018) and disgust in BDD (Hickey et al., 2010).

External shame was experienced by some of the participants in the studies who would try to regain control through avoidance and safety behaviours to prevent being judged by others. It may be that participants had developed a self-disgust schema which contributed to the expectation that others will find their perceived flaw disgusting (Powell et al., 2015), despite it not being observable by others. The use of avoidance and safety behaviours appeared to have a paradoxical effect as the behaviours used to prevent one from being judged and potentially rejected, led to some participants feeling more isolated due to not socialising, excluding friends and not entering romantic relationships. The time-consuming BDD behaviours coupled with the emotional experiences of BDD appeared to restrict the lives of the participants. These limited lives that some of the participants experienced complements findings by Phillips et al. (2008) who found that those with BDD had poor psychosocial impairment.

Sociocultural expectations contributed to the experiences for individuals with BDD feeling that they needed to look a certain way. Objectification of men within the gay community contributed to gay men feeling unsafe in gay spaces. Similarly, comments from family members and feeling one needs to look a certain way due to societal or cultural expectations reflects how people with BDD may see themselves as an object, to appease others. By feeling one does not meet these idealised expectations, shame related to their bodies was experienced, in line with objectification theory (Fredrickson & Roberts, 1997). Whilst some of the participants were supported by others, some spoke of misconceptions and being misunderstood. Experiences of living with BDD and being misunderstood have previously been acknowledged in patient stories (Schnackenberg & Petro, 2016). Only one study spoke of the experience of accessing healthcare for BDD with participants having mixed experiences (Brohede et al., 2016). As BDD is a distressing psychological condition which can be accompanied by a significant reduction in functioning (Phillips, 2004), it is key that individuals have access to the right healthcare at the soonest opportunity, to alleviate their distress.

Critique of included studies

All the studies included in the review had been published between 2010 and 2022, therefore the experiences of the participants were relatively recent. All studies met at least 7 of the 10 criteria on the CASP and tended to be of a high quality. This may reflect the protocol for the systematic review which only included studies published in peer-reviewed journals. Only three of the ten studies within this review met the criteria for reflexivity. Reflexivity is important in qualitative research to ensure transparency and that the author is aware of their own biases when designing the study, interviewing participants and analysing the data (Patnaik, 2013). Therefore, the studies which did not fully meet criteria for reflexivity may be more likely to be subject to researcher bias. As only two papers within the current study explored the experiences of young people with BDD, there may be further information specifically regarding young people that the current review and previous literature has not identified. All of the included studies were conducted in Western countries and only one participant was identified as living in a non-Western country. Therefore, the experiences of BDD for people from different countries may have differences which the current review did not identify.

Limitations and future directions

The current systematic review and thematic synthesis has some limitations. As only peer-reviewed journal articles were included in the review, there may be grey literature regarding the experiences of individuals with BDD which were not included. Similarly, as only journal articles published in English were included, there may be further literature on experiences of individuals with BDD which were also overlooked. This may have contributed to the very limited data available on experiences of BDD in non-Western countries within the review. As participants were interviewed about their experiences of BDD and many people with BDD do not seek help (Phillips, 2004), the current review does not capture the experiences of people living with BDD who lack insight or knowledge that they are not "deformed" but have a psychological condition. During the searches, two full text articles could not be accessed and therefore it is unknown whether they would have been suitable and contributed to the findings in the current review and thematic synthesis.

As reflexivity was not adequately discussed in the majority of the studies included in this review, it is unknown how much the authors were aware of any biases they held in the process of design, data collection and data analysis.

Further qualitative research would be useful to explore the experiences of young people with BDD and to explore the experiences of people with BDD in different cultural contexts. Research in these two areas may identify treatment needs. Muscle dysmorphic disorder was not included in the current review due to differences in presentation and a lack of studies during preliminary searches. Future research should explore qualitatively the experiences for individuals with muscle dysmorphic disorder. To ascertain whether objectification theory is relevant to men with BDD (Fredrickson & Roberts, 1997), it would be helpful to have further quantitative research exploring self-objectification in men of differing sexual orientations who have BDD.

Clinical implications

A number of clinical implications can be generated as a result of the current review. In terms of outreach, initiatives should be considered to raise awareness of BDD in collaboration with experts by experience. At a national level, a media campaign with relevant organisations and services could help raise awareness. At a local level, services should consider whether the demographics of their service users reflect the demographics of the local area and if not, target specific communities accordingly. Furthermore, due to a lack of awareness and misunderstandings on BDD in schools, in addition to BDD usually starting in adolescence (Bjornsson, 2017), staff from Children and Adolescent Mental Health Services (CAMHS) could come into schools to talk about BDD in assemblies to the teachers and pupils. Due to limited resources, online training on BDD for teachers, delivered by CAMHS staff, may be more feasible. Furthermore, this would enable multiple teachers from different schools to be trained simultaneously.

To prevent individuals with BDD undergoing unnecessary procedures that will not alleviate their distress, dentistry clinics, dermatology clinics and plastic surgeons should have access to educational resources or training on BDD and where to signpost service users to if an individual is highly distressed by a perceived flaw but the healthcare professional feels surgery is not required.

A number of suggestions can be made when treating individuals with BDD. To ensure that psychological therapy is meaningful and appropriate to the clients' needs, clinicians should ensure that any treatment for BDD is culturally relevant and takes into account social factors. Furthermore, as Oakes et al. (2017) reported that participants in their study had received psychoeducation about the reinforcing nature of safety behaviours in BDD and chose to continue them, in addition to Jassi et al. (2020) highlighting the role of family accommodation in BDD, where individuals or families feel stuck at dropping or colluding with safety behaviours, clinicians could consider adopting a motivational interviewing intervention before continuing with treatment as usual. Motivational interviewing techniques are advised when delivering the NICE recommended treatment Cognitive Behavioural Therapy (CBT) for BDD (National Institute for Health and Care Excellence, 2005; Veale & Neziroglu, 2010). In addition, due to disgust and shame often being reported as part of individuals' experiences with BDD, Compassion Focussed Therapy (CFT) may be helpful as an adjunct or following the NICE recommended treatment Cognitive Behavioural Therapy (CBT) for BDD (National Institute for Health and Care Excellence, 2005).

Finally, due to the difficulties in relationships for individuals with BDD, services should consider embedding a relational component into treatment for BDD such as fear of entering relationships, intimacy difficulties and remaining connected to friends.

Conclusion

BDD is a distressing psychological condition where individuals objectify themselves and are pre-occupied with their perceived flaw. Disgust and self-conscious emotions such as internal shame and external shame may be experienced. Safety behaviours where the individual tries to protect themselves from judgement from others tend to be counterproductive. Social and cultural factors may influence the development and maintenance of BDD. Services should ensure they are culturally appropriate, consider outreach initiatives and consider implementing CFT and Motivational Interviewing alongside treatment as usual. The current paper supports objectification theory in BDD, however, more research is needed to explore objectification theory in men with BDD, with differing sexual orientations. Further research is needed regarding the experiences of young people with BDD, BDD in different cultural contexts and muscle dysmorphic disorder.

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The Experience of Living with Hidradenitis Suppurativa for Affected Individuals and their Partners: An Interpretative Phenomenological Analysis

To be submitted to Social Science and Medicine (please see appendix six for full guidance)

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Highlights

- The first qualitative study on the experiences of HS for couples
- Self-conscious emotions may underpin many experiences for people with HS
- Dyadic coping was utilised to cope with losses and make accommodations during flares
- Poor healthcare experiences when seeking support for flares were common

Abstract

Introduction: Hidradenitis Suppurativa (HS) is a long-term dermatological condition. Sudden painful flares are a feature of the condition with often intimate and sensitive areas of the body effected. Consequently, HS has been found to be both distressing for patients and to have a significant impact on quality of life and relationship functioning. To date, no study has investigated the experience of couples in relation to the course of the condition.

Method: A dyadic IPA approach was used to examine the experiences of 6 couples where one person in the relationship has HS. Participants lived in the United Kingdom and the United States of America. All 12 participants were interviewed separately. The study focussed on the couples’ experiences of HS with specific focus on flares, pain, and impact on intimacy and relational functioning. The study also explored experiences of accessing healthcare.

Results: The analysis revealed the presence of three superordinate themes within the data. The first theme ‘being unheard: a frustrating journey to receiving care’ captured the difficulties related to accessing healthcare during flares of HS. The second theme ‘relational burden and dyadic coping’ details the impact of HS on the couple, the relationship and how they work together to find ways to cope. The final theme, ‘self-disgust and self-consciousness’ details the emotional experiences that people with HS face.

Conclusion: Flares of HS have a considerable impact for patients and partners. Training on HS, including its emotional and psychological consequences, may improve experiences of accessing healthcare for this patient group. Psychological therapy, embedded in dermatology services, may help patients and partners cope with their experiences.

Key Words

Hidradenitis Suppurativa; IPA; Qualitative study; United Kingdom; Couples experiences; Dyadic coping

The Experience of Living with Hidradenitis Suppurativa for Affected Individuals and their Partners: An Interpretative Phenomenological Analysis

Hidradenitis Suppurativa (HS) is a painful long-term dermatological condition which causes abscesses and scarring on regions of the body (Ingram, et al., 2019). Intimate areas such as genitals, buttocks and breasts can be affected (Ingram, et al., 2019). The global prevalence rate of HS is estimated to be between 0.4% to 4% (Dufour et al., 2014; Jfri et al., 2021).

Sudden flares in HS are unpredictable but typically occur once or twice a month. Safro et al. (2020) described HS flares as “prominent changes in symptoms, emotions and functions which cannot be assessed solely by physical exam” (p.218). A recent cross-sectional study conducted via Facebook with patients with HS found that that regardless of severity, pain was reported as the most defining aspect of HS flares (Fernandez et al., 2021). People with HS have also described flares as being itchy, messy, malodourous, and associated with prodromal ‘flu-like’ symptoms (Margesson & Danby, 2014; Safro et al., 2020).

Previous literature has investigated some of the psychological and psychosocial difficulties that patients with HS may experience. HS has been described as “one of the most distressing dermatological conditions” due to its impact on quality of life (Wolkenstein et al., 2007, p. 621) with patients at increased risk of suicidality (Patel et al., 2020). Cross-sectional studies have found that in comparison to control participants, patients with HS have poorer body image (Schneider-Burrus, et al., 2021), lower self-esteem, higher levels of social isolation, depression, and anxiety (Kouris et al., 2016), higher levels of state anger and emotional fragility (Tugnoli et al., 2020). Esmann and Jemec (2011) conducted a qualitative study via interviews and focus groups with patients with HS and reported a pattern of younger participants feeling “depressed, unworthy and unlovable” (p.332) and older participants trying to find ways to conceal their symptoms and lessen the associated burden. Alavi et al. (2018) compared the quality of life of patients with HS with differing malodour severities with results suggesting that a more severe malodour is associated with a poorer quality of life. In addition, due to the symptoms experienced during a flare, activities of daily living may be harder to do (Howells et al., 2021) and social functioning may be impacted due to fear of stigma (Keary et al., 2020).

Feelings of disgust may contribute to psychological distress experienced by many patients with HS. From an evolutionary perspective, disgust towards stimuli associated with infection protects us from acquiring a fatal disease (Curtis & de Barra, 2018). As the appearance and odour associated with HS may mirror signs of infection, some patients may unfairly experience disgust from others and undue self-disgust. Powell et al. (2015) proposed a model where self-directed disgust responses can develop into a maladaptive emotion schema. A change in self-concept, such as the development or progression of HS, may elicit a self-directed disgust response and when this part of the self is constant, unchangeable and important in how the individual sees themselves, over time a self-disgust schema may develop (Powell et al., 2015). Information is then processed through the lens of oneself being disgusting, influencing behaviours and contributing to psychological distress (Powell et al., 2015). Schienle and Wabnegger (2022) conducted a cross-sectional study with dermatology patients, including those with HS, and found 64% experienced self-disgust, with depression being a mediating factor between self-disgust and stigmatisation (Schienle & Wabnegger, 2022). Research suggests disgust traits may be associated with depression in dermatology patients, with self-compassion moderating this relationship (Clarke et al., 2020).

Shame may contribute to psychological suffering in patients with HS. Keary et al. (2020) found shame to be a central when exploring psychological difficulties in people with HS, with patients concealing their condition from others. Shame functions to keep people connected to others in their social group by alerting them to any negative aspects of oneself which could cause rejection (Ryan, 2017). External shame is when one believes others see them negatively, rejectable or inadequate whereas internal shame is seeing oneself this way (Woods & Irons, 2017) and may result from internalising experiences of stigmatisation, and societal expectations (Gilbert, 2015).

Unmet medical needs for patients with HS have been acknowledged. Shukla et al. (2020) highlighted in their US-based study that patients with HS had a delayed diagnosis and limited access to both professionals knowledgeable on HS and psychological support. A meta-synthesis on the experiences of patients with HS highlighted distrust of services due to feeling unheard and that their concerns are not taken seriously (Howells et al., 2021). Furthermore, Keary et al. (2020) explained that interactions with healthcare professionals can feel shaming and dismissing for patients with HS when told to lose weight and stop smoking.

Life partners of patients with HS may also experience difficulties due to the condition. To the best of the author's knowledge, only one study, which was cross-sectional, has been published regarding partners of patients with HS. Włodarek et al. (2020) found a moderate to extremely large effect on the quality of life for 62% of partners in a relationship with someone with HS, with worsened quality of life associated with HS severity. Aspects of quality of life most impacted for partners were HS-related financial costs, psychological distress, impact on physical wellbeing, additional household tasks and impact on recreational and leisure activities (Włodarek et al., 2020). As intimacy is affected by HS (Esmann & Jemec, 2011) this may be another aspect that both partners in a relationship struggle with.

Dyadic coping focuses on how couples manage each other's stressors which are outside the relationship (Falconier & Kuhn, 2019) and may be important for couples impacted by HS. Stressors can have an 'individual oriented-appraisal' where the stressor is viewed as a problem for one partner and the other provides support, or a ‘we oriented-appraisal’ whereby the stressor is viewed a problem for both partners (Falconier & Kuhn, 2019). Weitkamp et al. (2021) explored dyadic coping in couples impacted by long-term health conditions and found it was important for adapting to the condition, relationship satisfaction, improved psychological wellbeing and better management of the condition and treatment.

The impact of HS on individuals is under-researched and has been recognised as a research priority by The James Lind Alliance (Ingram, et al., 2014). Furthermore, there are currently no qualitative studies on the experience of HS for partners. As people with HS may experience self-disgust and shame, interviewing both partners may highlight discrepancies between how the patient and how the life partner make sense of the condition. Due to the significant impact of HS flares on pain and functioning, interviewing couples could provide an insight into how couples cope. The purpose of the current study is to investigate the experiences of accessing healthcare, pain, intimacy and relationship functioning during flares of HS.

Method

Design

A qualitative research design utilising an Interpretative Phenomenological Analysis (IPA: Larkin & Thompson, 2011; Smith et al., 2009) approach was chosen to investigate the experiences and meanings for couples where one partner in the relationship has HS. A qualitative methodology was selected over a quantitative methodology as the study did not aim to measure pre-identified objective phenonemona for couples where one partner has HS. A qualitative methodology was felt to be suitable for exploring in depth the individual lived experiences that the participants hold about being in a relationship where one of them has HS.

IPA was deemed to be most appropriate as it seeks to uncover, rather than explain, personal meaning that participants impacted by HS make of their experiences and is suitable when a research topic is important to participants (Larkin & Thompson, 2011). IPA has a double hermeneutic where the researcher is making sense of the participant making sense of their lived experience (Smith, 2004).

A dyadic IPA approach was used. IPA uses homogenous samples to investigate lived experience of a particular phenomenon (Larkin et al., 2019). When one person in a couple has a long-term health condition, both partners share the experience of being in a romantic relationship where the condition is a part of their lives. In addition, Larkin et al. (2019) described “our experiences of events and processes are subjective and relational” (p.194). Therefore, by utilising a dyadic IPA approach, different perspectives of the shared experience can be explored including how they influence each other.

An expert by experience spoke to the author about their own experience of HS, giving the author an insight into what living with HS and being in a romantic relationship is like, prior to the interview schedule being drawn. The expert by experience reviewed the interview schedule and recruitment materials prior to dissemination to ensure that they were relevant, understandable and sensitive to people with HS and their partners.

Recruitment

Relevant organisations and charities for people with dermatological conditions, and specifically HS, were contacted and asked if they could promote the study on their social media platforms and website (please see appendix seven). These organisations were sent a poster of the study (please see appendix eight), a participant information sheet (please see appendix nine) and consent form when contacted (please see appendix ten). The author and supervisors of the current research project also shared the study on their Twitter accounts. Additionally, the expert by experience shared the study with their network.

People interested in participation were asked to email the author for more information. At this point, information and consent forms were sent. If a person wished to participate and their partner was interested too, they were asked to copy their partner into the email and information and consent forms were subsequently sent to the partner. Participants were then asked to contact the author with their availability if they wished to proceed. Participants were advised that the interviews would be done separately.

The target sample size was twelve participants, from six different couples, where one person in the relationship has HS. Whilst there is no specific sample size for IPA studies, in keeping with a case-study approach, a small sample size is required, ensuring the analysis is thorough and the richness of individual experience of being in a relationship where one person has HS is captured (Smith et al., 2022).

Participants

Twelve participants, consisting of six couples, participated. Three couples had been in relationships with each other for over twenty years, one couple had been together for three years, one had been together for five years and the other is unknown but at least nine years. Please see appendix eleven for more information on the participants including their scores on the Dermatology Quality of Life Index (DQLI; Finlay & Khan, 1994).

The following inclusion criteria were utilised in this study: both partners in the couple were willing to participate, only one partner in the couple has HS, both partners can speak English, both partners are over the age of 18. No potential participants were excluded for not meeting the inclusion criteria.

Participants with HS completed the DLQI, a brief questionnaire, widely used in dermatology services, to assess in adults how much their dermatological condition impacts their quality of life (Basra et al., 2008). The purpose of the DQLI questionnaire being used was to provide simple, contextual information on how HS impacts the participants' quality of life. The DLQI has been found to be reliable (Basra et al., 2008) and valid (Gergely et al., 2020) for assessing quality of life in patients with HS. On the DLQI, all patients in the study had scores indicating HS to have a very large or extremely large impact on their quality of life.

Procedure

Participants were asked to be in a private place, where they would not be overheard, at the time of interview. Before commencing the interview, participants were reminded that participation was voluntary and that prior to data analysis, they could withdraw from the study at any time, with no consequences. As partners were interviewed separately, the partner in the relationship who was interviewed first was informed that nothing they say will be shared with their partner by the author when they are being interviewed. Participants were informed that their responses would be anonymous but there was a risk that following publication their partner may recognise their words. Participants were then asked to confirm the participant information form and consent form had been read before giving verbal consent to proceed.

Participants were given a link to a survey via Qualtrics to gather demographic data which included whether the participant has HS, age range, gender, partner's gender, ethnic group and marital status. For participants with HS, the DLQI was also collected via Qualtrics. Participants were allocated a number to use, ensuring their name was not on these surveys.

Semi-structured interviews were held via the videoconferencing platform, Microsoft Teams. Interview duration ranged from 19 to 65 minutes. Please see table 1 for the interview schedule. Prompting questions were only used when needed (please see appendix twelve). Interviews were recorded on an encrypted Dictaphone which was turned off at the end of the interview. A debrief followed which consisted of asking participants how they felt post interview and where they could access support if any difficult emotions or thoughts were evoked. A written debrief sheet (please see appendix thirteen) was then emailed to participants. After an interview, field notes detailing reflections from the interview were made and referred to in supervision.

Table 1

Interview Schedule

Questions for participants with HS
1. What is living with HS like for you? 2. How, if at all have things changed over time? 3. Can you tell me about how HS effects your relationship? 4. In relation to HS, what has you experience of accessing services been like?
Questions for participants without HS
1. In relation to HS, what is your experience of being in a relationship with (insert name of partner)? 2. In relation to HS, how if at all have things changed over time? 3. Can you tell me about how HS effects your relationship? 4. What has your experience of your partner accessing services been?

Data regarding the duration of couples' relationship, age of HS onset and stage of HS were extracted from interview transcripts. Where the stage of HS was not mentioned, this was identified from the presentation and treatment of HS detailed in the transcript by a supervisor, who is also a dermatologist[1].

Ethical considerations

Ethical approval was granted by Cardiff University School of Ethics Committee in June 2021 (reference number: EC.21.04.20.6336RA2; please see appendix fourteen). Prior to data collection, amendments were made to the ethics proposal, enabling the study to be advertised on all social media platforms, which was granted in August 2021 (please see appendix fifteen).

Ensuring participant anonymity and confidentiality was a priority. Data collected from the DLQI and participant demographics was transferred to an encrypted Excel spreadsheet. Aside from the first two interviews which were transcribed by the author, the audio recordings were submitted to a professional transcription service. A confidentiality form (please see appendix sixteen) was sent to the transcriber to read and agree to prior to commencing transcription. Once a transcript was produced, the audio recording was deleted, person identifiable information removed and the transcript was password protected. Please see appendix seventeen for information on the ethical issues of the study, including managing interviewing couples.

Analytical strategy

Standard IPA guidelines (Larkin & Thompson, 2011; Pietkiewicz & Smith, 2014) were followed during data analysis. Each transcript was analysed one at a time, enabling the author to immerse themselves in the data and experiences of the participant. Starting with the transcript from the first participant, a transcript was read once and any thoughts, feelings,

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[1] Please note that the dermatologist involved in the current study was not the personal consultant for any of the participants.

ideas and memories from the interview and reading the transcript were noted in the reflective journal. Free-coding then took place where exploratory ideas, quotes that grasped the author's attention, thoughts and emotions about the participant's experience were noted on the transcript (please see appendix eighteen). The purpose of this was to make the author aware of any biases they held and how their own experiences may influence data interpretation. Using a clean transcript, line-by-line coding pertaining to experiences and meanings for participants was conducted on the transcript (please see appendix nineteen). Emerging themes were placed in a table with the supporting quotes (please see appendix twenty) and a thorough summary of the transcript was written. This process was repeated with subsequent transcripts. A reflective journal was referred to during the data-analysis processes.

IPA follows a circular, rather than a linear process, and as new themes emerged from subsequent transcripts, the author would check back to see if the new theme fitted quotes from other participants and update their table of emerging themes accordingly. The author analysed the transcripts from participants with HS first and then analysed the transcripts from the partners without HS. As the emerging themes reflected much shared experience between both groups, data from all twelve participants were analysed together.

Once all transcripts were analysed, all themes and subthemes were used to create a global structure to merge the data. During this process, similarities and differences in the experiences of the participants were explored and themes and subthemes were refined (please see appendix twenty-one). Any themes not related to the study aims, such as experiences of partners without HS accessing healthcare for themselves, were removed. Themes were then further refined by collapsing similar concepts into each other and applying psychological theory to create the final list of superordinate and subthemes (please see appendix twenty-two).

Reflexivity

An essential aspect of IPA is reflexivity (Shaw, 2010). To facilitate reflexivity, discussions in supervision and a reflective journal were used across the lifetime of the project. The purpose of discussing and recording thoughts, ideas and reflections pertaining to the study was to aid the author's awareness of their own preconceptions and biases which might positively or negatively impinge on the data interpretation and therefore needed to be transparently considered (Biggerstaff & Thompson, 2008). During each stage of data analysis, notes were recorded in the reflective journal to engage in reflexivity and note key points (please see appendix twenty-three).

Quality control

An audit was conducted by a supervisor to ensure the data analysis followed the IPA approach and identified themes were justified. An audit form (please see appendix twenty-four) was used during this process.

Results

Three superordinate themes and fifteen subthemes resulted from the data analysis. Please see table 2 for further details on which themes presented in each participant interview. Participant's words were recorded as fitting under a theme if their transcript mentioned the theme when discussing their own or their partner's experiences. Please see appendix twenty-five for further quotes not discussed in the results section.

Table 2 - *Superordinate and Subthemes for Each Participant*

Superordinate Themes	**Subthemes**	**P1**	**P 2**	**P3**	**P 4**	**P 5**	**P 6**	**P 7**	**P 8**	**P9**	**P10**	**P11**	**P12**
1. Being unheard: A frustrating journey to receiving care	a. Invasive procedures and recovery process	✓		✓	✓	✓	✓	✓	✓	✓	✓		
	b. Lack of knowledge and sensitivity: feeling unheard, undermined or humiliated	✓	✓	✓	✓	✓	✓		✓			✓	✓
	c. Implications of insurance cover			✓		✓		✓	✓	✓	✓		
	d. Needing to be knowledgeable on	✓		✓	✓	✓	✓	✓	✓		✓	✓	✓

	HS and assertive to get care needs met												
	e. Valuing care from dermatologist or care team	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
2. Relational burden and dyadic coping	a. Impact on functioning and caregiving within the relationship	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓
	b. Feeling hopeless and helpless	✓	✓		✓	✓		✓	✓	✓	✓	✓	✓
	c. Unpredictable	✓	✓	✓	✓	✓	✓			✓	✓	✓	✓
	d. Making adaptations to cope with losses		✓	✓	✓	✓		✓	✓				✓

	e. Anger and a sense of unfairness	✓		✓	✓	✓			✓	✓	✓	✓	✓
	f. The relationship as a protective factor		✓	✓	✓			✓				✓	
	g. Guilt due to condition	✓	✓	✓		✓		✓		✓		✓	✓
3. Self-disgust and self-consciousness	a. Self-disgust, internal and intimate shame	✓	✓			✓	✓	✓			✓	✓	✓
	b. External shame and avoidance	✓	✓			✓		✓	✓			✓	✓
	c. Peer support as a buffer for internal shame	✓	✓			✓	✓			✓		✓	✓

1. Being unheard: A frustrating journey to receiving care

This superordinate theme captures the experiences for patients and their life partners when accessing treatment for flares of HS.

1a. Invasive procedures and recovery process

Many patients and partners spoke of requiring invasive surgeries and procedures during a flare such as incision and drainage, skin grafts and blood transfusions. One participant noted the irony of how abscesses form over surgery scars, requiring more surgery. Another patient spoke of being told a procedure would be needed in future and thought what he saw online looked "horrific". The invasiveness of these procedures was often reflected in the language used to describe them:

> This is a horrible procedure right here where they actually stick like gauze or like a silver laced cloth, depending on the type of wound, into the wound itself with tweezers or forceps, they really get it in there to force it (patient)

When patients with HS require surgery, the caregiving demands for the partner may increase. Partners may need to take time off work in order to care for their spouse:

> It's a lot of work, I usually take time off so I can be there for it and immediately after and make sure she's good before going back to work but for me it's just a part of what I signed up for by marrying her (partner)

1b. Lack of knowledge and sensitivity: feeling unheard, undermined and humiliated

Often a lack of knowledge regarding HS and a lack of sensitivity by the treating healthcare professional(s) were concurrent. This was spoken of by nine participants. Of the three remaining participants, two spoke of just a lack of knowledge of HS and one spoke of just a lack of sensitivity from the healthcare professional(s). Some participants felt they were not being believed when accessing healthcare. For example, one patient said “frequently I’m being told that it’s all in my head or I’m making it out to be worse that it is because I’m a hysterical female, that’s very prevalent here, or because I’m overweight”.

Some participants felt they or their partners were being judged by healthcare professionals, and made to feel as though they are a drug addict when trying to access treatment, including analgesics. One UK-based participant described it as a “battle” when trying to get tramadol from her GP. A partner described poor experiences when her partner accessed emergency services as “they treated him like a junkie or something, they sat him there in his pain and in an uncomfortable chair for hours. And he cried and just asked me to come pick him up”.

One patient spoke of being seen by a General Practitioner (GP) with an awareness of HS, who greatly upset her by saying her vagina was a “mess” and explained how “that GP made me feel more disgusting than anyone else had. It was outrageous. It genuinely took me years to get over that”.

Three participants mentioned healthcare professionals having a facial disgust response when they explained their symptoms or when the professionals saw the wounds. One patient said that “you explain it to them and the face that they pull will make you feel a bit ashamed”. Another patient felt it signalled compassion and was accompanied by good healthcare experiences, however, this was an exception.

Frustrating was frequently used by patients and partners regarding accessing healthcare for flares. Anger towards healthcare professionals when treated insensitively was also frequently mentioned. This was shown by one partner who was angered by how his partner was treated when accessing healthcare and said during the interview “what gives you the right to say that to anybody without getting a slap?”.

Many patients felt helpless when accessing medical support during a flare due to experiencing a lack of sensitivity and felt they were not being listened to. One patient spoke of feeling stuck in these situations, explaining “I can’t help myself if I’m not being listened to”.

1c. Implications of insurance cover

Eight participants were US-based and some spoke of how their insurance cover impacted the healthcare available during flares. Some participants spoke of how insurers will “fight on” what healthcare costs are covered. Some patients and their partners expressed gratitude and feeling lucky with the insurance cover. However, the possibility of the insurers stopping the funding of treatment could be a source of worry. One partner described her ongoing worry about the funding her husband’s monthly infusions, which reduces the number of flares he has, being stopped and explained “there’s always that, like, is the insurance going to quite covering it?”.

One patient’s insurance did not cover some essential supplies needed for wound care leaving the couple to carry the financial burden. The patient explained how costly these supplies were “one roll of bandaging that will last me maybe a week and a half is $190. That one item”.

1d. Needing to be knowledgeable on HS and assertive to get care needs met

Participants often spoke about needing to be knowledgeable on HS to compensate for the shortcoming of knowledge by healthcare professionals when accessing support for flares. One partner described this as a “nightmare, because he’s the one that has to go research everything, to see his GP or the nurse”.

To receive adequate care, some participants spoke of being assertive when inappropriate solutions for treatment were recommended or when not being listened to. One patient spoke of being assertive when she gave a doctor educational materials on HS and he placed it in the bin:

> One doctor in A&E literally put them in the bin in front of me even though he didn't know anything about HS. At that point I just asked for another doctor, I wouldn't have been seen by him either way (patient)

1e. Valuing care from dermatologist or care team

Whilst not specific to accessing support during flares, all patients and some partners spoke of valuing the care from the dermatologist or specific care team. Patients felt heard and valued their interpersonal skills, knowledge and ability to find innovative solutions to problems. Often patients spoke of feeling lucky to be in receipt of such good care. One partner explained that "the dermatologist herself, I just really appreciate that she exists because there's not many people like her".

Even if the treatment options for HS are limited, patients tended to view their dermatologist highly, which may be due to their interpersonal skills and knowledge, demonstrated by one patient's description of her dermatologist "he's lovely and I can't fault him. It's just my condition, there's nothing we can do".

Many patients and partners spoke about the relief associated with receiving good healthcare. One partner described these experiences as making "it a lot easier" as "it definitely lifts her spirits when somebody's listening and she feels heard and they're working with her to resolve it rather than telling her this is what she needs to fix it".

2. Relational burden and dyadic coping

This superordinate theme relates to the pain experienced during a flare, how it impacts the couple, and dyadic coping to manage it. The word "all-encompassing" was used by a few participants when describing their experience of pain during flares. Often couples used 'we-talk' when discussing their experiences of problems and coping with them.

2a. Impact on functioning and caregiving within the relationship

Participants spoke of how flares of HS had a marked impact on functioning for patients. Partners would often take on additional household tasks and attend to their partner. Impact of functioning for patients included activities of daily living, social functioning, showering and walking.

Couples would work together during wound care management. This felt intimate for some couples and was often associated with closeness. One patient described this experience as being "a bit awkward to begin with, having someone else put plasters on me, especially when I could physically do it myself, but now it is just part of our relationship".

Some partners spoke of additional loads placed of them due to HS. One partner appreciated wound care nurses visiting her husband as it lessened the caregiving load, making other tasks more manageable. Some partners spoke of feeling a need to be upbeat when supporting their partner during flares. One partner acknowledged how being upbeat was tiring, particularly in the context of the coronavirus pandemic where restrictions were placed and they spent more time together at home, "at home it's just me trying to feel upbeat on everything, sometimes you can't and it's draining".

2b. Feeling hopeless and helpless

All partners were empathic of the pain their partner was in. Feeling helpless was discussed by many participants in relation to the significant amounts of pain experienced by the patients with HS and was often associated with distress. One partner described this experience as being "very emotional" and how "there's times when I'll be laying in bed at night and just thinking why has this happened? What I could do to make it better?".

Limitations of analgesics also contributed to feelings of helplessness during flares. One patient spoke of being under a pain specialist but still finding nothing controlled the pain. Some patients felt that the stronger medications were ineffective whereas others felt these impacted their functioning. One patient described the detrimental impact of the medication “those highs or fixes, they ruined my day. I can’t do anything on tramadol because I’m so woozy”.

Some participants discussed feelings of hopelessness, desperation and low mood during flares. The chronicity of the condition, with no cure, contributed to this. One patient described how they feel “desperate sometimes as there is no real cure, there’s not really an end to this”.

2c. Unpredictable

Ten patients and partners spoke of the unpredictability of flares and how changes can happen rapidly. Often flares were accompanied by fatigue. One patient explained “there may not be any symptoms and then all of a sudden I can’t drag myself out of bed or cannot get through the day”.

As a result of these painful, unpredictable flares participants may cancel plans, evoking feelings of anger, frustration, embarrassment and guilt for some participants. One patient stated “I just want to stay in bed at home and not really go out, that can be embarrassing because it feels like you have to cancel a lot of things and not everyone knows”.

Alternatively, some participants avoid making plans to prevent disappointment. Other times, patients would force themselves to go to an event despite being in pain, to avoid disappointing themselves or their partner. One patient explained how she “really pushed through last night" as "if we didn't go, that would have obviously had a knock-on effect. I feel like he wouldn't be happy at me but I know it's the condition".

One partner spoke of their partner having the onset of a flare during an event and subsequently being unable to be present and enjoy the event due to fear of leakage and being exposed. They explained how this event unfolds: "you see him being extra-cautious, and then he's not enjoying the evening or the event, or anything that we're at".

2d. Making adaptations to cope with losses

Given the losses associated for some of the couples by HS, adaptations were made. Sexual intercourse was cited as being too painful during a flare. Where couples abstained from sexual intercourse entirely, the reasons cited were to do with the pain and the appearance of HS. One partner explained how "years ago that became a real issue and now it's something that's not feasible and so there's no intimacy in that sense".

For some couples, other types of intimacy such as hugging was too painful and couples could not be as physically close as they wanted. Partners would also have to think before touching their partners due to worrying it could cause them pain. One partner described how "you can't be close, you want to be close, then just hugging and even giving him a kiss a certain way hurts him".

Intimacy through holding hands and being in close proximity was deemed to be important for some couples who were unable to be intimate in the other ways they would like. A partner explained "the intimacy between us, hold hands, cuddle, that's there. And I love that".

Some couples spoke about their friendship within the relationship and spending lots of time together. When patients' HS was too severe to leave the house or they had flares, they would socialise at home with their partners. One partner discussed how he would make a homemade meal during these times so it felt like the couple had dined out.

2e. Anger and a sense of unfairness

A sense of unfairness regarding HS and their situation was discussed by participants. Often this was accompanied by feelings of anger towards the condition or sadness, one patient described how they would sometimes feel “angry because it’s not fair”.

One partner discussed unfairness and frustration when her husband was not engaging in self-management yet she was doing caregiving tasks. This was described as “the thing that mostly annoys me is when I feel like he’s not doing his part”.

Some participants blamed themselves for having HS and the anger was internalised, as described by one patient: “I get angry a lot. I get angry at myself for having this disease. I don’t know why I am angry at myself. I’ve not done anything to cause it”.

Importantly, no partners spoke of blaming their partner for having HS. One partner recognised they feeling “angry” at their partner at times and reflected that this needs to be redirected: “I need to be angry at the HS and not him”.

Two patients spoke of anger being directed at their life partner on occasion during flares. One patient spoke of her partner being understanding and valued his reaction to her anger when distressed during a flare and how “he’s like, “you’re right, you’re allowed to have an attitude right now”. He’s fantastic”.

2f. The relationship as a protective factor

Five participants spoke of how their relationship was a protective factor in coping with HS. Some patients felt their experience of HS would be worse if they did not have their partner. One partner described how “the love we have for each other” helped them cope.

2g. Experiences of guilt due to condition

Whilst grateful for the caregiving provided by their partners, some participants felt guilt over the restrictions that HS place on their partner's life. This included cancelled plans, feeling that they were holding their partner back or not contributing as much in the relationship as they felt they should. One patient described feeling guilty due to feeling they are "not being a full partner" or "picking up less than maybe I should".

3. Self-disgust and self-consciousness

The final superordinate theme pertains to how HS influenced self-disgust and self-conscious emotions in the patients with HS and the impact of this on their relationships.

3a. Self-disgust, internal shame and intimacy

Eight participants spoke of how they or their partner experienced self-disgust or internal shame as a result of the appearance, leakage and odour associated with HS. The language used highlighted how this was a distressing experience. One patient explained her experience of HS as making her feel "like some kind of monster" and that "as humans we stay away from disease and here I am with a visible disease".

For patients impacted by self-disgust, it developed overtime in tandem with their symptoms worsening. The feeling of leakage would contribute to this, as described by one patient: "it moved from being just a predominately upper body thing to going to lower body and that makes me feel really gross especially if I could feel things oozing".

Feelings of internal shame were also discussed. The word "mess" was sometimes used by patients to describe the state of their skin and how they subsequently saw themselves, as explained by one patient: "with HS, it's even more mega confirmation that I am just a mess".

Although not diagnosed, one patient suspected their partner also had HS, which may have been a protective factor in not experiencing internal shame: “he’s kind of normalised this whole having zits on your crotch, if you will”.

Some participants spoke of feeling worried during sexual intercourse due to the appearance of abscesses, scars, leakage or odour associated with HS. One patient mentioned how “my buttocks has a lot of abscesses and that’ll just enter my mind out of nowhere and suddenly I don’t want to be having sex anymore”.

Only two of the couples had their current severity of HS before entering the relationship. Feelings of internal shame and intimacy being associated with vulnerability was more pronounced at the start of the relationship. With time, patients with HS learnt to trust their partners and that they would not be disgusted by them. One partner described how “at the start it was quite a big thing. It was more about her self-confidence than anything. She wouldn’t feel comfortable showing her body to me”.

One patient spoke of how before engaging in sexual intercourse he needed to ensure that all of his “dressings are secure, that they’re not going to leak or smell or anything” as he would be “mortified” if they were to come off.

Two patients with HS spoke of permanently abstaining from sexual intercourse altogether since symptoms worsened. One patient with HS felt that there was no solution to this due to the unpleasantness of symptoms: “even if not in pain, the issue remains of the leaking and seeping which makes for a nasty situation, there is no way around that”.

Partners in the study were sensitive and attuned to how the condition made their partner feel about themselves and how this may impact intimacy. One partner explained “if she doesn't feel good then she's not going to be as comfortable with it because of the positioning of it being in groin and under breast so she doesn't feel as attractive”.

3b. External shame and avoidance

Seven participants spoke of external shame the patients may experience, including when out in public, in relation to the HS. One patient explained “obviously when people are looking at your skin and wondering what’s wrong with you it’s very harsh. It can be harsh”. Two patients spoke of how wearing bras during flares caused pain and friction but felt exposed if they left the house without wearing one.

Some patients spoke of worries of a malodour which ranged from worrying about it when out to avoiding going out because of it. One patient spoke about how they felt their symptoms were “not socially acceptable” as “anyone around me is impacted by HS as they can see or smell or touch or being aware of what’s going on”.

One patient spoke of being able to smell when an abscess would burst. To help manage the anxiety this caused, her partner would have “a little sniff” and provide reassurance by saying “you’re fine, you don’t smell weird” which she described as being “calming” and can “really help”.

3c. Peer support as a buffer for internal shame

Five participants spoke of how engaging in peer support with others was normalising, helping them feel understood and validated. One patient explained that in the support group she attends “we are open, we all understand. I don’t have to explain myself”.

Two participants did not have access to a face-to-face peer support group but felt it would be normalising. One partner appeared burnt-out from the HS and spoke of interest in peer support for both themselves and their partner: “I think that would really help. Also, the support for people that have to support the person with HS as well”.

Some patients spoke of using online support groups for HS and sharing tips for managing the condition. Occasionally it was noted that engaging with groups could be distressing due to seeing people with more severe symptoms. One participant discussed finding content in online peer support groups distressing due to seeing people do harmful things to alleviate their pain. One patient explained how “watching what people do to themselves trying to fix it and making it worse makes me cry a lot so I don’t stay in those groups”.

There was a sense of the HS community supporting each other. One patient spoke of how she sent some dressings that she could not use to a stranger and responded online whenever someone suggested doing something unknowingly harmful to manage the HS. One patient was training to be an aesthetician, enabling her to then help others with HS. Another patient spoke of successfully lobbying for some dressings, designed by someone with HS, to be made available on the NHS. One patient explained that “we’ve all got to be there for each other, and we all know that because it’s so unknown”.

Discussion

The current study is the first qualitative one with couples where a partner in the relationship has HS. The study focussed on the experiences of accessing healthcare, pain, intimacy and relationship functioning during flares. The superordinate themes were ‘being unheard: a frustrating journey to receiving care’, ‘relational burden and dyadic coping’ and ‘self-disgust and self-consciousness’.

Poor healthcare experiences when accessing treatment for flares were identified in this study, often underpinned by a lack of knowledge on HS, contributing to a lack of sensitivity by the treating professional(s). Subsequently, patients with HS felt their symptoms, including pain, were unacknowledged. These experiences complement previous research documenting patients with HS feeling unheard, not taken seriously (Howells et al., 2021; Keary et al., 2020) and having limited access to healthcare professionals knowledgeable on HS (Shukla et al., 2020). This was incredibly frustrating for participants, especially due to the considerable impact of flares and pain on functioning, which is also documented in the literature (Howells et al., 2021; Keary et al., 2020) and the invasive procedures for managing HS. Understandably, participants felt angry. Patients in the current study were assertive and knowledgable on HS to help get their needs met. Likewise, Rivera et al. (2022) who found in a sample of women, that prior to their inflammatory vulvar dermatoses diagnosis, negative healthcare experiences including a lack of sensitivity and knowledge, drove self-advocacy. Good healthcare interactions in the study reflected sensitivity and knowledge of HS from dermatologists and patients' care teams. Although not all were flare specific, the theme is useful in highlighting the relief and containment these interactions brought couples. Some participants, including one partner, felt that healthcare professionals could be disgusted by the HS symptoms. Whilst not specific to HS, Hadjittofi et al. (2020) found disgust from healthcare professionals to be a common but unspoken experience, with professionals trying to hide these responses from patients. However, with self-disgust as a schema (Powell et al., 2015), patients' perceptions of how healthcare professionals viewed them may also be biased, fitting their view of being disgusting.

For the US-based participants, implications of insurance cover and worry of valued treatments being withdrawn created further burden. Individuals with HS are more likely to have lower socioeconomic status due to reduced quality of life (Wertenteil et al., 2018). Therefore, many US-based people with HS may be unable to work, missing out on insurance from their employer and therefore not getting needed care. A parallel issue for UK-based patients is limitations of what the NHS funds and persuading GPs for medical supplies, as mentioned by some participants.

Couples utilised dyadic coping when faced with, often unpredictable, flare-related stressors. ‘We’ was often used when explaining problems faced, and how these were managed. Dyadic coping among participants included delegating household tasks, caregiving, and finding ways together to cope with losses. Couples impacted by physical illness are deemed to cope better when they communicate about the stressor, hold the same views on the illness and any supportive dyadic coping, from an individual oriented-appraisal, reflects patient’s needs (Weitkamp et al., 2021). All patients in this study were grateful for the care their partners provided, potentially reflecting positive dyadic coping (Falconier & Kuhn, 2019). However, all patient participants experienced guilt over caregiving demands or couple losses. Similarly to Howells et al. (2021), some patients in this study felt like an inadequate partner. Varying experiences of guilt may be attributed to internal shame, dyadic coping, caregiving demands and losses experienced. Importantly, no partners in the study blamed the patient for having HS. One partner acknowledged feeling angry towards their partner at times and needing to redirect this solely to HS. As this participant did not always communicate these feelings to their partner and felt pressure to lift their mood, the anger may reflect protective buffering (Falconier & Kuhn, 2019), or not yet accepting losses (Walker et al., 2004). In this study, some participants felt their relationship protected them from HS and flare related stressors, complementing findings of support networks, including partners, helping patients with HS cope (Kirby, 2016). Helplessness and hopelessness during flares were experienced by couples, often in relation to experiencing or witnessing their partner’s pain, inadequate pain relief and accessing healthcare. Helplessness, despair and feeling a lack of control has been previously found for dermatology patients, including HS, as well as their family members, including partners (Basra & Finlay, 2007; Howells et al., 2021; Evers et al., 2005; Fisher et al., 2020). As hopelessness is future-orientated (Beck et al., 1974), its experience may reflect the chronicity and potential for HS to progress, treatment limitations and the couples distress due to HS (Kouris et al., 2016; Tugnoli et al., 2020; Włodarek et al., 2020).

A sense of unfairness and anger was experienced by participants, complementing previous studies (Howells et al., 2021; Tugnoli et al., 2020). Some participants in this study, experienced self-blame and self-directed anger. Similarly, Hughes and Hunter (2022) highlighted self-directed and other-directed anger in their qualitative study with patients with psoriasis. Perceived disempowerment led anger being externalised to psoriasis or internalised to themselves (Hughes & Hunter, 2022). Self-directed anger in some patients with HS in this study may also reflect internal shame and self-disgust as these are associated with self-criticism, self-devaluation and anger (Gilbert & Procter, 2006; Powell et al., 2015).

Self-consciousness and self-disgust underpinned experiences for many patients in the study. All participants who experienced a malodour, or concerns of one, reported symptoms of self-disgust during flares. Internal shame regarding the appearance of HS was also present in these participants. Self-consciousness also impacted intimacy. Vulnerability when intimate in new relationships has been documented previously due to the appearance of HS (Esmann and Jemec, 2011) causing embarrassment and fear of rejection (Keary et al., 2020). In this study, self-confidence and external shame in intimacy improved after building trust with a new partner. Unlike the current study, Esmann and Jemec (2011) discussed how some of their participants felt previous partners lost interest in them when absesses appeared. Two couples spoke of being close to their partner but as the HS progressed they abstained from sexual intimacy, with the patients citing the appearance and leakage as a factor in this, with their language indicating self-disgust. No partners spoke of disgust towards their partner’s HS, indicating their symptoms were not objectively disgusting. The findings from this study suggest that people with HS could develop a self-disgust schema due to the condition, with a malodour further impacting this.

External shame driven avoidance was discussed in this study with some patients concerned of their HS symptoms being exposed, when out in public, and being judged. Concealing symptoms and avoidance has been discussed previously in patients with HS (Howells., 2021; Keary et al., 2020). Given shame's function, patients with HS may feel vulnerable to rejection if exposed. Similarly, as symptoms of HS flares could be mistaken for infection, people with HS may have unfairly experienced disgust from others or stigmatisation. Further, with self-disgust as a schema interfering with information processing (Powell et al., 2015), patients may have a heightened sense of threat towards external shame and others viewing them as disgusting.

Peer support within the HS community helped some participants by normalising their experiences and lessening internal shame. Howells et al. (2021) suggested peer support can improve the self-worth of people with HS. Similarly, in a sample of participants with alopecia, Iliffe and Thompson (2019) found online peer support to help with self-acceptance, accepting their condition and belonging.

Limitations

There are some limitations within the study. As both partners needed to participate, potentially only participants in supportive relationships took part. Further, as only patients with partners were interviewed, this study may have overlooked patients with HS who avoid entering relationships due to external shame and fear of rejection. As some of the demographics details of participants were not captured, it may be harder for readers to know if the results are relevant to their clinic population. Another limitation is pertaining to the sample as one patient suspected their partner had HS. As they were not diagnosed or in receipt of services, this couple was included in the study, however, their experiences of coping with the patient's HS may differ.

As the DLQI was administered prior to interview, it may have influenced how participants interpreted and responded to questions. Further, the Hidradenitis Suppurativa Quality of Life scale (HISQOL; Kirby et al., 2020) is a specific HS measure which could have provided further information.

Clinical implications

As there was a lack of knowledge and lack of sensitivity towards the patients with HS, it would be of benefit for healthcare professionals at GP services and A&E to receive training on HS, including the physical and emotional experiences for patients and partners. Potentially this training could be delivered by psychologists, who have collaborated with dermatologists when creating the training content. To increase outreach and due to limited resources, this training could perhaps be delivered virtually.

Psychological support should be offered to patients and their partners experiencing any HS related distress, including losses. For ease of access, pathways for psychological support could be embedded in dermatology services and provided on an individual, couple or group basis. Facilitated peer support groups or skills-based groups, including how to be assertive with healthcare professionals and how to communicate about HS-related stressors, may suit those wishing to connect with others and find coping strategies. As patients with HS may experience self-disgust and shame, interventions aimed at increasing self-compassion, like Compassion Focused-Therapy, may help.

Conclusion

Flares of HS considerably impact the daily functioning, psychological distress and relationship functioning for patients and their life partners. Future research should explore further self-disgust in HS, compassion-focussed interventions for people with HS, experiences of patients who avoid entering relationships due to HS, and experiences of HS and being in a relationship without the requirement of both partners participating.

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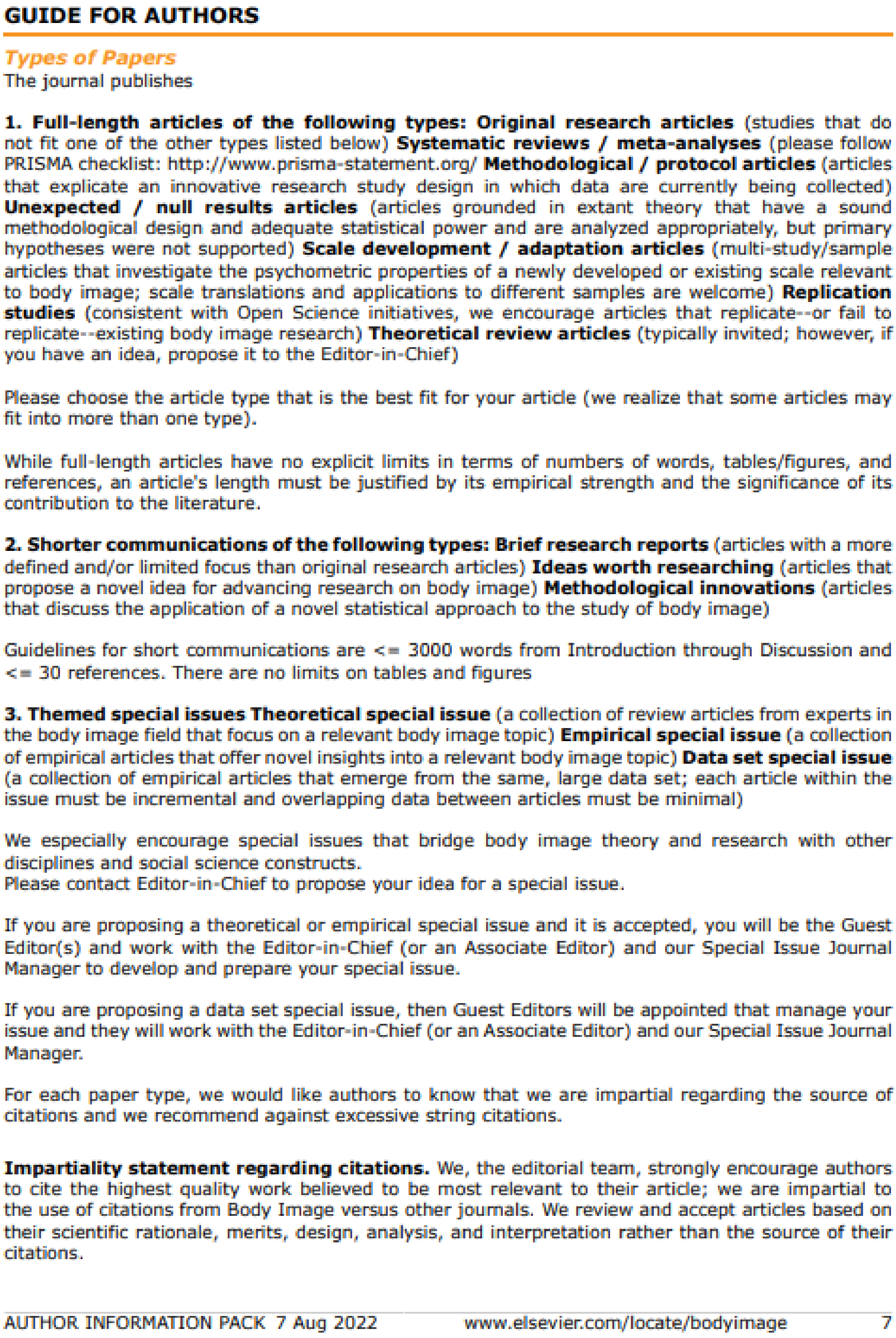
Appendices

Appendix one – author guidance for submission to Body Image



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While full-length articles have no explicit limits in terms of numbers of words, tables/figures, and references, an article's length must be justified by its empirical strength and the significance of its contribution to the literature.

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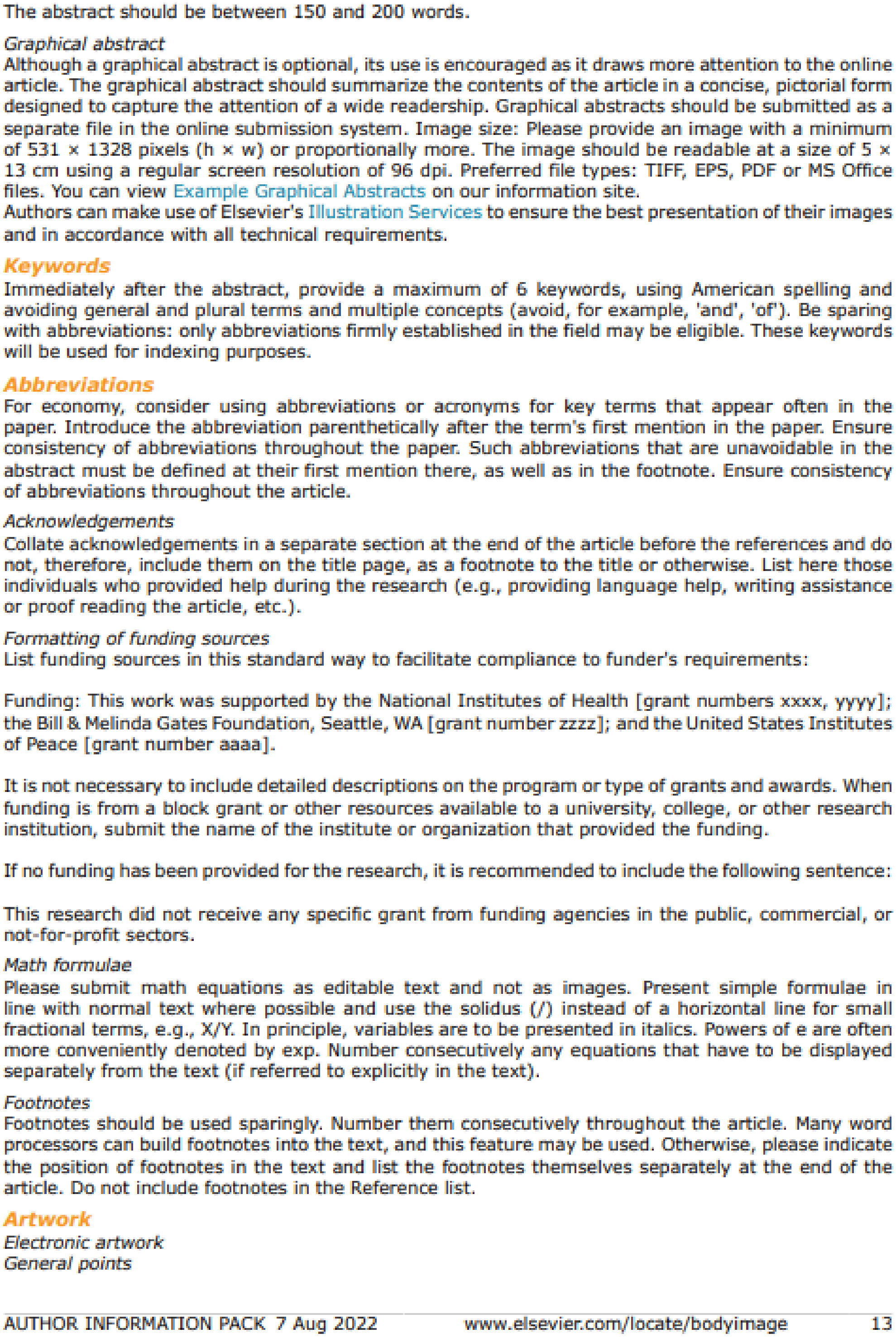

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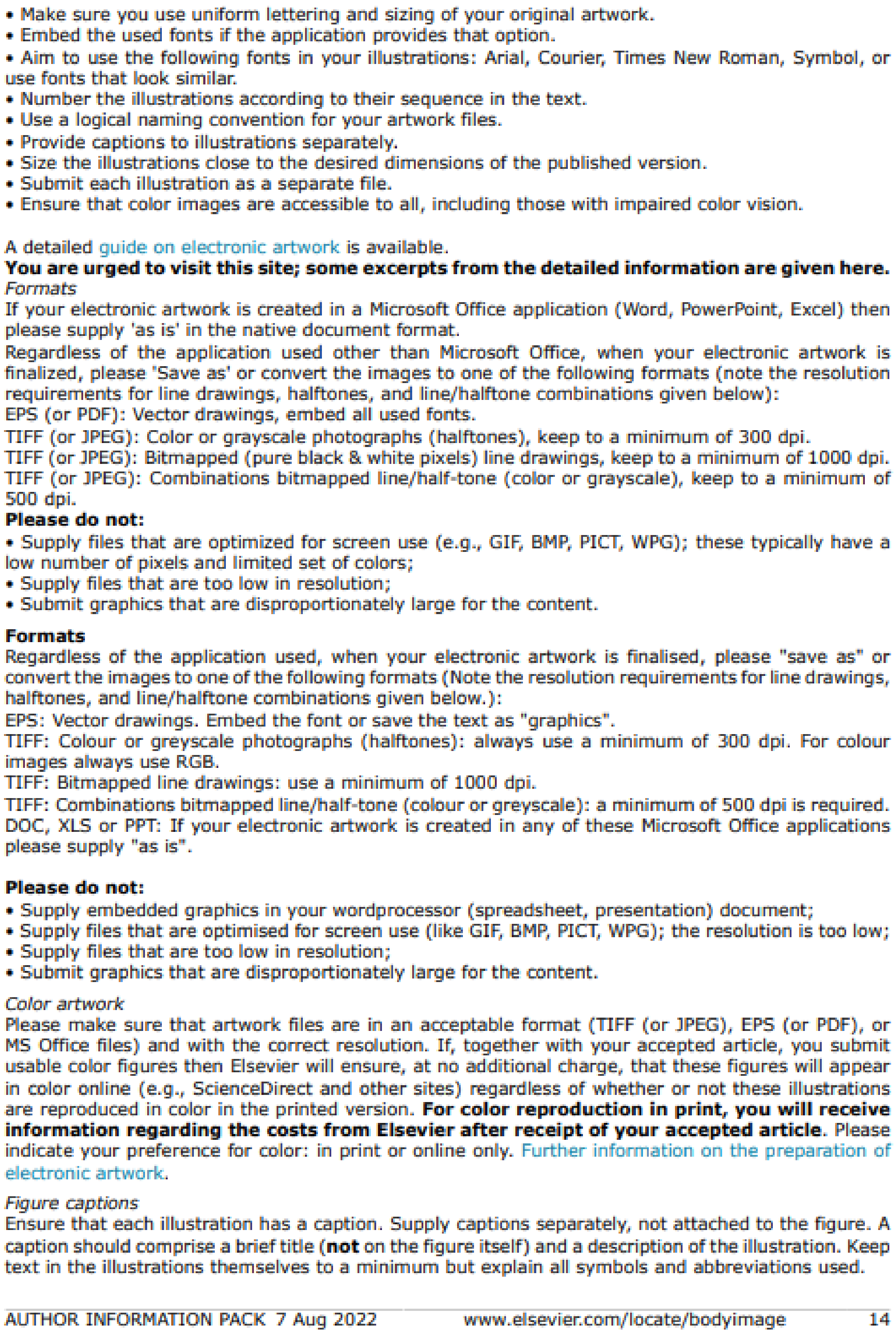

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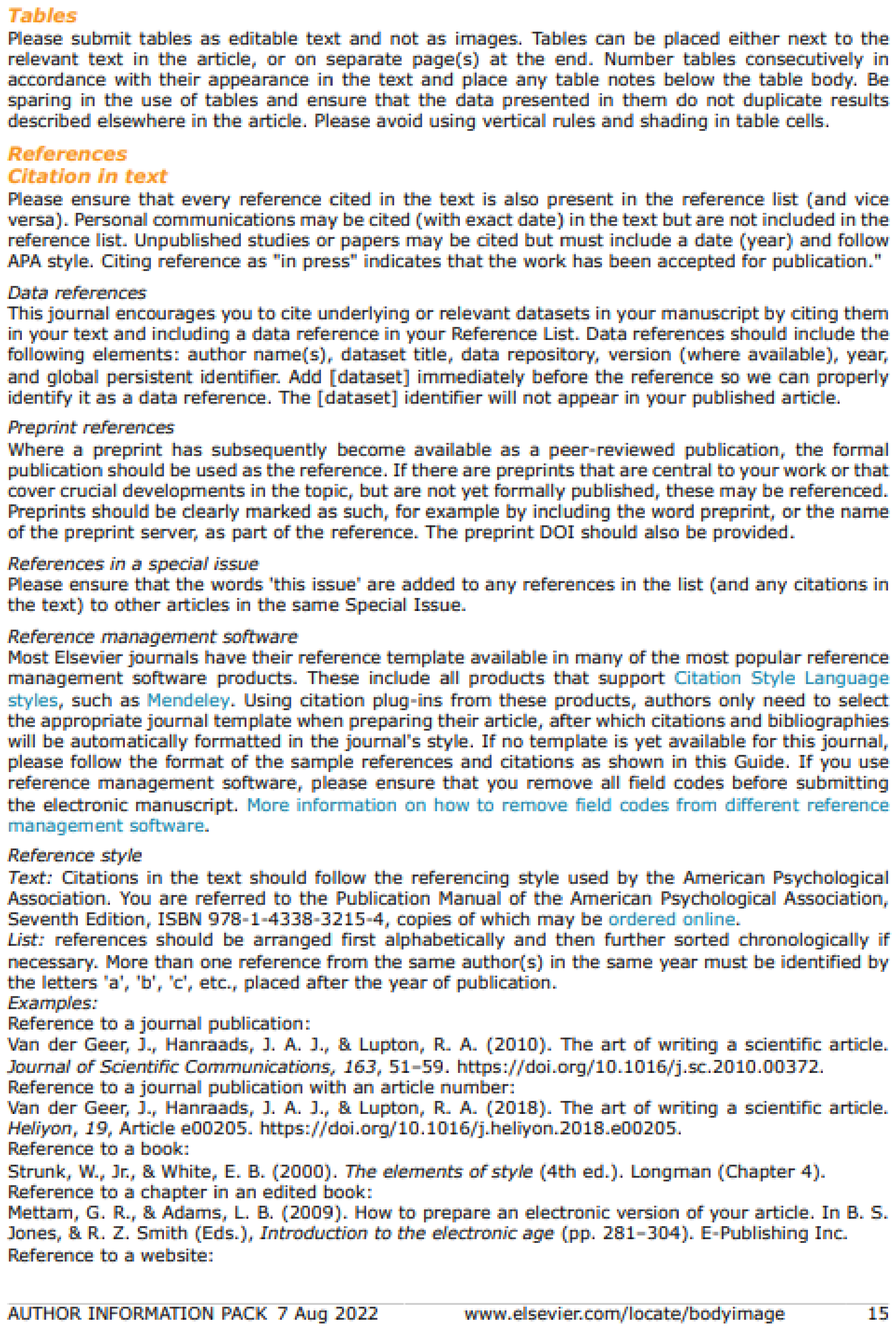

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Powertech Systems. (2015). *Lithium-ion vs lead-acid cost analysis*. Retrieved from http://www.powertechsystems.eu/home/tech-corner/lithium-ion-vs-lead-acid-cost-analysis/. Accessed January 6, 2016
Reference to a dataset:
[dataset] Oguro, M., Imahiro, S., Saito, S., & Nakashizuka, T. (2015). *Mortality data for Japanese oak wilt disease and surrounding forest compositions*. Mendeley Data, v1. https://doi.org/10.17632/xwj98nb39r.1.
Reference to a conference paper or poster presentation:
Engle, E.K., Cash, T.F., & Jarry, J.L. (2009, November). *The Body Image Behaviours Inventory-3: Development and validation of the Body Image Compulsive Actions and Body Image Avoidance Scales*. Poster session presentation at the meeting of the Association for Behavioural and Cognitive Therapies, New York, NY.
Reference to software:
Coon, E., Berndt, M., Jan, A., Svyatsky, D., Atchley, A., Kikinzon, E., Harp, D., Manzini, G., Shelef, E., Lipnikov, K., Garimella, R., Xu, C., Moulton, D., Karra, S., Painter, S., Jafarov, E., & Molins, S. (2020, March 25). *Advanced Terrestrial Simulator (ATS) v0.88 (Version 0.88)*. Zenodo. https://doi.org/10.5281/zenodo.3727209.

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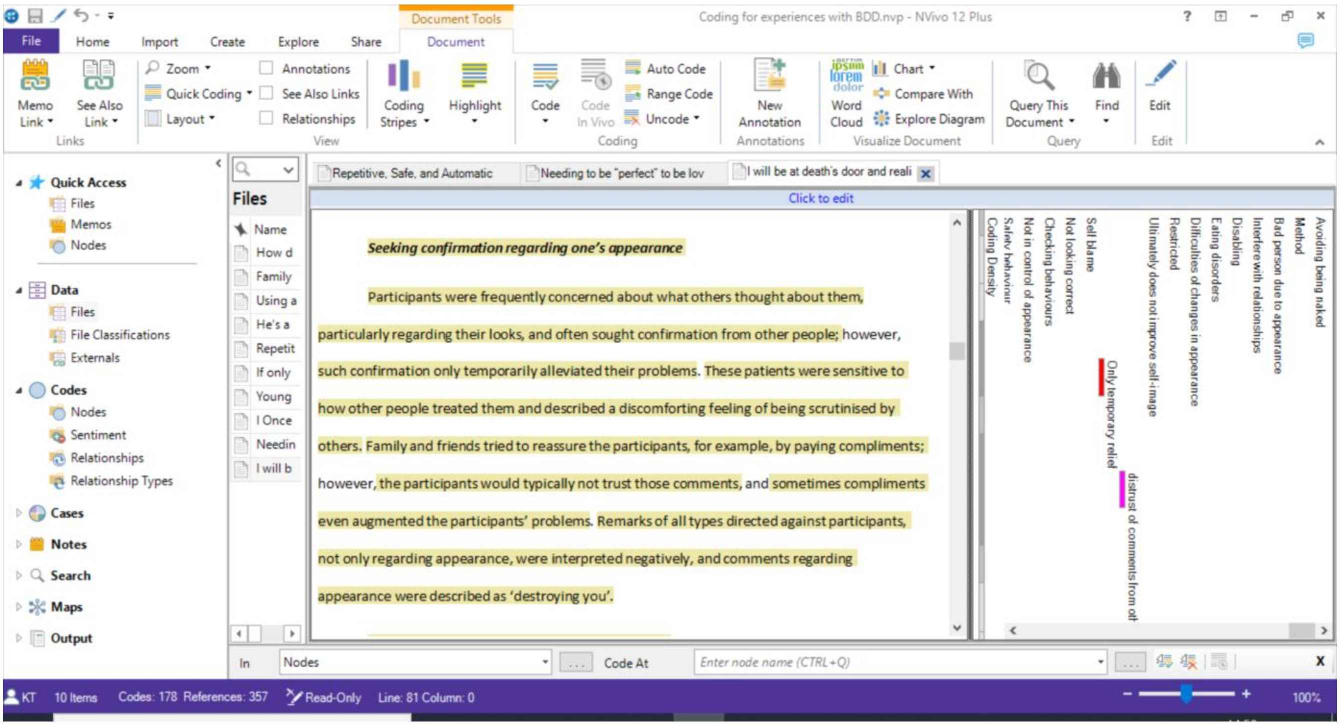
Appendix two –coding using NVivo

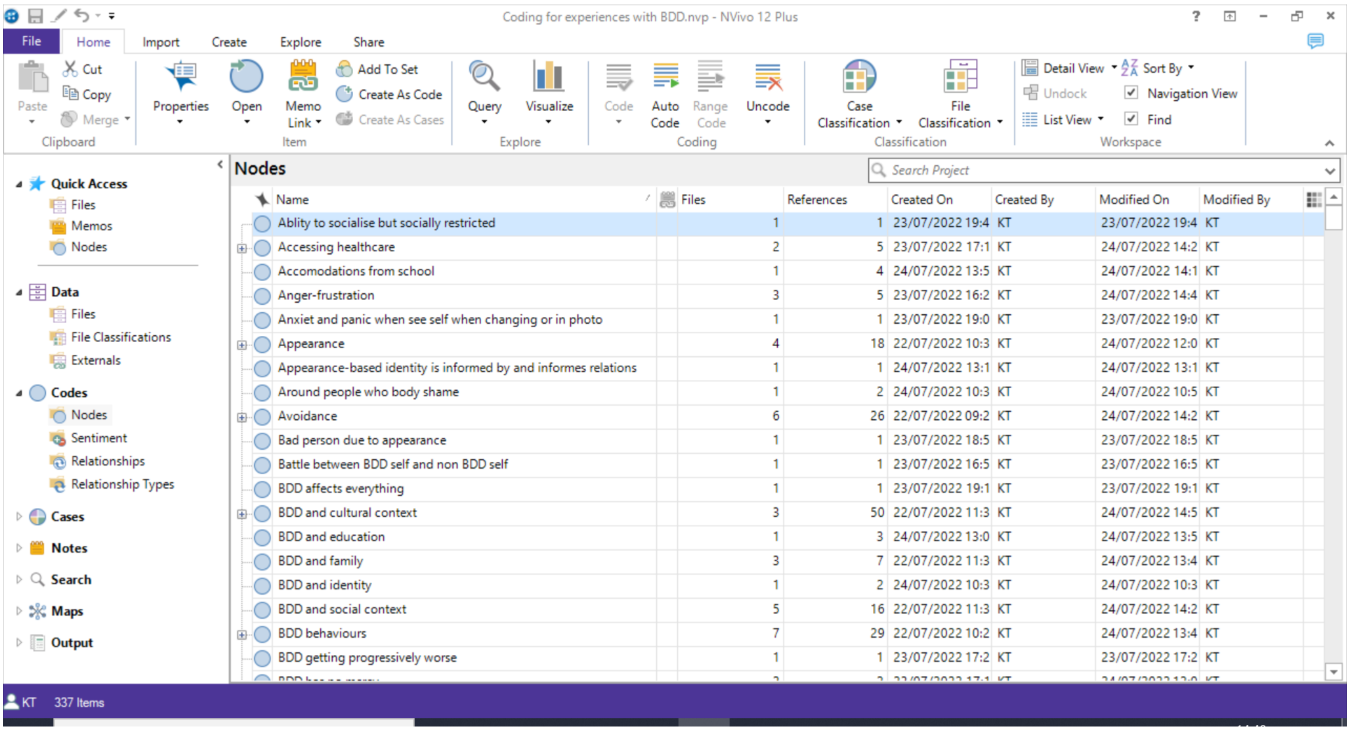
Section of a coded transcript showing the coding strips to the right



Seeking confirmation regarding one's appearance

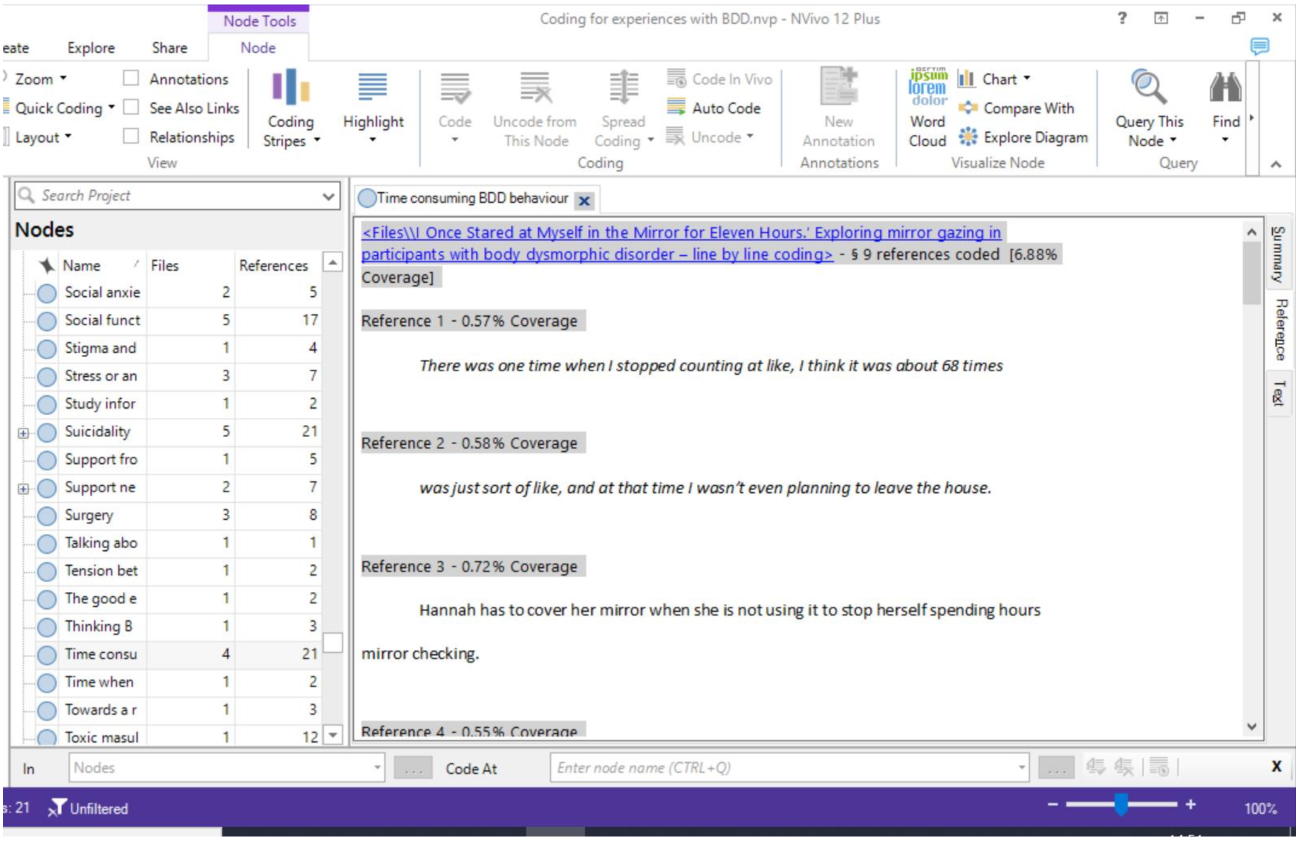
Participants were frequently concerned about what others thought about them, particularly regarding their looks, and often sought confirmation from other people; however, such confirmation only temporarily alleviated their problems. These patients were sensitive to how other people treated them and described a discomforting feeling of being scrutinised by others. Family and friends tried to reassure the participants, for example, by paying compliments; however, the participants would typically not trust those comments, and sometimes compliments even augmented the participants' problems. Remarks of all types directed against participants, not only regarding appearance, were interpreted negatively, and comments regarding appearance were described as 'destroying you'.

List of initial codes



Name	Files	References	Created On	Created By	Modified On	Modified By
Ablity to socialise but socially restricted	1	1	23/07/2022 19:4	KT	23/07/2022 19:4	KT
Accessing healthcare	2	5	23/07/2022 17:1	KT	24/07/2022 14:2	KT
Accomodations from school	1	4	24/07/2022 13:5	KT	24/07/2022 14:1	KT
Anger-frustration	3	5	23/07/2022 16:2	KT	24/07/2022 14:4	KT
Anxiet and panic when see self when changing or in photo	1	1	23/07/2022 19:0	KT	23/07/2022 19:0	KT
Appearance	4	18	22/07/2022 10:3	KT	24/07/2022 12:0	KT
Appearance-based identity is informed by and informes relations	1	1	24/07/2022 13:1	KT	24/07/2022 13:1	KT
Around people who body shame	1	2	24/07/2022 10:3	KT	24/07/2022 10:5	KT
Avoidance	6	26	22/07/2022 09:2	KT	24/07/2022 14:2	KT
Bad person due to appearance	1	1	23/07/2022 18:5	KT	23/07/2022 18:5	KT
Battle between BDD self and non BDD self	1	1	23/07/2022 16:5	KT	23/07/2022 16:5	KT
BDD affects everything	1	1	23/07/2022 19:1	KT	23/07/2022 19:1	KT
BDD and cultural context	3	50	22/07/2022 11:3	KT	24/07/2022 14:5	KT
BDD and education	1	3	24/07/2022 13:0	KT	24/07/2022 13:5	KT
BDD and family	3	7	22/07/2022 11:3	KT	24/07/2022 13:4	KT
BDD and identity	1	2	24/07/2022 10:3	KT	24/07/2022 10:3	KT
BDD and social context	5	16	22/07/2022 11:3	KT	24/07/2022 14:2	KT
BDD behaviours	7	29	22/07/2022 10:2	KT	24/07/2022 13:4	KT
BDD getting progressively worse	1	1	23/07/2022 17:2	KT	23/07/2022 17:2	KT

List of all lines under the code 'time consuming BDD behaviours'



Nodes

Name	Files	References
Social anxie	2	5
Social funct	5	17
Stigma and	1	4
Stress or an	3	7
Study infor	1	2
Suicidality	5	21
Support fro	1	5
Support ne	2	7
Surgery	3	8
Talking abo	1	1
Tension bet	1	2
The good e	1	2
Thinking B	1	3
Time consu	4	21
Time when	1	2
Towards a r	1	3
Toxic masul	1	12

<Files\\I Once Stared at Myself in the Mirror for Eleven Hours.' Exploring mirror gazing in participants with body dysmorphic disorder – line by line coding> - § 9 references coded [6.88% Coverage]

Reference 1 - 0.57% Coverage

There was one time when I stopped counting at like, I think it was about 68 times

Reference 2 - 0.58% Coverage

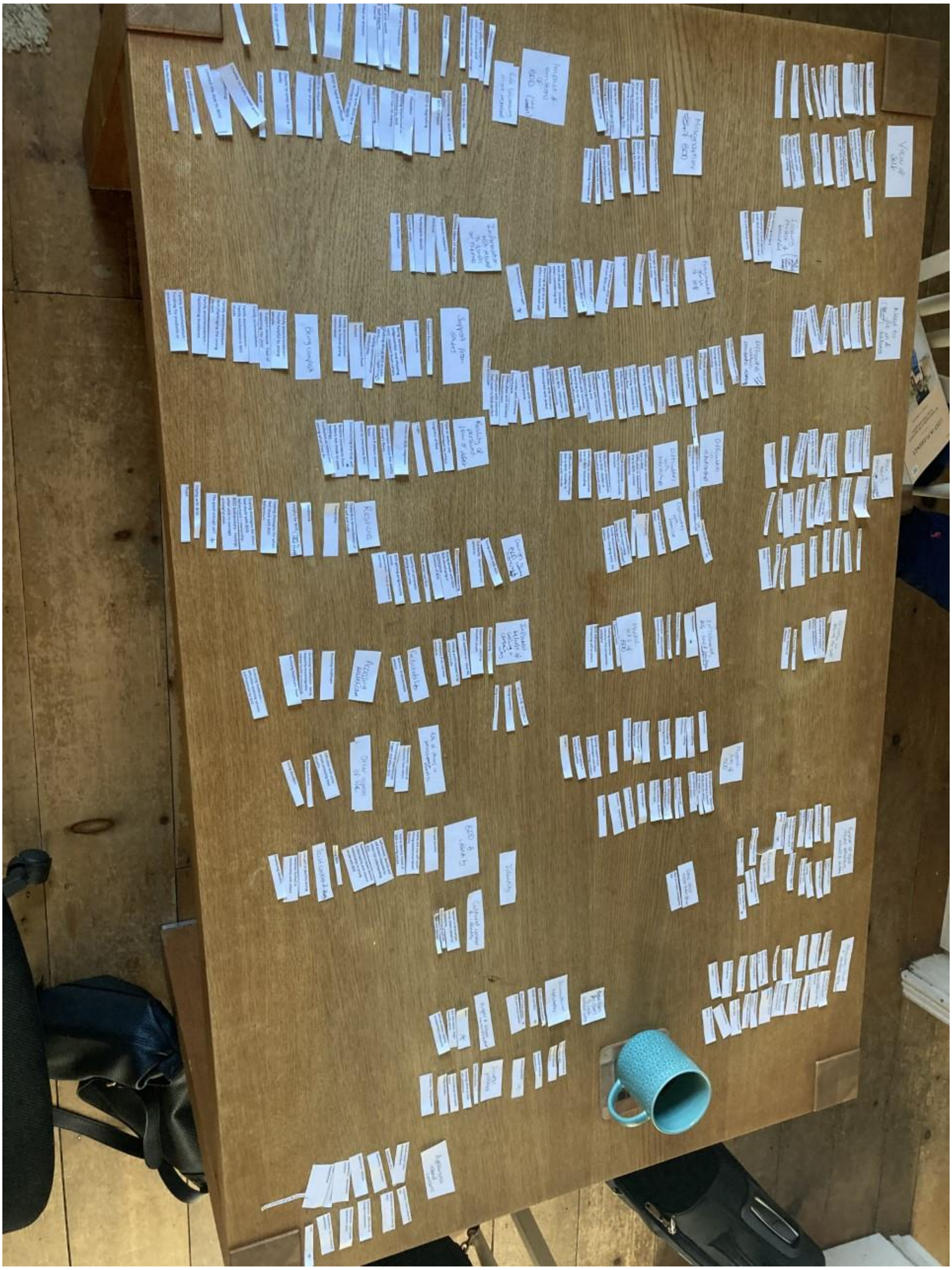
was just sort of like, and at that time I wasn't even planning to leave the house.

Reference 3 - 0.72% Coverage

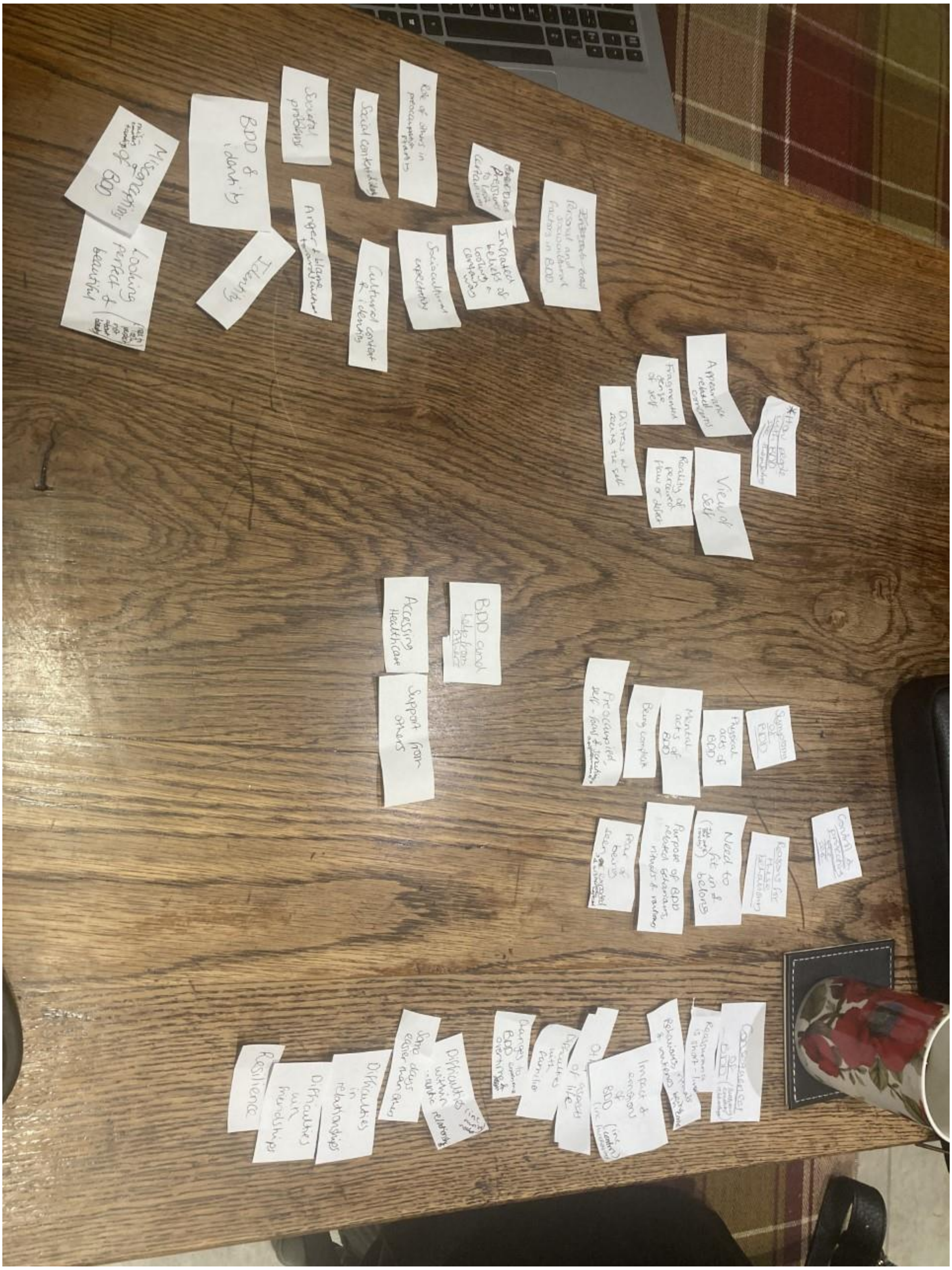
Hannah has to cover her mirror when she is not using it to stop herself spending hours mirror checking.

Reference 4 - 0.55% Coverage

Appendix three - structure using initial themes



Appendix four – refined structure before analytical stage of thematic synthesis



Appendix five - CASP ratings for each study

	Clear aims stated	**Qualitative methodology appropriate**	**Appropriate research design**	**Appropriate recruitment strategy**	**Appropriate data collected**	**Reflexivity and relationship between researcher and participants**	**Ethical considerations**	**Rigorous data analysis**	**Clear statement of findings**	**Research is valuable**
Brohede, Wijma, Wijma, & Blomberg (2016)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓
Craythorne, Shaw, & Larkin (2020)	✓	✓	✓	✓	✓	**X**	✓	**?**	✓	✓
Jassi, Baloch, Thomas-Smith, & Lewis (2020)	✓	✓	✓	✓	✓	**X**	✓	✓	✓	✓
Morgan-Sowada & Gamboni (2021)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Oakes, Collison, &	✓	✓	✓	✓	✓	**X**	✓	✓	✓	✓

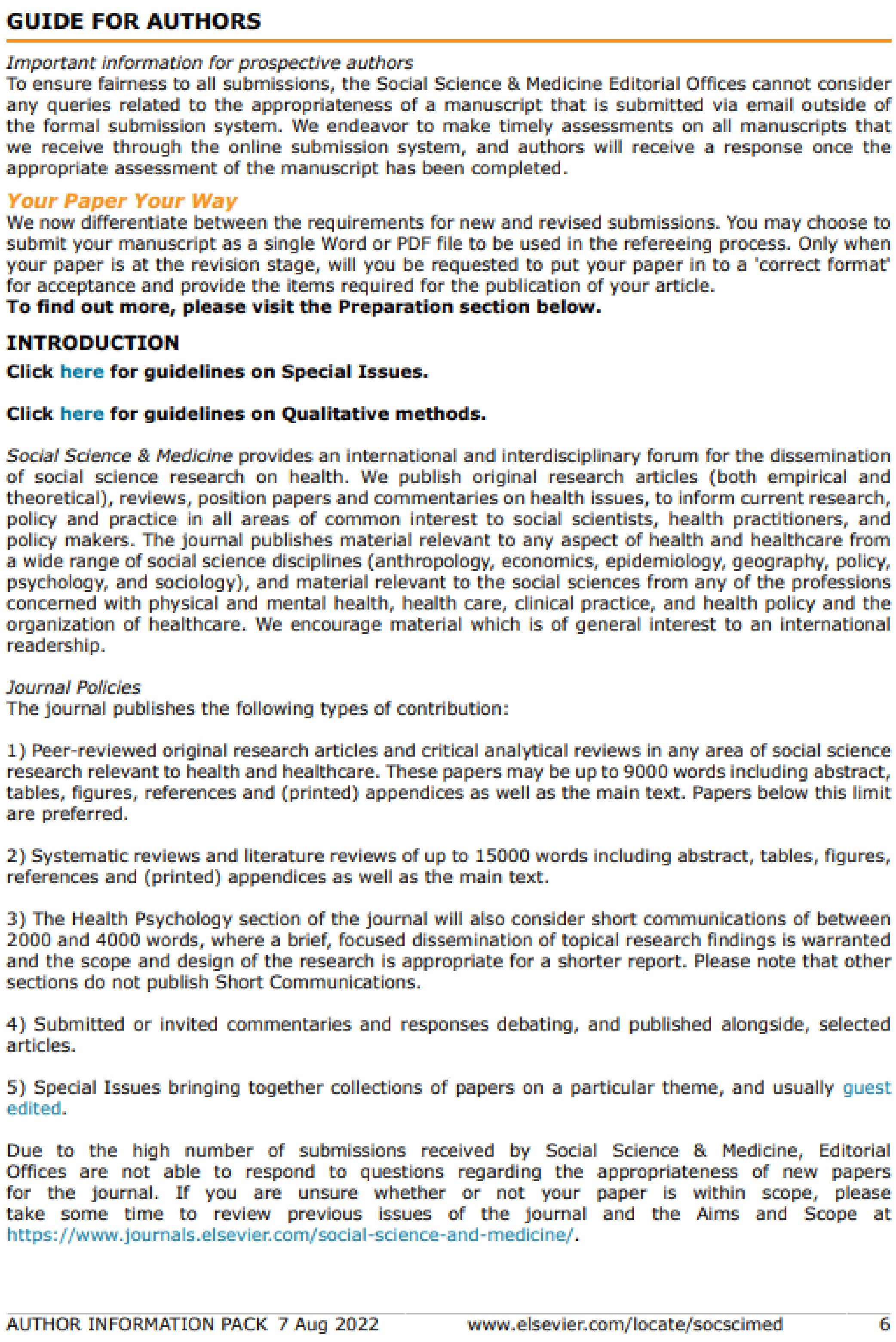
Milne-Home (2017)										
Schnackenberg (2021)	✓	✓	✓	✓	**?**	✓	✓	**?**	✓	✓
Silver & Farrants (2016)	✓	✓	✓	✓	✓	**X**	✓	**?**	✓	✓
Silver & Reavey (2010)	✓	✓	✓	✓	✓	**X**	✓	**?**	**X**	✓
Silver, Reavey, & Finebery (2010)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓
Stechler & Henton (2022)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

✓ - met criteria

X – does not meet criteria

? – unable to tell

Appendix six - author guidance for submission to Social Science and Medicine



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- Ensure all figure and table citations in the text match the files provided
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Graphical Abstracts / Highlights files (where applicable)
Supplemental files (where applicable)

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- All references mentioned in the Reference List are cited in the text, and vice versa
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- All identifying information has been removed from the manuscript, including the file name itself
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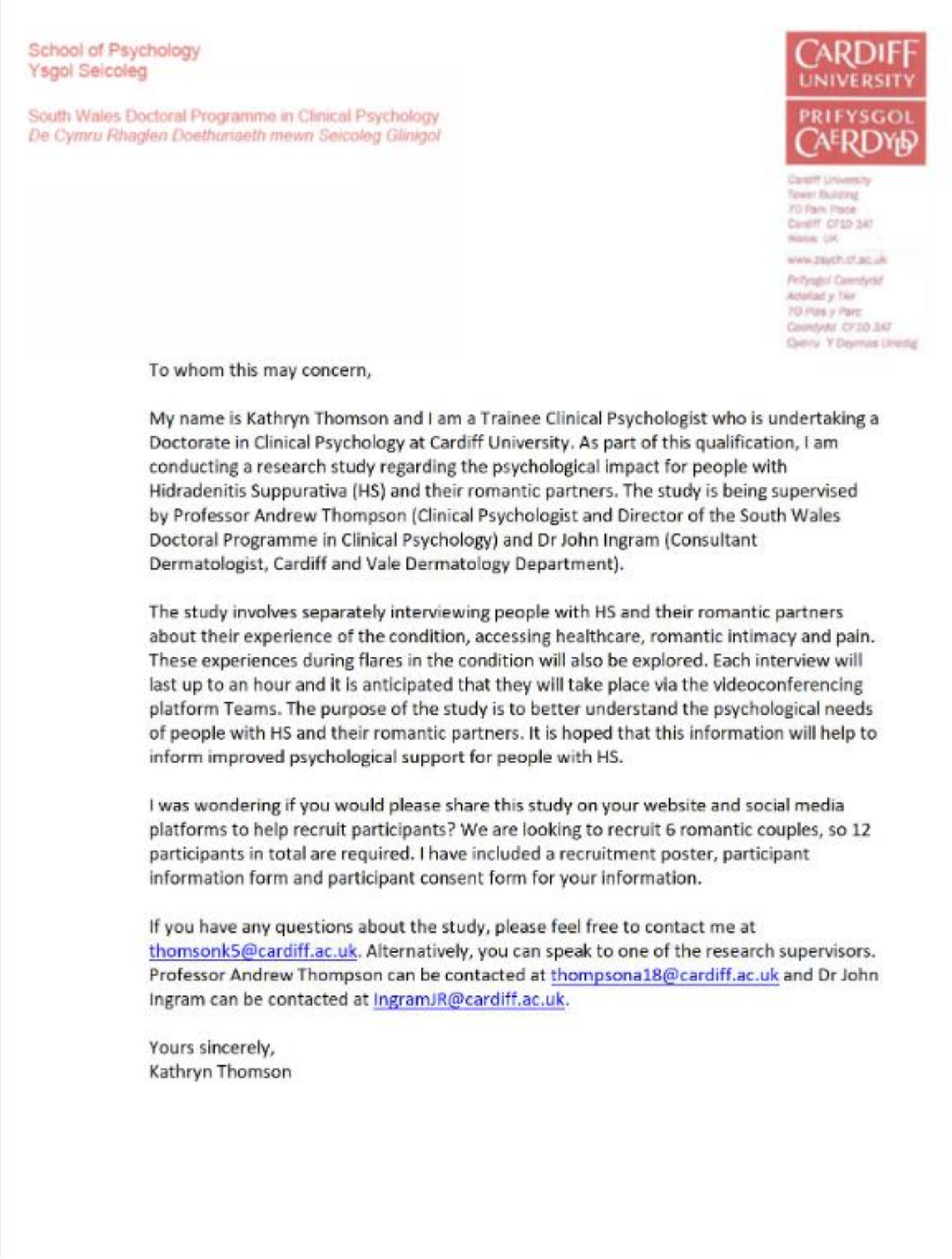
Appendix seven – letter sent to organisations asking to recruit study on social media platforms



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To whom this may concern,

My name is Kathryn Thomson and I am a Trainee Clinical Psychologist who is undertaking a Doctorate in Clinical Psychology at Cardiff University. As part of this qualification, I am conducting a research study regarding the psychological impact for people with Hidradenitis Suppurativa (HS) and their romantic partners. The study is being supervised by Professor Andrew Thompson (Clinical Psychologist and Director of the South Wales Doctoral Programme in Clinical Psychology) and Dr John Ingram (Consultant Dermatologist, Cardiff and Vale Dermatology Department).

The study involves separately interviewing people with HS and their romantic partners about their experience of the condition, accessing healthcare, romantic intimacy and pain. These experiences during flares in the condition will also be explored. Each interview will last up to an hour and it is anticipated that they will take place via the videoconferencing platform Teams. The purpose of the study is to better understand the psychological needs of people with HS and their romantic partners. It is hoped that this information will help to inform improved psychological support for people with HS.

I was wondering if you would please share this study on your website and social media platforms to help recruit participants? We are looking to recruit 6 romantic couples, so 12 participants in total are required. I have included a recruitment poster, participant information form and participant consent form for your information.

If you have any questions about the study, please feel free to contact me at thomsonk5@cardiff.ac.uk. Alternatively, you can speak to one of the research supervisors. Professor Andrew Thompson can be contacted at thompsona18@cardiff.ac.uk and Dr John Ingram can be contacted at IngramJR@cardiff.ac.uk.

Yours sincerely,
Kathryn Thomson

Appendix eight – study recruitment poster

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Study on Hidradenitis Suppurativa (HS)

We are carrying out a study exploring the experience of HS for people with the condition and their romantic partners. We are currently seeking volunteers to participate in this study.

Who can take part?

Couples in a romantic relationship where only one member has HS are invited to take part. You are eligible to take part in this study if: your partner is also willing to participate, you are both over the age of 18 and both speak English.

What are we asking you to do?

The study would involve interviewing you and your romantic partner separately about the psychological impact HS has had on you. These interviews should not last longer than 60 minutes each and will be held over a videoconferencing platform such as Teams.

This study is being undertaken as part of a Doctorate in Clinical Psychology at Cardiff University. It is hoped that the study will provide a better understanding of the psychological needs for people with HS and their romantic partners.

If you are interested in participating or have any questions about the study, please contact the lead researcher, Kathryn Thomson (Trainee Clinical Psychologist) at thomsonk5@cardiff.ac.uk

Appendix nine – participant information sheet

Participant Information Sheet

Study Title:
The experience of living with Hidradenitis Suppurativa (HS) for affected individuals and their partners: An interpretative phenomenological analysis

You are invited to take part in the above research study. Please read this information sheet to help you make an informed choice about whether you would like to participate or not.

What is the study about?
The study is regarding the experience of being in a romantic relationship where one of the partners has HS. The study will explore the experience of HS and its flares on pain and sexual intimacy. The experience of accessing healthcare, including psychological support, will also be explored.

To the best of the researcher's knowledge, this will be the first qualitative study done with couples regarding HS.

Who is involved in this study?
This study is being conducted by Kathryn Thomson (Trainee Clinical Psychologist) who is completing a Doctorate in Clinical Psychology at Cardiff University. The supervisors for this study are Professor Andrew Thompson (Clinical Psychologist and Clinical Psychology Programme Director, Cardiff University) and Dr John Ingram (Clinical Reader and Consultant Dermatologist, Cardiff University).

Who can take part?
Couples in a romantic relationship where only one member has HS are invited to take part. To be eligible to take part in this study, your partner would also need to be willing to participate. This study is only open to participants over the age of 18. It is a requirement that both members of the couple can speak English.

What are we asking you to do?
The study would involve interviewing you and your romantic partner separately about the psychological impact HS has had on you. These interviews should not last longer than 60 minutes each and will be held over a videoconferencing platform such as Zoom or Teams.

What will happen with my data?

The interviews will be audio recorded and then transcribed by a transcriber employed by Cardiff University. The transcript from each interview will be produced in approximately 14 days after the interview has taken place. All information will be anonymised prior to being analysed. All participant identifiable information collected from the interviews will be changed to protect anonymity and saved in a password protected document.

All data collected will be saved electronically for 7 years before being destroyed.

We will seek your consent to use anonymised excerpts from the interview transcript in presentations and in academic publications.

Do I have to take part?

No. Participation in this study is completely voluntary and choosing to take part or not will not impact the healthcare that you receive. If you chose to take part, you can withdraw at any point prior to the research being analysed.

Are there any benefits of taking part?

By taking part in the study, you would be contributing to our existing knowledge of HS. It is hoped that information gained from the study can be disseminated to other healthcare professionals so that existing support for people with HS and their partners is improved.

Are there any risks associated with taking part?

There is a possibility that you may feel upset talking about your experience of HS. We will give you information for support and psychological services after the interview should you feel upset and want to discuss your feelings with someone.

All information collected in the study will be anonymised, however, there is a possibility that your partner may identify what you say.

How can I make a complaint?

If you have any concerns or wish to make a complaint regarding this study, you can contact the lead researcher Kathryn Thomson by emailing thomsonk5@cardiff.ac.uk. Otherwise, you can contact the other researchers involved in this study to raise your concerns. Professor Andrew Thompson (Clinical Psychologist and Clinical Psychology Programme Director, Cardiff University) can be contacted via email on thompsona18@cardiff.ac.uk and Dr John Ingram (Clinical Reader and Consultant Dermatologist, Cardiff University) can be contacted on IngramJR@cardiff.ac.uk.

If you have contacted the researchers regarding your complaint and feel that the response received has not been satisfactory, you can escalate this by contacting the School of Psychology Research Ethics Committee on psychethics@cardiff.ac.uk.

If you have any questions about the study or are interested in taking part: please contact Kathryn Thomson on thomsonk5@cardiff.ac.uk

Appendix ten – participant consent form

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HS Study Consent Form

Please read the following statements to ensure that you understand all the information given before taking part in this study.

Please tick or delete the following:

I have read the participant information sheet and understand what is involved in participating in the study	
I have been given the opportunity to ask questions about this study	
I understand that my participation in this study is completely voluntary. I understand that I can withdraw from the study without giving an explanation and without any consequences. I understand that I can withdraw at any time before the interview transcript has been analysed and written up. In addition, should I not wish to answer any particular question or questions, I am free to decline.	
I understand that my participation in this study will have no impact on my/my partner's (*delete as appropriate) health care	
I understand that my responses will be confidential and therefore I will not be identifiable in the report or reports that result from this study	
I understand that the interview will be digitally recorded and transcribed by a transcriber employed by Cardiff University. A transcript from the interview will be produced approximately 14 days after the interview.	
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.	
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	
I agree for the data collected from me to be stored anonymously and potentially used in future research.	
I agree to assign the copyright I hold in any materials generated as part of this project to Cardiff University	

I give my consent to take part in this study	

Name of **Participant:** __________________________________

Signature __________________________________ Date: ______________

Name of **Researcher**:______________________________

Signature __________________________________ Date: ______________

Appendix eleven – demographic details, information on HS and DLQI scores of participants

Participant with HS/ without HS	**Age range of couple**	**Marital status**	**Sexuality**	**Ethnicity**	**Country of residence**	**Age of HS onset**	**Severity of HS**	**DLQI score (effect on quality of life)**
Patient with HS	26-40	Co-habiting	Heterosexual relationship	Caucasian	United Kingdom	“Mid-teens”	Severe (Hurley stage 3)	22 (extremely large effect)
Patient with HS	41-55	Married	Heterosexual relationship	Caucasian	United States	17	Severe (Hurley stage 3)	24 (extremely large effect)
Patient with HS	41-55	Married	Heterosexual relationship	Caucasian	United States	14	Moderate (Hurley stage 2)	26 (extremely large effect)

Patient with HS	41-55	Married	Heterosexual relationship	Latino	United States	Unknown	Severe (Hurley stage 3)	23 (extremely large effect)
Patient with HS	26-40	Married	Heterosexual relationship	Caucasian	United States	16	Mild (Hurley stage 1)	11 (very large effect)
Patient with HS	26-40	Married	Same-sex relationship	Caucasian	United Kingdom	Unknown	Moderate (Hurley stage 2)	22 (extremely large effect)
Partner without HS	26-40	Co-habiting	Heterosexual relationship	Caucasian	United Kingdom	N/A	N/A	N/A
Partner without HS	41-55	Married	Heterosexual relationship	Caucasian	United States	N/A	N/A	N/A
Partner without HS	26-40	Married	Heterosexual relationship	Indian	United States	N/A	N/A	N/A
Partner without HS	26-40	Married	Same-sex relationship	Caucasian	United Kingdom	N/A	N/A	N/A

Partner without HS	41-55	Married	Heterosexual relationship	Mexican	United States	N/A	N/A	N/A
Partner without HS	41-55	Married	Heterosexual relationship	Caucasian	United States	N/A	N/A	N/A

Appendix twelve – full interview schedule with prompts

Questions for participants with HS	**Prompts**
1. What is living with HS like for you?	a. Prompt: Please can you describe to me your experience of when your HS flares up. What is it like for you? b. Prompt: Can you tell me a little more about the physical effects? Please tell me about your experience of pain and other symptoms during a flare-up. c. Prompt: Can you tell me a little more about the emotional effects?
2. How, if at all have things changed over time?	a. Prompt: Has it always been like it is at the present time? b. Prompt: What was it like at the start?
3. Can you tell me about how HS effects your relationship?	a. Prompt: How has it influenced how you act and feel in your present relationship? b. Prompt: Can you tell me how it effects intimacy or closeness (explore mood, thoughts, physical aspects of HS)? c. Prompt: How does HS affect your sexual relationship? d. Prompt: How do flare-up's up effect this aspect of your life?
4. In relation to HS, what has your experience of accessing services been like?	a. Prompt: What services/NHS/private/websites etc have you used? b. Prompt: How have the areas we discussed above been supported?
Questions for participants without HS	
1. In relation to HS, what is your experience of being in a relationship with (insert name of partner)?	a. Prompt: Please can you describe to me your experience of when your partner's HS flares up. What is it like for you? …and for both of you? b. Prompt: Can you tell me a little more about physical intimacy?

	c. Please tell me about your experience of their pain during a flare-up. d. Prompts: Can you tell me a little more about the emotional effects?
2. In relation to HS, how if at all have things changed over time?	
3. Can you tell me about how HS effects your relationship?	a. Prompt: How has it influenced how you act and feel in your relationship? b. Prompt: Can you tell me how it effects intimacy or closeness (explore mood, thoughts, physical aspects of HS)? c. Prompt: Can you tell me about your sexual relationship and how HS effects this (explore mood, thoughts, physical aspects of HS)? d. Prompt: How do flare-up's up effect this aspect of your life?
4. What has your experience of your partner accessing services been?	a. Prompt: What services/NHS/private/websites etc have they used? b. Prompt: How have the areas we discussed above been supported?

Appendix Thirteen - Participant Debrief Sheet

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HS Study Debrief Sheet

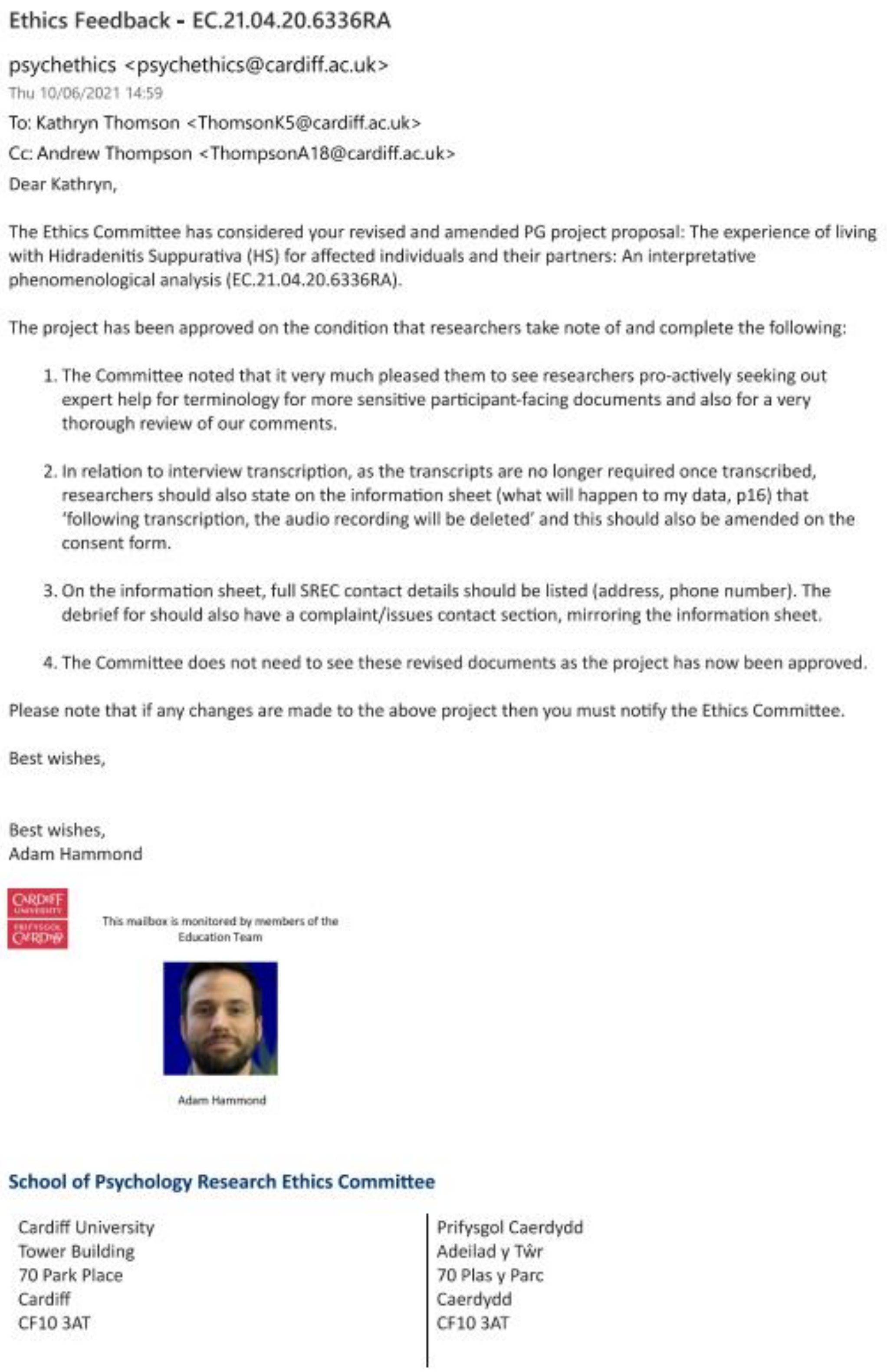
Thank you for your contributions to this study. It is hoped that the information collected from the interviews can be used to identify the needs of people with HS and their romantic partners so that a better understanding of psychological needs support can be identified. It is hoped that from this, better psychological provision for people with HS and their romantic partners can be put in place.

Sometimes people may feel upset after they have shared their personal experiences. If this has happened to you, we recommend that you discuss this with you GP. You may also find the following organisations helpful:

- Samaritans
    - A free listening service run by trained volunteers. This service operates 24/7. You can access support from the Samaritans by calling 116 123. For more information, please visit their website: www.samaritans.org

- The Hidradenitis Support Trust
    - Provides information and support to people with HS, their family and friends. For more information, please visit their website: www.hstrust.org

Appendix fourteen – proof of ethical approval from Cardiff Ethics Committee



Ethics Feedback - EC.21.04.20.6336RA

psychethics <psychethics@cardiff.ac.uk>
Thu 10/06/2021 14:59
To: Kathryn Thomson <ThomsonK5@cardiff.ac.uk>
Cc: Andrew Thompson <ThompsonA18@cardiff.ac.uk>

Dear Kathryn,

The Ethics Committee has considered your revised and amended PG project proposal: The experience of living with Hidradenitis Suppurativa (HS) for affected individuals and their partners: An interpretative phenomenological analysis (EC.21.04.20.6336RA).

The project has been approved on the condition that researchers take note of and complete the following:

1. The Committee noted that it very much pleased them to see researchers pro-actively seeking out expert help for terminology for more sensitive participant-facing documents and also for a very thorough review of our comments.
2. In relation to interview transcription, as the transcripts are no longer required once transcribed, researchers should also state on the information sheet (what will happen to my data, p16) that 'following transcription, the audio recording will be deleted' and this should also be amended on the consent form.
3. On the information sheet, full SREC contact details should be listed (address, phone number). The debrief for should also have a complaint/issues contact section, mirroring the information sheet.
4. The Committee does not need to see these revised documents as the project has now been approved.

Please note that if any changes are made to the above project then you must notify the Ethics Committee.

Best wishes,

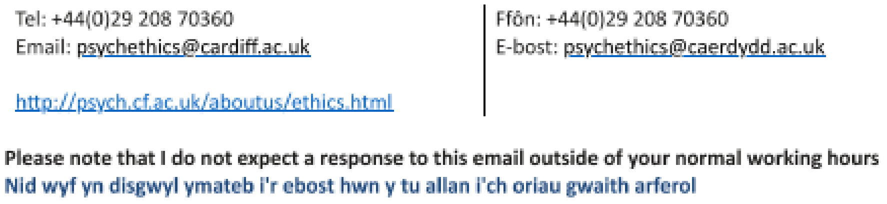
Best wishes,
Adam Hammond

This mailbox is monitored by members of the Education Team

Adam Hammond

School of Psychology Research Ethics Committee

Cardiff University Tower Building 70 Park Place Cardiff CF10 3AT	Prifysgol Caerdydd Adeilad y Tŵr 70 Plas y Parc Caerdydd CF10 3AT



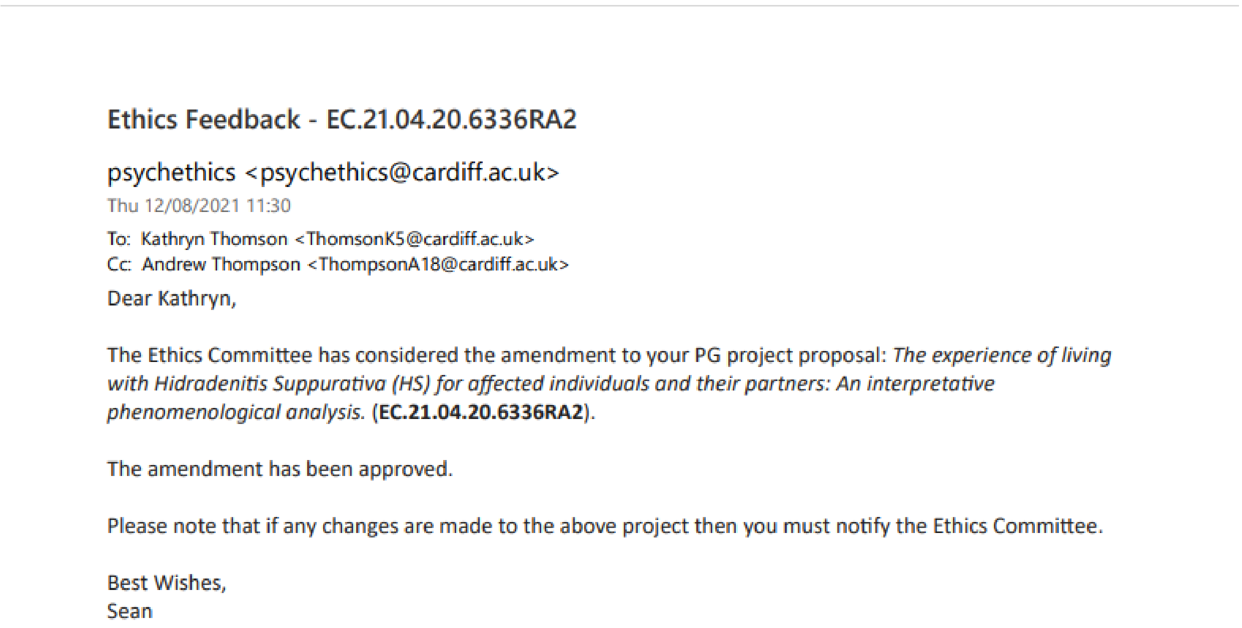
Tel: +44(0)29 208 70360
Email: psychethics@cardiff.ac.uk

http://psych.cf.ac.uk/aboutus/ethics.html

Ffôn: +44(0)29 208 70360
E-bost: psychethics@caerdydd.ac.uk

Please note that I do not expect a response to this email outside of your normal working hours
Nid wyf yn disgwyl ymateb i'r ebost hwn y tu allan i'ch oriau gwaith arferol

Appendix fifteen – proof of amendments granted from ethical committee



Ethics Feedback - EC.21.04.20.6336RA2

psychethics <psychethics@cardiff.ac.uk>
Thu 12/08/2021 11:30
To: Kathryn Thomson <ThomsonK5@cardiff.ac.uk>
Cc: Andrew Thompson <ThompsonA18@cardiff.ac.uk>

Dear Kathryn,

The Ethics Committee has considered the amendment to your PG project proposal: *The experience of living with Hidradenitis Suppurativa (HS) for affected individuals and their partners: An interpretative phenomenological analysis.* (**EC.21.04.20.6336RA2**).

The amendment has been approved.

Please note that if any changes are made to the above project then you must notify the Ethics Committee.

Best Wishes,
Sean

Appendix sixteen – Confidentiality form for transcriber

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Transcribing Confidentiality Form & Guidance Notes

Title of Project:
The experience of living with Hidradenitis Suppurativa (HS) for affected individuals and their partners: An interpretative phenomenological analysis

Researcher's name: Kathryn Thomson

The recording you are transcribing has been collected as part of a research project. Recordings may contain information of a sensitive nature, which must be kept confidential and not disclosed to others.

Please read the following statements. The researcher is only able to work with transcriber(s) who understand and agree to the following items below.

Please tick or delete the following items:

1. I will discuss the content of the recording only with the individual involved in the research project	
2. If transcribing digital recordings – I will only accept files provided on an encrypted memory stick or via secure digital transfer method	
3. I will keep any encrypted memory stick supplied in a secure place when not in use	
4. When transcribing a recording I will ensure it cannot be heard by others	
5. I will treat the transcription of the recording as confidential information	
6. If the person being interviewed on the recordings is known to me I will undertake no further transcription work on the recording	
7. If I become upsetting when listening to the audio recording, I will stop the transcription and raise this with the researcher as soon as possible	

Name of **Transcriber:** ___________________________________

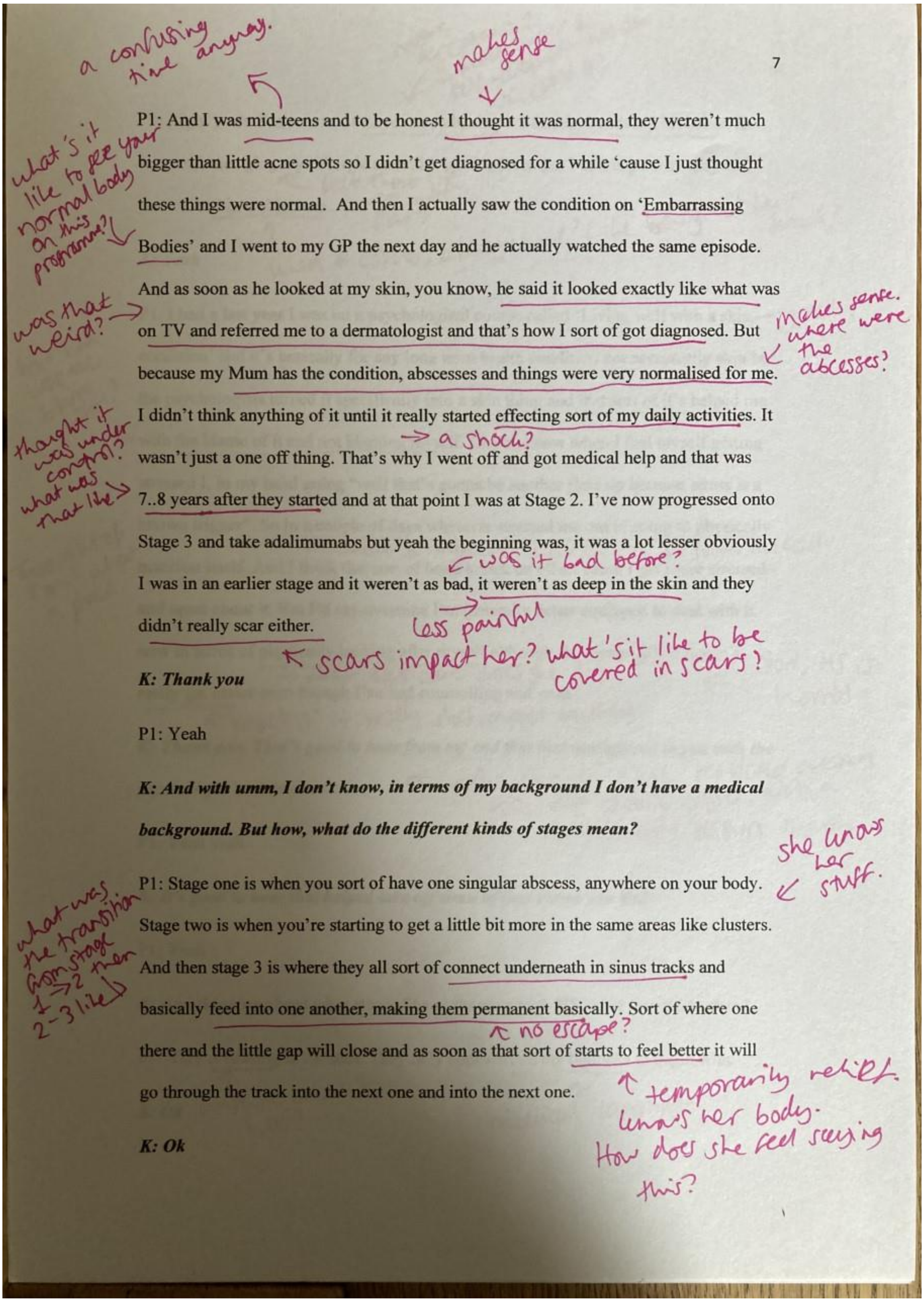
Signature ___________________________________ Date: ______________

Appendix seventeen – ethical issues of the study and how this was managed

A number of ethical issues can be associated with conducting indepth interviews on sensitive topics (Thompson & Russo, 2004). This study sought to minimise the risk of distress to participant by following general quidelines on conducting qualitative interviewing as laid down by Thompson and Chambers (2012). As per the guidance set out by Thompson and Chambers (2012) it is imporant to be mindful of issues such as participants becoming distressed, power imbalances and discusses ethical issues in supervision as they arise. As the author is a trainee clinical psychologist, they have experience of exploring sensitive topics with patients, supporting people in distress and have received training in basic counselling skills such as being empathic, reflecting and summarising what the participant has shared. Participants were informed and multiple time points that the Dictaphone can be turned off and the interview stopped, including during instancies where emotive topics were being discussed. To address power imbalances, the author reminded the participants that they did not need to answer any question they did not wish to, informed them that they can ask the reasons why any particular quesitons are being asked and were asked at the end of the interview if they would like a summary of the findings (i.e. the preface) once the findings from the study were written up.

Moreover, further ethical issues may also arise when interviewing couples, particularly when they are interviewed separately. This study drew on the advice provided by Forbat and Henderson (2003) when designing the study. Interviewing couples raises a number of specific ethical issues such as partners having different reasons and expectations for participating, the interview with the second partner being influenced by what was discussed by the first partner, maintaining confidentiality between partners during interview and partners recognisising each others words once results are disseminated (Forbat & Henderson, 2003). In all but one dyad, couples were interviewed on the same day, straight after the other had been interviewed. This helped prevent the author being influenced by the initial partner’s response when interviewing the second person in the relationship. For the other dyad, they were interviewed a week apart. All transcripts were analysed separately, then themes from the participants with HS were collectively analysed, and then the themes from the partners before all data was analysed together. By not analysing the information from each couple together, the chances of a person in a relationship recognising their partner’s words were reduced. Furthermore, the author purposefully inserted the table with demographic information and DLQI scores in the appendices, rather than the main body of the thesis, to protect the confidentiality of the participants and reduce the likelihood of participants recognising their partners’ words.

Appendix eighteen – example of free-coding



a confusing time anyway.

makes sense

P1: And I was mid-teens and to be honest I thought it was normal, they weren't much bigger than little acne spots so I didn't get diagnosed for a while 'cause I just thought these things were normal. And then I actually saw the condition on 'Embarrassing Bodies' and I went to my GP the next day and he actually watched the same episode. And as soon as he looked at my skin, you know, he said it looked exactly like what was on TV and referred me to a dermatologist and that's how I sort of got diagnosed. But because my Mum has the condition, abscesses and things were very normalised for me. I didn't think anything of it until it really started effecting sort of my daily activities. It wasn't just a one off thing. That's why I went off and got medical help and that was 7..8 years after they started and at that point I was at Stage 2. I've now progressed onto Stage 3 and take adalimumabs but yeah the beginning was, it was a lot lesser obviously I was in an earlier stage and it weren't as bad, it weren't as deep in the skin and they didn't really scar either.

what's it like to see your normal body on this programme?

was that weird?

makes sense. where were the abscesses?

thought it was under control?

→ a shock?

what was that like

was it bad before?

less painful

scars impact her? what's it like to be covered in scars?

K: Thank you

P1: Yeah

K: And with umm, I don't know, in terms of my background I don't have a medical background. But how, what do the different kinds of stages mean?

P1: Stage one is when you sort of have one singular abscess, anywhere on your body. Stage two is when you're starting to get a little bit more in the same areas like clusters. And then stage 3 is where they all sort of connect underneath in sinus tracks and basically feed into one another, making them permanent basically. Sort of where one there and the little gap will close and as soon as that sort of starts to feel better it will go through the track into the next one and into the next one.

she knows her stuff.

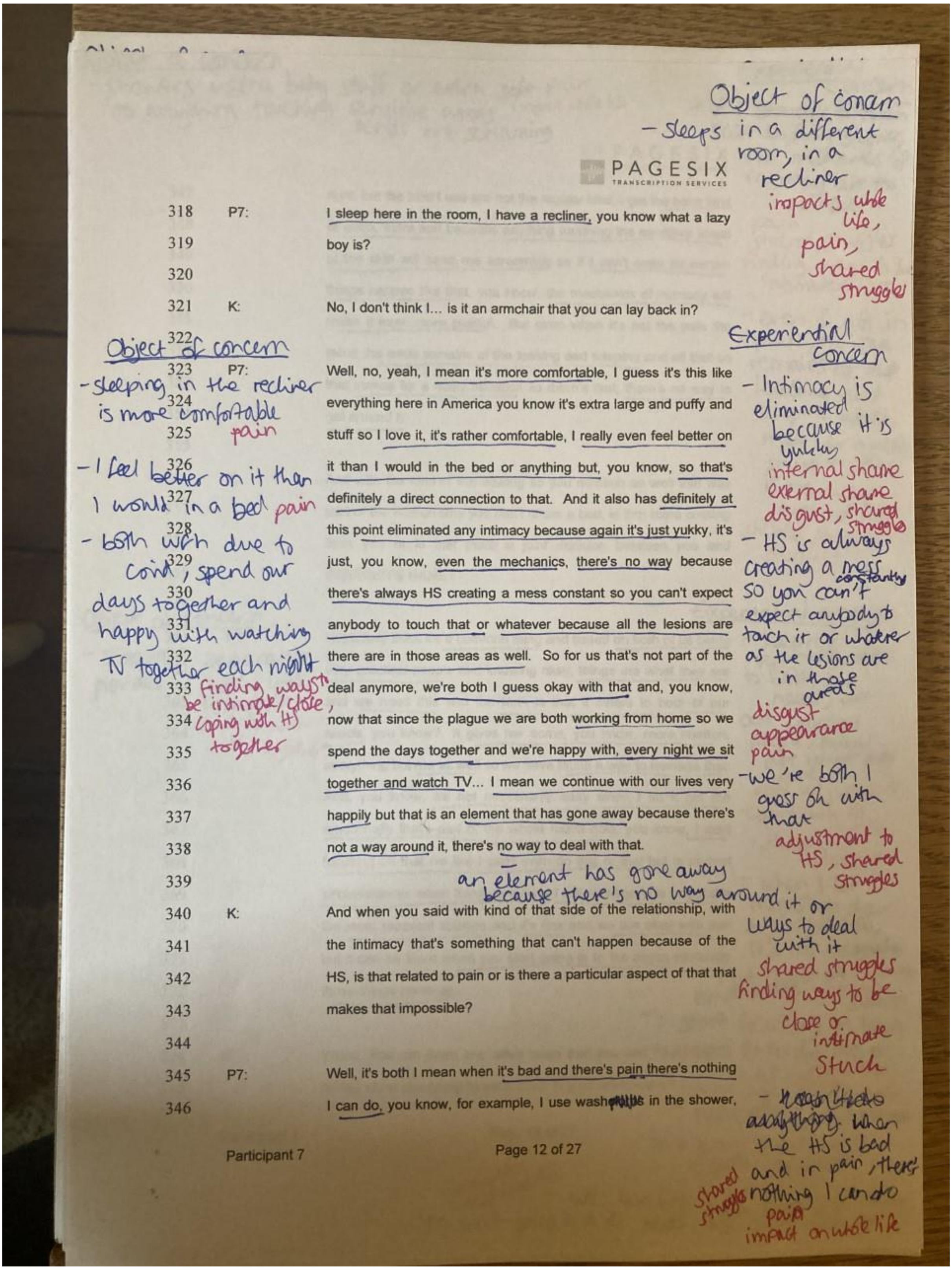
what was the transition from stage 1 → 2 then 2 – 3 like

no escape?

temporarily relief. knows her body. How does she feel seeing this?

K: Ok

Appendix nineteen – example of a line-by-line coding



Object of concern
- Sleeps in a different room, in a recliner
impacts whole life, pain, shared struggles

PAGESIX
TRANSCRIPTION SERVICES

P7: I sleep here in the room, I have a recliner, you know what a lazy boy is?

K: No, I don't think I... is it an armchair that you can lay back in?

P7: Well, no, yeah, I mean it's more comfortable, I guess it's this like everything here in America you know it's extra large and puffy and stuff so I love it, it's rather comfortable, I really even feel better on it than I would in the bed or anything but, you know, so that's definitely a direct connection to that. And it also has definitely at this point eliminated any intimacy because again it's just yukky, it's just, you know, even the mechanics, there's no way because there's always HS creating a mess constant so you can't expect anybody to touch that or whatever because all the lesions are there are in those areas as well. So for us that's not part of the deal anymore, we're both I guess okay with that and, you know, now that since the plague we are both working from home so we spend the days together and we're happy with, every night we sit together and watch TV... I mean we continue with our lives very happily but that is an element that has gone away because there's not a way around it, there's no way to deal with that.

an element has gone away because there's no way around it or ways to deal with it

K: And when you said with kind of that side of the relationship, with the intimacy that's something that can't happen because of the HS, is that related to pain or is there a particular aspect of that that makes that impossible?

P7: Well, it's both I mean when it's bad and there's pain there's nothing I can do, you know, for example, I use wash[illegible] in the shower,

Participant 7 Page 12 of 27

Object of concern
- sleeping in the recliner is more comfortable
pain
- I feel better on it than I would in a bed
pain
- both w[illegible] due to covid, spend our days together and happy with watching TV together each night
finding ways to be intimate/close, coping with HS together

Experiential concern
- Intimacy is eliminated because it is yukky
internal shame
external shame
disgust, shared struggles
- HS is always creating a mess constantly so you can't expect anybody to touch it or whatever as the lesions are in those areas
disgust
appearance
pain
- we're both I guess ok with that
adjustment to HS, shared struggles
shared struggles
finding ways to be close or intimate
Stuck
- [illegible] When the HS is bad and in pain, there's nothing I can do
shared struggles
pain
impact on whole life

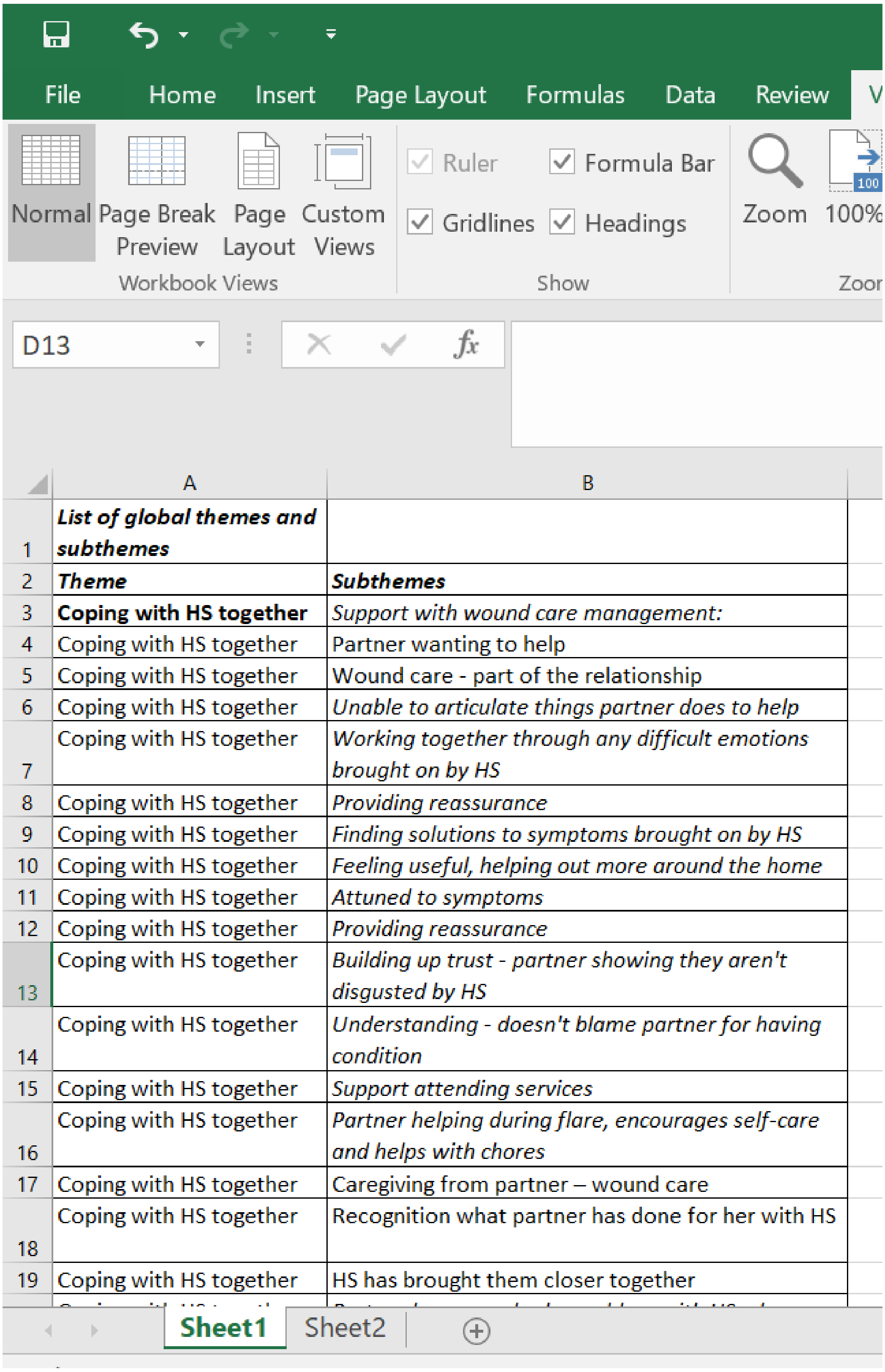
Appendix twenty – example of table with list of themes and subthemes

Themes and Quotes – Participant One

THEME (definition) and subthemes (where applicable)	**QUOTE (and line number)**
COPING WITH HS TOGETHER (Couples working together to manage the condition, felt from reading the data that the couple felt like a team working together)	*Support with wound care management:* With his help, the plaster is put on properly and not uncomfortable (257) I don't like others helping me (180) Puts my dressings on me and helps me clean up my skin and stuff (179) Seeks support from partner when struggling (253). Struggle putting on plasters on armpits on own (254) He (partner) helps me, he plays nurse (178) Putting on dressings was awkward at first but helps, part of our relationship (251-252) Partner wanting to help: He says he likes it as not much else he can do (249 - 250) Part of the relationship: Putting on dressings was awkward at first but helps, part of our relationship (251-252) *Unable to articulate things partner does to help:* He does [help], I just don't know how to put it into words (247) *Working together through any difficult emotions brought on by HS:* Talked about it since (223) *Providing reassurance:* Others may think it's weird, I feel calmed (239-240) Going out into cramped places, it helps (241) *Finding solutions to symptoms brought on by HS:* Eventually we made it work (pain)(290-291)
SHARED STRUGGLES (difficulties experienced by both members of the relationship)(the term shared was used as both members of the couple are having difficulties)(language may reflect KT not wanting to blame the patient for the other having difficulties)	*Emotional impacts of changes caused by HS:* We are both affected by HS and the change it causes (299) *Co-morbid conditions and their impact:* We both have BPD (268) Things get intense for us, very quickly (274) *Partner feeling emotionally impacted when she is tough on herself:* Talking down to myself internally impacts him (206) He doesn't like me berating myself (275) *Partner knows being hard on worsens her mental-health:* Trigger a full BPD episode, full of self-hatred (277) *Would want to help him if it was the other way round:* If I were him, I'd do all I can to help him when upset (279)

Appendix twenty-one – process of creating global structure with themes and subthemes

List of global themes and subthemes transferred onto an Excel spreadsheet

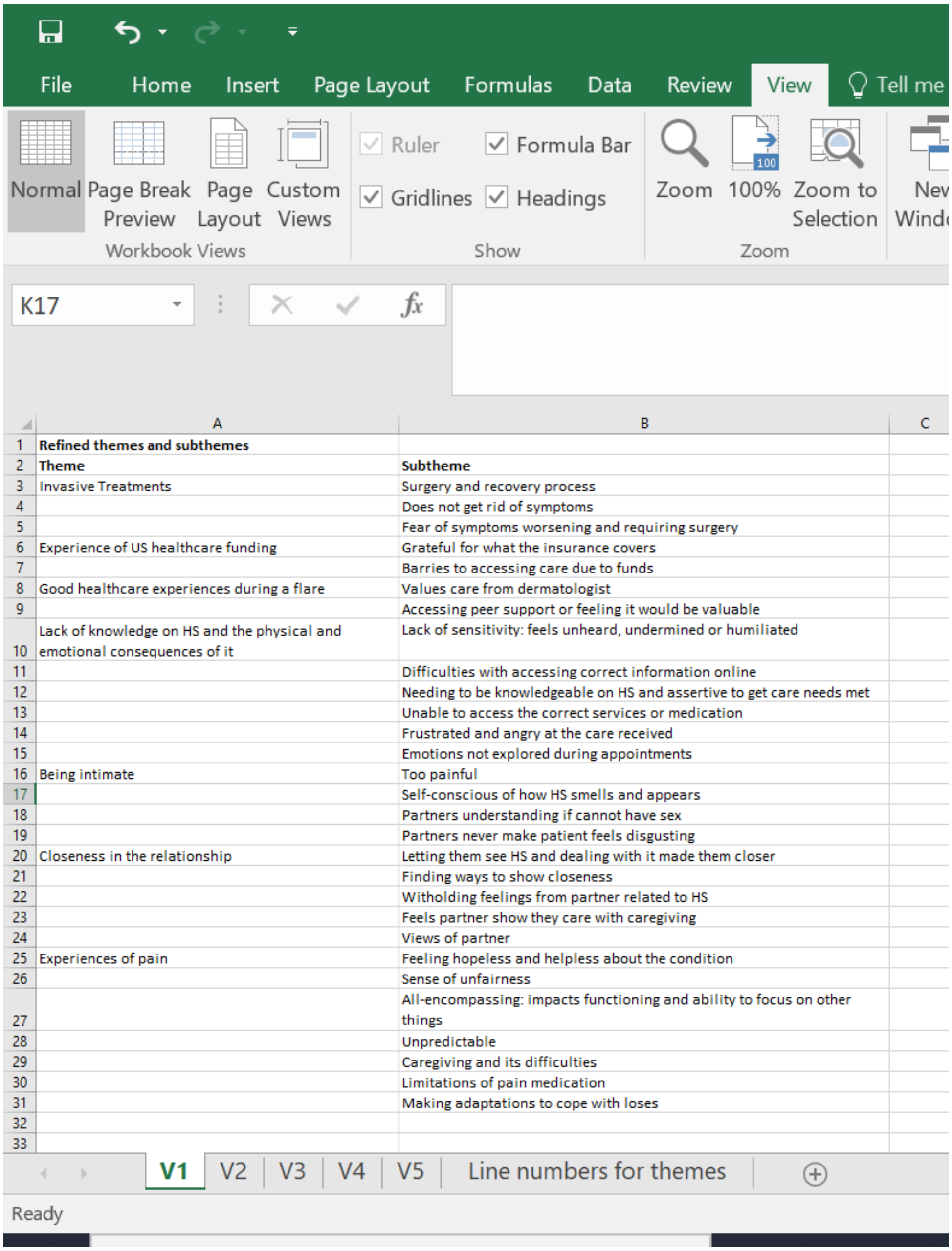


	A	B
1	***List of global themes and subthemes***	
2	***Theme***	***Subthemes***
3	**Coping with HS together**	*Support with wound care management:*
4	Coping with HS together	Partner wanting to help
5	Coping with HS together	Wound care - part of the relationship
6	Coping with HS together	*Unable to articulate things partner does to help*
7	Coping with HS together	*Working together through any difficult emotions brought on by HS*
8	Coping with HS together	*Providing reassurance*
9	Coping with HS together	*Finding solutions to symptoms brought on by HS*
10	Coping with HS together	*Feeling useful, helping out more around the home*
11	Coping with HS together	*Attuned to symptoms*
12	Coping with HS together	*Providing reassurance*
13	Coping with HS together	*Building up trust - partner showing they aren't disgusted by HS*
14	Coping with HS together	*Understanding - doesn't blame partner for having condition*
15	Coping with HS together	*Support attending services*
16	Coping with HS together	*Partner helping during flare, encourages self-care and helps with chores*
17	Coping with HS together	Caregiving from partner – wound care
18	Coping with HS together	Recognition what partner has done for her with HS
19	Coping with HS together	HS has brought them closer together

All the of themes and subthemes were cut out to create a global structure

Appendix twenty-two – process of refining themes and identifying superordinate and subthemes

Initial list of superordinate and subthemes after creating a global structure



	A	B	C
1	**Refined themes and subthemes**		
2	**Theme**	**Subtheme**	
3	Invasive Treatments	Surgery and recovery process	
4		Does not get rid of symptoms	
5		Fear of symptoms worsening and requiring surgery	
6	Experience of US healthcare funding	Grateful for what the insurance covers	
7		Barries to accessing care due to funds	
8	Good healthcare experiences during a flare	Values care from dermatologist	
9		Accessing peer support or feeling it would be valuable	
10	Lack of knowledge on HS and the physical and emotional consequences of it	Lack of sensitivity: feels unheard, undermined or humiliated	
11		Difficulties with accessing correct information online	
12		Needing to be knowledgeable on HS and assertive to get care needs met	
13		Unable to access the correct services or medication	
14		Frustrated and angry at the care received	
15		Emotions not explored during appointments	
16	Being intimate	Too painful	
17		Self-conscious of how HS smells and appears	
18		Partners understanding if cannot have sex	
19		Partners never make patient feels disgusting	
20	Closeness in the relationship	Letting them see HS and dealing with it made them closer	
21		Finding ways to show closeness	
22		Witholding feelings from partner related to HS	
23		Feels partner show they care with caregiving	
24		Views of partner	
25	Experiences of pain	Feeling hopeless and helpless about the condition	
26		Sense of unfairness	
27		All-encompassing: impacts functioning and ability to focus on other things	
28		Unpredictable	
29		Caregiving and its difficulties	
30		Limitations of pain medication	
31		Making adaptations to cope with loses	
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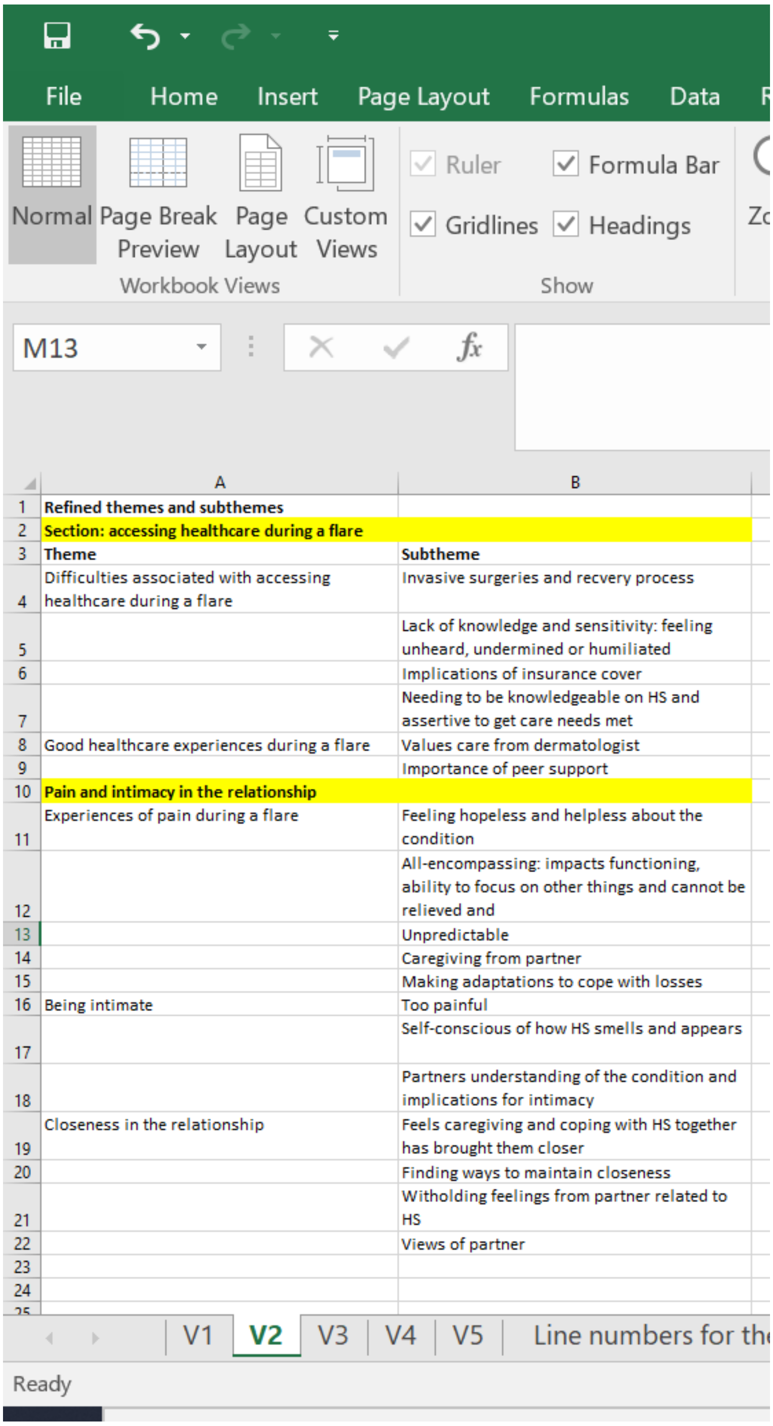
Themes were collapsed into each other when refining the superordinate themes and subthemes



	A	B
1	**Refined themes and subthemes**	
2	**Section: accessing healthcare during a flare**	
3	**Theme**	**Subtheme**
4	Difficulties associated with accessing healthcare during a flare	Invasive surgeries and recvery process
5		Lack of knowledge and sensitivity: feeling unheard, undermined or humiliated
6		Implications of insurance cover
7		Needing to be knowledgeable on HS and assertive to get care needs met
8	Good healthcare experiences during a flare	Values care from dermatologist
9		Importance of peer support
10	**Pain and intimacy in the relationship**	
11	Experiences of pain during a flare	Feeling hopeless and helpless about the condition
12		All-encompassing: impacts functioning, ability to focus on other things and cannot be relieved and
13		Unpredictable
14		Caregiving from partner
15		Making adaptations to cope with losses
16	Being intimate	Too painful
17		Self-conscious of how HS smells and appears
18		Partners understanding of the condition and implications for intimacy
19	Closeness in the relationship	Feels caregiving and coping with HS together has brought them closer
20		Finding ways to maintain closeness
21		Witholding feelings from partner related to HS
22		Views of partner
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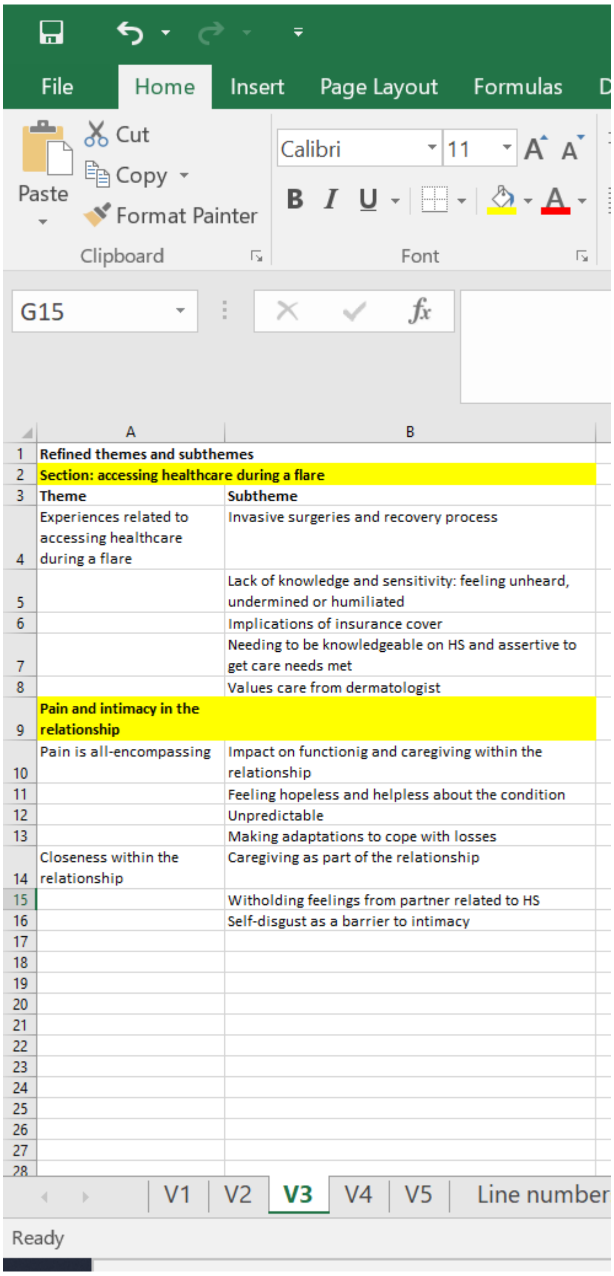
Themes were further collapsed into each other when refining the superordinate themes and subthemes



	A	B
1	**Refined themes and subthemes**	
2	**Section: accessing healthcare during a flare**	
3	**Theme**	**Subtheme**
4	Experiences related to accessing healthcare during a flare	Invasive surgeries and recovery process
5		Lack of knowledge and sensitivity: feeling unheard, undermined or humiliated
6		Implications of insurance cover
7		Needing to be knowledgeable on HS and assertive to get care needs met
8		Values care from dermatologist
9	**Pain and intimacy in the relationship**	
10	Pain is all-encompassing	Impact on functionig and caregiving within the relationship
11		Feeling hopeless and helpless about the condition
12		Unpredictable
13		Making adaptations to cope with losses
14	Closeness within the relationship	Caregiving as part of the relationship
15		Witholding feelings from partner related to HS
16		Self-disgust as a barrier to intimacy
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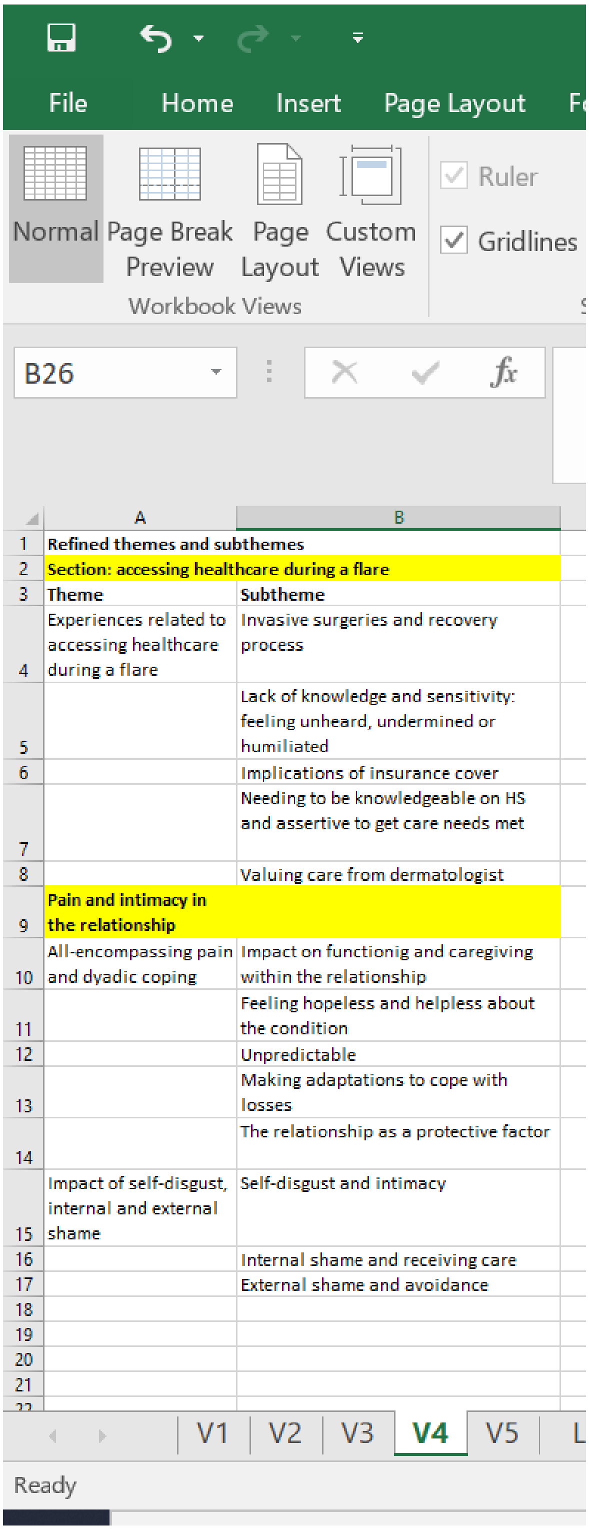
Themes were collapsed into each other when refining the superordinate themes and subthemes with interpretation added



	A	B
1	**Refined themes and subthemes**	
2	**Section: accessing healthcare during a flare**	
3	**Theme**	**Subtheme**
4	Experiences related to accessing healthcare during a flare	Invasive surgeries and recovery process
5		Lack of knowledge and sensitivity: feeling unheard, undermined or humiliated
6		Implications of insurance cover
7		Needing to be knowledgeable on HS and assertive to get care needs met
8		Valuing care from dermatologist
9	**Pain and intimacy in the relationship**	
10	All-encompassing pain and dyadic coping	Impact on functionig and caregiving within the relationship
11		Feeling hopeless and helpless about the condition
12		Unpredictable
13		Making adaptations to cope with losses
14		The relationship as a protective factor
15	Impact of self-disgust, internal and external shame	Self-disgust and intimacy
16		Internal shame and receiving care
17		External shame and avoidance
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Appendix twenty-three – examples of reflexivity

Reflections after liaising with HS Connect who agreed to advertise the study

Everyone seems so touched by the study and the organisation are really excited. They've mentioned never seeing a study like it. I can't help but feel like a fraud. HS is so important to so many people, yet this study is part of my doctorate, helping me. I really want to do it well and get it published for the HS community. I hadn't heard of HS until recently but the condition really does seem to be consuming. I remember when writing the LSRP proposal, a paper identified it as being the most distressing dermatological condition, I can completely see why from what I've read about it so far and speaking to the expert by experience.

Reflections in journal regarding an interview with a partner

He really loves her. You can tell how much he thinks the world of her and just wants his wife to be happy and comfortable. He really admires his wife and recognises how knowledgeable she is on HS.

He used the word frustrating a lot, a wonder if that is because it is more socially accepted than anger?

His wife has so much shame yet he seems so accepting and loving. I wonder what the experience would be like for someone with HS whose partner isn't like this.

Reflections in journal regarding an interview with a patient

I feel quite tired doing the interview after driving from placement. Part of me hoped he would cancel but when he said he was looking forward to the interview and it was important for me to stay focussed as he was very generously giving me his time and words.

He seems really depressed and hopeless. HS really does seem to impact his whole life. I feel quite sad from meeting him and hearing what his experiences are like. It was hard hearing the he sleeps in the living room as his bed is too painful and he doesn't want to disturb his wife.

He seems to have better healthcare than other patients in the study so far. I wonder if that is a reflection on how severe his symptoms are.

I wonder if the HS impacts the relationships with his daughter, he didn't really mention that.

During the debrief, he spoke of finding some topics hard to discuss. I hope he didn't feel pressured to discuss information. I had told him at the start that he didn't but I'm conscious of a perceived power imbalance. I wouldn't ever want to upset anyone.

Appendix twenty-four – audit checklist for quality control

Audit checklist for quality control

1) Is there evidence of free-coding for every transcript?
Yes/Partially/No

2) Is there evidence of line-by-line coding for every transcript?
Yes/Partially No

3) Is there evidence of reflexivity?
Yes/Partially/No

4) Is there evidence of a systematic process where the themes have been refined and redefined?
Yes/Partially/No

5) Has the data been coded consistently? (by looking at a random selection of excerpts from transcripts and codes the quotes have been given)
Yes/Partially/No

6) Do the quotes adequately provide evidence for the superordinate and subthemes?
Yes/Partially/No

Appendix twenty-five – further examples of quotes from themes

Theme	**Subtheme**	**Example of quote**
Being unheard: a frustrating journey to receiving care	Invasive procedures and recovery process	*"Just under my arm she said probably, eventually, I'll need to have an operation but when you look at the operation it's quite horrific what they have to do so that's always at the back of your mind as well" (patient)* *"I've recently had a whole track removed in my armpit. The scarring is quite bad at the minute and ironically I've now got abscesses on top of the scar. Which means they're now going to have to be removed so it's more surgery" (patient)*
	Lack of knowledge and sensitivity: feeling unheard, undermined and humiliated	*"You wouldn't believe the lengths I would have to go to to convince them I'm not breastfeeding and it's not mastitis. Because I've never had a child" (patient)* *"Doctors are more than willing to go "oh are you an addict?" but they don't actually listen to the pain that you are in and understand why you are in pain" (partner)* *"Some people just kind of recoil and like 'oh that must be horrible'" (partner)*
	Implications of insurance cover	*"They will fight on what they want to cover or not" (patient)* *"I got very fortunate that my insurance changed a few months before" (patient)*
	Needing to be knowledgeable on HS and assertive to get care needs met	*"And there were about seven doctors that ran all excited wanting to pop the abscess. Just there's nothing about that that's okay. Nothing about that that's okay. Thank God I'm experienced enough and I'm strong enough to stand up for myself" (patient)*

	Valuing care from dermatologist or care team	*“The dermatologist is the only one that I will go to for anything related to HS because he’s the only one that I don’t feel gross around” (patient)* *“Her General Practitioner and a surgeon and a* PA [Physician Associate] that really works with her good *and believes what she is saying” (partner)* *“So it’s relieving and then it’s less of a mental burden of trying to keep everything together, keep track of everything that’s going on and making sure we’re getting the best treatment possible” (partner)*
Relational burden and dyadic coping	Impact on functioning and caregiving within the relationship	*““Sit on the couch, I’ll look after you today, not a problem, do you need any bandages changing?” That’s fine” (partner)*
	Feeling hopeless and helpless	*“I wish I could take his pain away from him” (partner)* *“But the pain is probably an 8 or 9 and there’s nothing really you can do for it” (patient)* *“Nothing controls the pain very well, even though I see a pain specialist” (patient)* *“I think that’s the real hard part of it is the understanding there is and to feel you can never feel happy”* (partner)
	Unpredictable	*“My skin can change in a matter of two hours, I can have a flare up and a massive abscess that just wasn’t there an hour or two ago” (patient)* *“And he was angry and he was upset that we missed the concert but there was frustration…” (partner)* *“We can’t really plan much of anything because, no, it could be.. 24 hours could be a total difference between that morning and that night” (partner)*

	"We tried for a while and it became something that was kind of frustrating because he wasn't comfortable and he couldn't last very long so we kind of felt like we had wasted our money" (partner)
Making adaptations to cope with losses	*"Like "oh", you know, like resting my hand on her thigh or something like that so it's like suddenly I would pull my hand back or I would move it in an awkward position that was very unnatural" (partner)* *"So we're all sitting together, because if I sit at the other…on the other chair, it feels like I'm distancing myself and I don't want that" (partner)* *"Well, we are the best of friends" (patient)* *"We talk all the time, we're in the house together and we text, we chat, we Facetime so we're very connected and I'm grateful for that" (partner)* *"We do a lot more, you know, if we're going to do something together, watch a movie, we order in and do it here" (patient)*
Anger and a sense of unfairness	*"You think "oh wow, this is a lot" and it's one of those things where it's hard to see someone you care about have more and more mental load from stuff they've can't necessarily control" (partner)*
The relationship as a protective factor	*"I think if I was on my own I would have a lot worse feelings about it than I do" (partner)*
Guilt due to the condition	*"I do feel guilt and sometimes I feel that I'm holding them back a little bit if I can't do something or I don't want to do something or we have to change our plans really quickly" (patient)*

Self-disgust and self-consciousness	Self-disgust, internal shame and intimacy	*"At the start it was quite a big thing. It was more about her self-confidence than anything. She wouldn't feel comfortable showing her body to me"* (partner) *"I don't think my partner is as self-conscious about it or at least she doesn't show being as self-*conscious *about it" (partner)* *"I know my buttocks has a lot of abscesses and that'll just enter my mind out of nowhere and suddenly I don't want to be having sex anymore" (patient)* *"It makes me not want to be naked ever" (patient)*
	External shame and avoidance	*"No one can smell it. No one can even see it because it's bandaged and you're saying you stink. You're fine. I'm fine" (partner)* *"I'm always conscious when you're out and about if my wound was leaking, even though you can't, you just worry that it smells or that people will know what you've got or can see your dressings, that type of thing"* *(patient)*
	Peer support as a buffer for internal shame	*"I think it would be quite good to meet other people with HS and maybe feel a bit more normal about things"* *(patient)*