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Furthering understanding of the lived experience of hyperemesis gravidarum: A meta-ethnography of qualitative research focused on first-hand experience and an interpretative phenomenological analysis of first hyperemesis gravidarum experiences

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Contents

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Thesis Portfolio Abstract

Background: Hyperemesis gravidarum (HG) is a rare complication of pregnancy involving severe nausea and/or vomiting, having a profound physiological, psychological, social, and occupational impact on the individual. This thesis aims to improve understanding of HG by studying lived experiences so that services can be designed to provide effective care and support.

Aim: The first chapter of this thesis consists of a systematic review and meta-ethnography seeking to explore and synthesise the existing published qualitative research drawing on perspectives of those with lived experience of HG. The second chapter comprises of an interpretative phenomenological analysis (IPA) focused on first encounters with HG and what others contribute to that lived experience.

Methods: For the systematic review, an updated version of Noblit and Hare's (1988) seven-step approach to meta-ethnography was utilised. MEDLINE, PsycINFO, Embase, CINAHL, and ProQuest were searched electronically. The Critical Appraisal Skills Programme checklist was utilised for quality appraisal. For the empirical project, lived experiences of HG were explored using IPA. Eight women were recruited via social media. Video interviews were performed remotely and transcribed verbatim.

Results: The meta-ethnography included synthesis of twelve qualitative studies. Three main themes emerged: "…one of the hardest things I have ever gone through"; 'Trying to make sense'; and 'What does and doesn't help?' The IPA included an overarching theme; 'Journey to understanding', which encapsulated four main themes: "What's wrong with me?", '(How) Can we get through this?', 'What others bring to the HG experience', and 'Looking back, looking ahead'.

Conclusion: This thesis contributes to the existing literature by deepening understanding of HG and highlighting that individuals lacking an illness prototype are more vulnerable to dismissive

and misinformed interactions which can contribute to self-blame and isolation. The severe, multifaceted impact of HG was highlighted and explored in depth, demonstrating a need for understanding and support from professionals and individual support networks. Existing HG research has contributed to a partial understanding of the phenomena and has informed guidelines; however, the IPA findings suggest said guidelines are not being uniformly implemented. Roles for clinical psychologists are proposed to support with the psychological impact during and after HG experiences and with the development of psychologically informed services. Suggestions for future research and clinical improvements follow based on the meta-ethnography and IPA.

Thesis Portfolio Lay Summary

Hyperemesis gravidarum (HG) is a severe form of morning sickness which can last up to the whole pregnancy for up to 3 out of every 100 pregnancies. The condition is overwhelming and affects every area of the pregnant person's life and can also impact greatly on their family and others around them. There are health risks to both the pregnant individual and the child exposed to HG during pregnancy, which can be fatal in rare instances. Because most have heard of morning sickness but not HG, trying to figure out why symptoms are so severe can be confusing. Others are similarly unaware of HG, so speaking to partners, family, friends, employers, and even health professionals can be difficult as many assume it is morning sickness and not something more serious and disabling. Individuals with HG can become isolated and often have complicated experiences with health services in terms of having their condition recognised then treated appropriately. Some struggle so much that they terminate pregnancies they had wanted or decide they won't have any more children for fear of having HG again. Many report a significant mental health impact during and after their HG experiences. Some research has been done but there are lots of unanswered questions about HG and room for health services to improve.

A systematic review and meta-ethnography were completed to find out what research had already been done which focused on the views of individuals who have suffered through HG and to see whether extra insight could be gained from comparing this previous work. This involved completing a thorough online search for published work focusing on individual experiences of HG, then checking the quality of the twelve pieces of research which were found. Three main broad topics were found, the first highlighting how varied and overwhelming the impact of HG is, the next about how people try to understand what's happening to them, and the last about what people find helpful and unhelpful. The review showed that the most vulnerable to the worst experiences were those without previous awareness of HG because they were more confused themselves and they were more easily influenced by others (often for the worse).

Compassionate, understanding support from others seemed valuable, as did access to peer-support if possible. Recommendations were made for more research and improvements to clinical practice.

An original study was also carried out using a type of research called interpretative phenomenological analysis (IPA). This involved the researcher doing online video interviews with eight women found through social media about their first experiences of HG. At the broadest level, it seemed clear the women all went through a journey of developing understanding of what was happening as they went through their HG experiences. Other broad topics included dealing with the initial shock of the range of symptoms HG includes, trying to figure out if it's going to be possible to get through the pregnancy, how other people contribute to the experience, and what it's like to look back on HG and consider the future when the pregnancy finishes. The IPA helped understand more about first experiences of HG and some of the ways healthcare experiences could be better.

Journal Article 1: Systematic Review

What helps or hinders during experiences of hyperemesis gravidarum? A systematic review and meta-ethnography of women's perspectives

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Abstract

Background: Hyperemesis gravidarum is a rare complication of pregnancy involving severe nausea and/or vomiting, having a profound physiological, psychological, social, and occupational impact on the individual. More must be understood about the lived experience of hyperemesis gravidarum so that services can be designed to provide effective care and support. Research on lived experiences of hyperemesis gravidarum has been sporadic and of varying quality despite the high level of need.

Aim: This systematic review and meta-ethnography sought to synthesise research relating to individuals' hyperemesis gravidarum experiences to build towards a comprehensive understanding of the phenomenon.

Methods: An updated version of Noblit and Hare's (1988) seven-step approach to meta-ethnography was utilised to systematically seek then synthesise qualitative studies focused on experiences of individuals with hyperemesis gravidarum. MEDLINE, PsycINFO, Embase, CINAHL, and ProQuest were searched electronically. The Critical Appraisal Skills Programme checklist was utilised for quality appraisal.

Results: The final sample included twelve qualitative studies. Three main themes emerged: "…one of the hardest things I have ever gone through"; 'Trying to make sense'; and 'What does and doesn't help?'

Conclusion: This synthesis highlights that individuals lacking an illness prototype for hyperemesis gravidarum are more vulnerable to dismissive and misinformed interactions which can contribute to self-blame and isolation. The severe, multifaceted impact of hyperemesis gravidarum was highlighted and explored in depth, demonstrating a need for understanding and

support from professionals and individual support networks. The influence of others on dynamic sense-making throughout highlights why social influence can be positive or negative. Research and clinical implications are discussed in the context of the review's results and limitations.

Keywords: Hyperemesis gravidarum, HG, Nausea and vomiting of pregnancy, Meta-ethnography, Women's experiences, Qualitative, Systematic review, Pregnancy sickness, Perinatal mental health, Women's health, Complications of pregnancy

Introduction

Some degree of nausea and vomiting of pregnancy (NVP), or what is often referred to as 'morning sickness', is reported as affecting up to 70% of pregnant individuals during the initial trimester [1]. Between 0.3-3.6% of pregnant individuals are afflicted by a severe form of NVP known as hyperemesis gravidarum (HG), the research on which has highlighted profound physiological, psychological and social impact [2]. Building a comprehensive research literature on HG has been a challenge due to variations in how it has been defined diagnostically internationally [3]. This task will hopefully be made easier now that a multi-national collaboration has arrived at the Windsor Definition, which defines HG as beginning within the 1st 16 weeks of pregnancy, involves severe levels of vomiting and/or nausea, being unable to drink and/or eat normally, and interferes with the ability to perform normal daily behaviours [3]. Alongside what is listed in the diagnostic criteria, potentially fatal health outcomes for the pregnant individual include refeeding syndrome brought on due to difficulties in how one regains nutrition following an episode of malnourishment [4, 5] and Wernicke's encephalopathy related to thiamine deficiency [6]. There is also evidence of HG impacting the child exposed to HG during pregnancy in ways which could inform development and outcomes in later life [7], including increased risk of lower birth weight, being born small for gestational age, and prematurity [4]. A recent review of child health outcomes advised caution due to the quality of evidence, but listed slightly increased rates of neurodevelopmental disorders, mental health presentations and testicular cancer [8].

There are several aetiological theories relating to HG in contemporary research including features relating to hormones, immunology, genetics and infective factors [1, 9, 10]. Prior to the emergence of these more recent theories, there has been a legacy of suggested psychosomatic causation contextualising HG as being linked to hysteria [11] or as a neurotic conversion disorder [12]. When subject to scrutiny in more recent reviews, the evidence in support of psychogenic causality of HG has been found to be lacking in empirical rigour [13, 14]. Despite this, there is

evidence that these less well-founded aetiological theories are still influential and present in some accounts of individuals trying to access medical care and support when suffering from HG, suggesting updates in the research literature have not filtered into wider awareness uniformly [15]. Contributors to the area of HG research such as Munch [14] have theorised that this could be an example of gender bias in women's health related medical research, as it has been highlighted by other researchers that after psychogenic causation has been mooted, it can be very persistent [16].

Gradual progress appears to be being made in terms of healthcare providers such as the National Health Service (NHS) having access to recently updated guidelines such as those originally published in 2016 by the Royal College of Obstetrics and Gynaecology [17]. These guidelines are noteworthy for acknowledging the psychological impact of HG as well as the importance of psychologically informed care. The guidelines also advise consideration of signposting to peer support or referral to specialist mental health services if appropriate. The organisation was also careful to demonstrate an awareness of the aforementioned aetiological history by stating their mental health recommendations are an acknowledgement that these difficulties often arise not as a cause of HG, but as a consequence. The recommendations are contextualised by citing research which has found higher levels of post-traumatic stress symptoms [18], greater rates of psychological distress and depression compared to non-HG expectant mothers as well as greater levels of somatisation [19]. Rates of both anxiety and depression were found to be higher in those with HG [20] and research would suggest the psychological impact can continue after birth [21].

Further hope can be taken from the more active acknowledgement of mental health needs in the perinatal period by the Scottish Government [22] via strategic funding commitments. Investment in research and improved healthcare standards for those suffering from HG also seems logical from an economic standpoint, as the impact of NVP in general has been estimated at over £62m

annually [23]. Figures specific to what proportion of those estimated costs are attributable to HG are not given within that article, however as HG is a severe form of NVP and is characterised by higher rates of hospitalisation and disruption to work attendance it is likely they would account for a disproportionate amount of economic impact relative to those with lesser NVP severity. Higher rates of negative outcomes linked to HG such as termination of wanted pregnancies, suicidal ideation, depression, and anxiety have been highlighted in those with negative experiences of engagement with medical staff [15, 24]. An action research study captured perspectives from the providers of medical care to patients presenting with HG as well as HG patients. The former included themes such as attributing psychosocial causation to symptoms, scepticism about symptom severity and querying the validity of hospitalisation of those with HG, while the latter included feeling unpopular with healthcare staff and undeserving of medical care [25]. Further research exploring why healthcare staff hold these views would be beneficial to understanding whether this is the result of a lack of up-to-date HG knowledge.

A previous systematic review on qualitative studies on varying severities of NVP certainly highlighted a need for further high-quality research in this area, but did not focus exclusively on HG or on the perspectives of those with HG [26]. Recommendations included attending more deliberately to geographic and socioeconomic diversity and exploring how HG affects different groups, such as those with children to look after already. The most prominent psychosocial themes included social isolation; suicidal ideation, termination of pregnancy; a sense of dying; difficulties caring for self and others; and psychological difficulties. These psychological difficulties included guilt, loss of self, depression, and anxiety. A need to take time off work and changing plans to have more children were also highlighted as subthemes [26]. One reviewed paper also highlighted that their sample included instances in which occupational difficulties had led to job loss and relationship strain had resulted in divorce [15]. Future research would benefit from actively exploring occupational expectations and impact in relation to HG.

The present review seeks to address the research gap of there not having been a systematic review of qualitative studies exclusively focused on HG. A review focused solely on HG from the perspective of the pregnant individual provides an opportunity to tap into unique aspects of living through this condition that help distinguish it from milder forms of NVP. The impact of HG is clearly significant on the individual, their family, and the wider systems they interact with, and so to try to make this review as helpful as possible in terms of informing policy from a qualitative perspective, the questions of 'What is experienced as easing burden whilst living with HG?' and 'What is experienced as increasing burden whilst living with HG?' will be held in mind.

Methodology

The guidelines provided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and Meta-ethnography Reporting Guidance (eMERGe) were consulted for this review [27, 28]. The methodology of meta-ethnography was felt to be well suited to this task as it provides the opportunity to go beyond the conclusions of the source papers, whilst still grounding conclusions in the original data [29]. The review was registered with the International Prospective Register of Systematic Reviews (PROSPERO) on 10th July 2023 (Registration number: CRD42023442017).

An updated version of Noblit and Hare's [30] seven-step approach to meta-ethnography was utilised [29, 30]. These steps included: 1) getting started; 2) deciding what is relevant to the initial interest; 3) reading the studies and extracting data; 4) determining how the studies are related; 5) translating the studies into each other; 6) synthesising the translations; and 7) expressing the synthesis [30]. The updated version includes greater detail for steps 4-6 as these have previously been described as the most difficult to perform and with least guidance available [29].

Efforts to perform the meta-ethnography in as standardised a fashion as possible were taken to address the common critique that this methodology has historically been inconsistently applied [31]. This was done by consulting the eMERGe guidelines and Sattar and colleagues' [29] updated seven-step process.

Search strategy and process

On 10th July 2023, MEDLINE, PsycINFO, Embase, CINAHL, and ProQuest were searched electronically. Manual reference and citation list checks were also conducted of relevant studies between 10th July and 14th August 2023. The search was repeated on 19th January 2024 prior to analysis. The search terms shown in Table 1 were developed by recording the various keywords

and synonyms used throughout references as they were discovered in addition to MeSH terms until no novel terms were being discovered.

Table 1 - Search Terms

HG Synonyms	Qualitative Synonyms
"hyperemesis"	"experience*"
"severe nause*...pregnan*"	"attitude*"
"severe vomit*...pregnan*"	"perception*"
"severe morning sickness"	"belief*"
"pernicious vomit*...pregnan*"	"perspective*"
"pernicious nausea*...pregnan*"	"quality of life"
"intractable vomit*...pregnan*"	"psychosocial aspects"
"intractable nausea*...pregnan*"	"preference*"
	"thematic analysis"
	"qualitative"
	"grounded theor*"
	"phenomenological"
	"satisfaction"

Inclusion and exclusion criteria

The present systematic review included studies which satisfied the following criteria: 1) utilised a primarily qualitative methodology; 2) focused on the experience of HG; 3) included qualitative data from individuals with first-hand experience of actively suffering or having suffered HG; 4) published in a peer-reviewed journal; 5) based on qualitative analysis of primary data; 6) published in English. Having consulted an expert in the field of HG, severe nausea and vomiting of pregnancy was accepted as a synonym for HG when searching for appropriate literature.

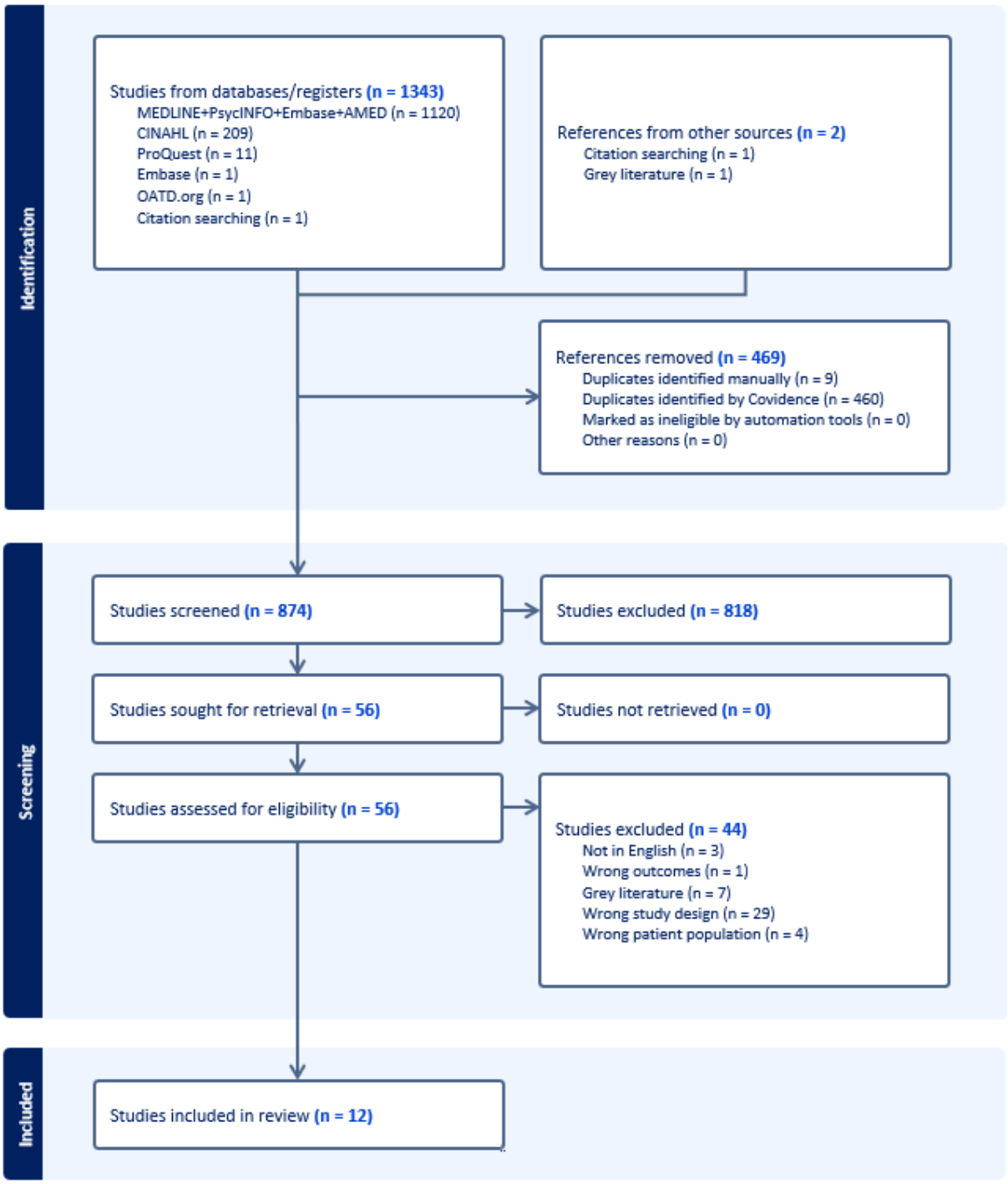
The review excluded studies if: 1) data related to the first-hand experience of HG was not explicitly reported on; 2) others' perspectives are the primary focus of the study (e.g., partners or healthcare staff); 3) severity of nausea and vomiting of pregnancy does not meet threshold for HG (e.g., mild or moderate NVP); 4) quantitative or mixed methodologies were used; 5) secondary analysis was the focus (e.g., reviews); and 6) they were not published in a peer reviewed journal (e.g., dissertations).

Study selection process and outcome

A flowchart describing the study selection process was included in accordance with PRISMA guidelines (Fig 1) [27]. 'Covidence', an online systematic review management tool was utilised throughout the study selection process. From the number of studies returned from search (N=1343), duplicates were removed (N=469), leaving the titles and abstracts of the remainder (N=874) to be screened against the inclusion and exclusion criteria of the review. The lead researcher (NM) screened all titles and abstracts whilst a second reviewer (JK) screened just over 20% (N=198). Disagreements regarding screening outcome were resolved via discussion and more detailed consultation of the inclusion and exclusion criteria. Based on titles and abstracts, studies which did not meet inclusion criteria or ran afoul of exclusion criteria (N=818) were deemed irrelevant to the review.

Full texts of the remaining studies (N=56) were then screened by the lead researcher, once again using the review's inclusion and exclusion criteria. A total of forty-four studies were excluded at this stage: twenty-nine were not the sought-after study design; four were not focused solely on those with first-hand HG experience; three were not published in English; one was not exclusively focused on the experience of HG; and seven were classified as grey literature. The grey literature included a mixture of theses and articles from publications without peer-review processes in place. These were excluded partly to ensure quality in case of articles not subject to peer-review, but also because some thesis data was analysed in the form of subsequent peer-reviewed publications included in the review. One further paper meeting the review criteria was found to have been published between the original literature search and when the database search was repeated in January 2024, which was added to the previously identified papers for review.

Fig 1 - PRISMA Flowchart of Study Selection Process *[27]*



Quality appraisal process

Several quality appraisal tools were considered: Evaluation Tool for Qualitative Studies [33], Critical Appraisal Skills Programme (CASP) [34], Walsh and Downe's checklist [35], and the Joanna Briggs Institute checklist for Qualitative Research [36]. Based on its relative ease of use,

recognition within qualitative evidence synthesis literature, the experience level of the reviewer, and focus on relevance, the CASP checklist was selected.

The subjective nature of quality appraisal in qualitative evidence synthesis is well documented, as is the question of benefit to the overall process [37]. In addition to a lack of consensus on how to apply the available tools, there are also a great many overlapping tools to choose from [35]. Somewhat akin to the post-hoc sensitivity analyses described by Carroll and Booth [37], rather than potentially exclude qualitative studies based on their quality, relative contributions, to the overall analysis, of studies of varying 'quality' will be discussed.

Reading and data extraction approach

All papers were read at least twice in full by the lead reviewer, with notes taken throughout. Various descriptive data was gathered informed by the Cochrane Collaboration Qualitative Methods Group guidelines [38]. This data included the authors, year of publication, location of sample, study aim, sample characteristics (such as age range), number in sample, specified methodology (e.g. thematic analysis, interpretative phenomenological analysis), data collection method (e.g. focus group, interview), and key themes. NVivo was used to organise the extraction of themes and accompanying first- and second-order constructs from the data within each included paper. Distinctions between first-, second- and third-order constructs are outlined in Table 2.

Table 2 - Key Terms

Key Term	Definition
First-order Construct	Accounts and interpretations from individuals about their experiences of HG
Second-order Construct	Authors' analysis and interpretations of individuals' accounts and interpretations of their experiences of HG
Third-order Construct	Qualitative evidence synthesis authors' views based on analysis and interpretations of the first- and second-order constructs

Determining how the studies are related

Guided by Sattar's [29] updated meta-ethnography steps, a list of themes mentioned in each of the included papers was made. This made it easier to deduce where the studies under review differed or shared findings and conclusions. Categories were created to organise similar themes. The descriptive features of the papers were also considered throughout this process so that it was possible to comment on whether differing settings appeared to alter findings. All efforts to organise and categorise the data were conducted iteratively and with regular reference back to the source material from the included papers, in keeping with the original and updated meta-ethnography guidance [29, 30].

Process of translating studies

This is one of the steps in Noblit and Hare's original [30] guidance which Sattar [29] set out to elaborate on in her updated guidance. The included papers were organised chronologically, then the main themes from the earliest published paper [39] were outlined with care to acknowledge the context this study was conducted in [29]. Paper 2 [40] was then subjected to the same process, whilst also mentioning the ways it was similar or different to the first paper. This process was repeated sequentially until a full synthesis of all primary author findings had been produced. A journal was kept throughout this process to document decision making [29].

Synthesis process

The synthesis process refers to how the third-order constructs are arrived at; these are the current review's novel interpretations and analysis based on the first- and second-order constructs summarised and translated in previous steps. This was another step in Noblit and Hare's original [30] guidance which Sattar [29] elaborated on. It should be noted that Sattar's [29] guidance does not represent a definitive 'correct' way to perform a meta-ethnography, but it does move towards greater clarity and consistency for future research. As most studies included in

this review had themes in common, a reciprocal translation was felt to be more appropriate than a refutational synthesis, though what few points of divergence were found are discussed below. Reciprocal translations are the recommended type of synthesis if the studies in question are sufficiently similar in their focus and conclusions, whereas refutational synthesis would be the recommended approach if the findings conflicted with each other. The reciprocal translation phase involved reading the synthesis of primary data prepared during the previous step alongside the table of translations grouped by category, then extracting the main points to form new third-order constructs [29].

Following this, a lines of argument synthesis was conducted, which involved comparing different configurations of the third-order constructs to iteratively arrive at a model which attempts to understand how the different concepts relate to each other. This process was carried out in consultation with author CP and various arrangements were considered before the final synthesis was agreed upon. Reference to first-order constructs and contextual factors of the source papers were key in deciding upon which was the most appropriate synthesis to best represent the findings of this review.

Results

Study characteristics

Twelve papers were included in this review which represent the experiences of 244 individuals with experience of HG. Two of the included papers [39, 40] are different analyses of the same US-based data, and so have only been counted once in terms of numbers of participants and number of studies. One other study was based in the USA (n=2), two in Canada (n=2), two in Ireland (n=2) and the rest in the Netherlands (n=1), the UK (n=1), Sweden (n=1), Australia (n=1), and Greece (n=1). Five of the included papers were published between 2000-2006, whilst the other seven were published within the last 10 years. Four of the studies reported utilising a mixture of participants interviewed during the antenatal or postnatal period (n=4), with three recruiting exclusively antenatally (n=3), two in the postnatal period (n=2), and it being unclear in the remaining two (n=2). The most common means of gathering data was via individual interviews (n=9), with one study utilising focus groups [41] and another analysing the content of online blogs [42]. One study interviewed some participants twice then utilised a focus group to gather feedback on the emergent theory [43]. One study utilised a follow-up session of more direct questions after the initial interview [44]. Settings varied for the studies included, with four within participants' homes (or a location of their choosing) (n=4), three in tertiary care hospital settings (n=3), two online (n=2), one on an antenatal care ward (n=1), and one at a research institute (n=1). Table 3 summarises the study characteristics in full.

Table 3: Summary of study characteristics

Authors(s) (Year) Country	**Number and Age of participants**	**Timing, setting and method of data collection, and qualitative methodology**	**Study Aim(s)**	**Key Findings**
Munch (2000) USA [39]	96 women aged 20-38 (mean 27.65)	13 antenatal & 83 postnatal; tertiary care hospital - Semi-structured telephone interviews; Content analysis	What humanistic qualities of doctors are deemed important to women who have experienced HG, thereby contributing to patient satisfaction with the medical care received from physicians who treated HG	Four main themes identified: "Believes patient's story"; The context; Women's responses to being believed; Women's responses to *not* being believed. Four sub-themes identified: Making the diagnosis; Delay in seeking medical care as a strategy; Patients and self-doubt; Other health care professionals
Munch (2002) USA [40]			This paper reports the qualitative findings from a larger study (Munch,1998) that investigated, in part, patients' own beliefs about the causal explanation of HG, seriousness of the illness, and impact of the illness upon patients' daily lives.	Three main themes identified: 'Causal Explanation'; 'The Role of Stress'; 'Referral to Psychosocial Resources'
O'Brien et al (2002) Canada [43]	24 women aged 18-41	Antenatal & Postnatal; Tertiary Care Hospital - Semi-structured interviews (16 interviewed once, 4 interviewed twice), 4	To understand how women cope with severe nausea, vomiting, and/or retching during pregnancy	Two Core categories: the process of increasingly complete physical, social, and emotional isolation to cope with unrelenting and severe symptoms (Characterised by five stages: (a) rationalisation, (b) recognition (internal and external), (c) domination, (d) annihilation, and (e) renewal); Tensions experienced: (a) profound loneliness coexisting with a need for

		in a focus group for feedback on emerging theory; Grounded Theory		almost complete social and physical withdrawal; (b) loss of control over self and virtually every aspect of living coexisting with a need for recognition and support to cope with symptoms; and (c) guilt while immersed in feelings of helplessness
Meighan and Wood (2005) USA [44]	8 women aged 19-35	Appears to be postnatal; Participants' homes or another site chosen by them - Interviews then follow-up direct questions session; Grounded Theory	To investigate the perceptions of women who had been diagnosed and treated for HG and to better understand its impact on their lives and their assumption of the maternal role	Three Core categories: Struggling With Sickness (Subcategories: Seeking a Cause; Seeking a Remedy; and Seeking an End to Misery Versus Learning to Live With It); followed by Regaining Control; and Making Up for Lost Time
Agren and Berg (2006) Sweden [45]	10 women aged 23-38	Antenatal (7-13 weeks gestation); Antenatal care ward - 3 tactile massages then a brief interview (12-25 minutes); Phenomenological 'lifeworld' approach	To describe hospitalised women's experiences of Severe Nausea and Vomiting of Pregnancy and tactile massage	Two main themes (with subthemes): Experience of Severe Nausea and Vomiting of Pregnancy (The body is hypersensitive and drained of power; The grip on everyday life is lost; A need for unconditional care arises) and Experience of treatment with tactile massage (A soothing relaxation; Thoughts are shattered and trust is born; A feeling that the body is functioning again)
Nicholson (2018) UK [46]	10 women aged 32-48	9 postnatal & 1 antenatal (with subsided HG symptoms); Writing at home - Semi-structured	To analyse the experiences of women using writing therapy to address issues associated with pregnancy sickness	Three Super-ordinate themes (with associated sub-themes): 1) Writing as an opportunity to externalise the HG experience (1. Expressing the unspoken; 2. Voicing the anger; 3. Venting the lived experience); 2) Writing as a space to process the HG experience (1. Validating the feelings; 2. Forming a narrative; 3.

		telephone interviews; Thematic Analysis		Making sense of the experience); 3) Writing as a means of reclaiming relationship with self and others (1. Increased sense of agency; 2. Increased self-awareness; 3. Increased self-directedness; 4. Increased emotional proximity to others); 4) Writing as a place to heal and recover (1. Healing; 2. New resource for coping; 3. Inadequate emotional support; 4. Recovery from HG as an ongoing process)
van Vliet et al (2018) Netherlands [47]	13 women aged 19-33	Unclear whether anyone still pregnant but participant invited if had received hospital treatment for HG within last 4 years; Social media and online recruitment - In-depth unstructured interviews; Thematic Analysis	To describe women's experiences and preferences of HG care. Which aspects of care did they find helpful and led to recovery? Which areas of care need improvement? What were their main concerns and needs during and after their HG episode?	Five main themes, (some with associated subthemes): 1) Caregivers' Attitudes; 2) Medical Treatment (1. Early Medical Intervention; 2. (Early) Nasogastric Tube Feeding; 3. Communication about the Different Treatment Options; 4. Single Room in Hospital; 5. Location of Therapy; 6. Support after Hospital Admission during Pregnancy); 3) Psychological Support (1. Psychological Aid; 2. Frequent Ultrasound Checks); 4) Aftercare; 5) Provision of Information
Groleau et al (2019) Canada [48]	15 women (11 immigrants, 4 Canadian-born) aged 20-35	Antenatal; Participants' homes following hospital discharge - Interviews; Qualitative Comparative Analysis	Aimed to explore the illness meaning and experience of HG among immigrant pregnant women	Three Main themes: Experience of HG; Experience of clinical care; Cultural knowledge of HG

Tsalkitzi et al (2021) Greece [49]	14 women aged 26-48	Antenatal (12-14 weeks gestation); Obstetrics department of a tertiary military hospital - Semi-structured interviews; Content Analysis	To recognise and understand the conscious fantasies about the unborn baby among women with HG	Four Main themes: “If the baby didn’t exist”; “The baby hurts me”; “I don’t imagine the baby”; “I don’t feel maternal”
Beirne et al (2023) Ireland [41]	11 women aged 32-40	6 antenatal & 5 postnatal; Research institution - Semi-structured focus groups of 2-3 women (2 antenatal, 2 postnatal); Thematic Analysis	To gain insight into the personal and healthcare experiences of women with HG in an Irish maternity setting	Four Main themes (and subthemes): The HG treatment journey (The suboptimal care environment; Unmet needs in the aftermath of HG; Clinical ownership of HG – where does it lie; Positive treatment experiences – a lifeline); The reluctant treatment of HG (Perceived lack of insight and clinical experience among healthcare professionals; Fear of medication); Far-reaching burden (The impact of HG on relationships and family dynamics; Beyond nausea and vomiting; Financial burden); The emotional toll of HG (Expectations of the ideal pregnancy vs. the HG pregnancy; Isolation and loss of sense of self)

Doherty et al (2023) Ireland [50]	10 women aged 25-44	Unclear whether had given birth or not following clinic attendance; Setting selected by interviewee (their own home, online from home or at the research site) - Semi-structured Interviews; Reflexive Thematic Analysis	To ascertain women's experiences of HG and the new hydration clinic (IRIS clinic). Aiming to help assess the clinic's viability and highlight possible recommendations for improvement to enhance care	Four main themes (each with 3-5 sub-themes): 1) Hyperemesis: Not just morning sickness (1. Recognition of HG & HG in the public eye; 2. Getting through the day; 3. Psychological impact of HG; 4. Family, family planning & social impact; 5. Employment & Finances); 2) IRIS: Not just a clinic (1. Management at the clinic; 2. Continuity of care & individualised treatment; 3. Validation; 4. Network of support; 5. Small comforts); 3) Relationships (1. Midwives; 2. Dieticians; 3. Comrades); 4) The future of IRIS (1. Expansion; 2. System pressures; 3. Recommendations for improvement)
Beck (2023) Australia [42]	33 blogs from HG survivors of unknown age on Hyperemesis Australia Website	HG Survivors implies postnatal data collection; Online Blogs - Online blogs; Content Analysis	To learn firsthand from mothers' blogs about their pregnancies complicated by HG to provide infusion nurses with insight, as they are in frequent contact with women who come to the emergency department or are admitted as inpatients for rehydration therapy	Six themes: (1) debilitating physical and mental health problems: digging deep to persevere, (2) heartbreaking choices, (3) lack of understanding and dismissed, (4) so much guilt surrounding their unborn infant, (5) it takes a village to support women with hyperemesis gravidarum, and (6) warriors and survivors: giving back

Quality of studies

Table 4 contains the outcome of the quality appraisals. Nine of the included papers were scored 'Yes' for most items. No studies were scored 'Yes' on all criteria. The criteria with fewest 'Yes' scores and the most 'No' scores related to whether there was evidence the researchers had considered their relationships to the participants. Where a 'Yes' wasn't scored, the most common other score was 'Can't Tell'. A single paper was scored 'No' for whether ethical considerations had been taken into account [42]. This same paper scored more 'Can't Tell's than any other paper, as it was difficult to know whether the author had met scoring criteria as there wasn't an account of those details in the article. Despite this, it was felt the more transparent decision would be not to exclude contributions from the study based on possible methodological weaknesses as it would have risked excluding one of the more unique sources; that being the only study to utilise blog entries from HG sufferers. Relative strengths of most or all the papers appraised included that there were clear statements of aims and findings, appropriate choice of qualitative methodology, research design, and data collection strategy.

Outcome of determining how the studies are related

The papers considered vary in geographical location and setting, but there was felt to be enough in common to perform a reciprocal translation. Whilst some authors highlighted tensions within the experiences of participants, there were no refutational findings identified between the twelve studies included. Eleven categories emerged from synthesising the 2nd order constructs, which were then adapted as appropriate during latter phases. These categories included: 'Efforts at Coping', 'Physical Impact', 'Emotional Impact', 'Emotional Burden Relief', 'Exacerbated Emotional Burden', 'Social Factors', 'Factors affecting internal relationship with and understanding of HG', Suggestions for Clinical Improvements', 'Positive Treatment Experiences', 'Negative Treatment Experiences', and 'Post-HG Reflections'.

Table 4: Summary of quality assessments using CASP

Quality Appraisal Criteria	Munch 2000 [39]	Munch 2002 [40]	O'Brien et al 2002 [43]	Meighan & Wood 2005 [44]	Agren and Berg 2006 [45]	Nicholson 2018 [46]	van Vliet et al 2018 [47]	Groleau et al 2019 [48]	Tsalkitzi et al 2021 [49]	Beirne et al 2023 [41]	Doherty et al 2023 [50]	Beck 2023 [42]
Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the research design appropriate to address the aims of the research?	C	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	C
Was the recruitment strategy appropriate to the aims of the research?	C	C	Y	C	C	C	C	Y	C	Y	Y	C
Was the data collected in a way that addressed the research issue?	Y	Y	Y	C	Y	Y	Y	Y	Y	C	Y	C
Has the relationship between researcher and participants been adequately considered?	C	N	C	N	Y	Y	C	N	C	N	N	N
Have ethical issues been taken into consideration?	C	C	Y	Y	Y	Y	C	Y	Y	C	Y	N
Was the data analysis sufficiently rigorous?	C	Y	Y	C	C	Y	C	C	C	C	C	C
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	C

** Y= Yes; C=Can't Tell; N=No*

Outcome of translation and synthesis process

Three main themes and 10 sub-themes were generated from the synthesis. These were used to produce a line of argument synthesis to facilitate a richer understanding of HG experiences. Definitions of sub-themes were developed following their identification. Table 5 contains a summary of themes, sub-themes, definitions and which papers fed into each sub-theme. Each sub-theme was informed by more than one paper, though there were no cases in which all papers contributed to any sub-theme.

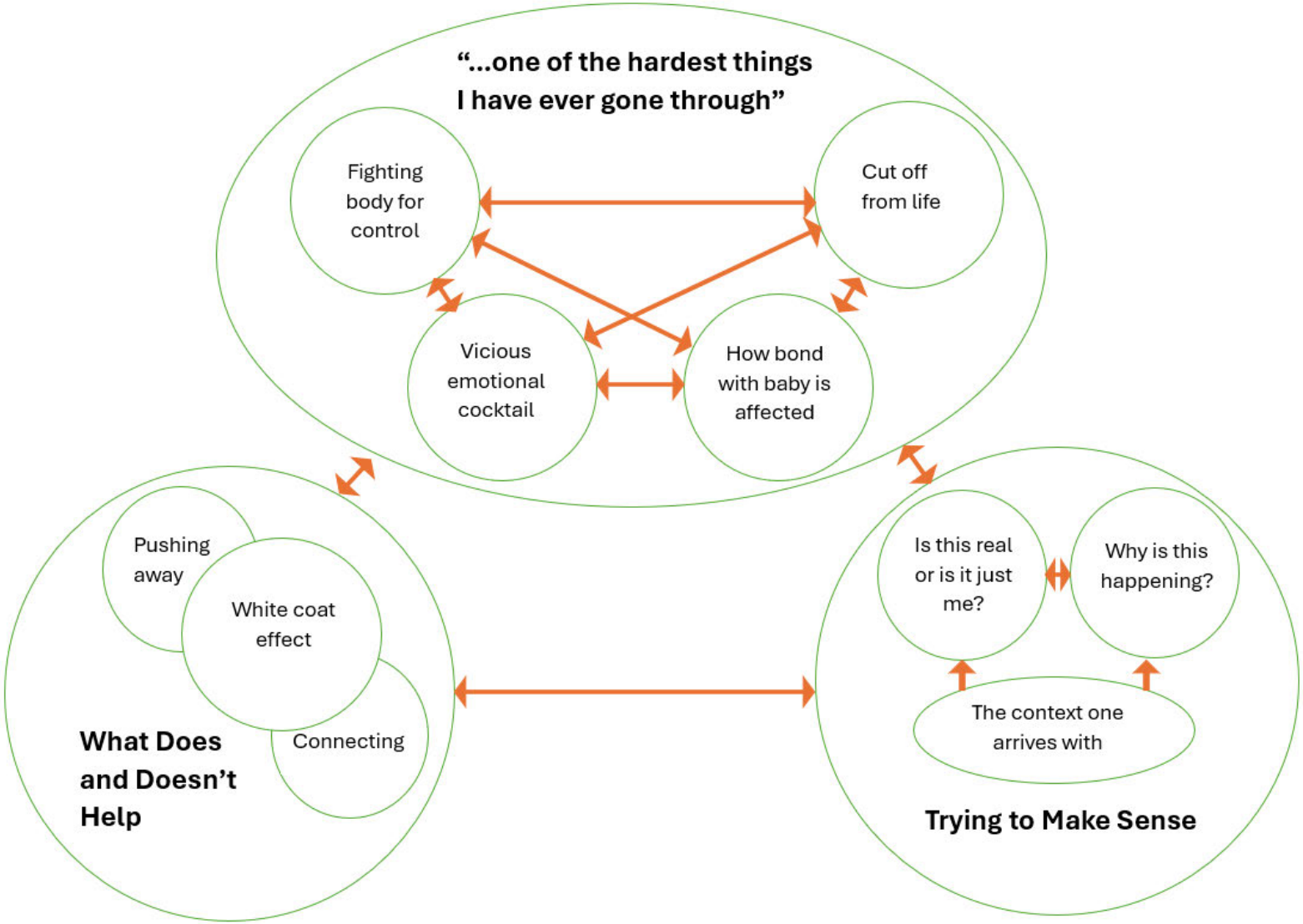
Table 5: Summary table of 3rd order constructs

Line of Argument (Themes)	**3rd order constructs (Sub-themes)**	**Definition (translation) of the 3rd Order construct**	**Papers that contributed to construct development**
Trying to Make Sense	Is this real or is it just me?	The degree to which the individual recognises their experience as a health condition	[39, 41-44, 46, 48]
	Why is this happening?	Things are not going as anticipated and the individual wants to know why; they're going to attribute it to something or someone	[39-41, 47]
	The context one arrives with	Role of prior beliefs, internalised cultural norms and expectations for pregnancy	[39, 41, 44, 46, 48, 49]
What Does and Doesn't Help	Pushing away	Experiences with others and/or settings which leave the individual feeling poorly understood and/or not believed or that others don't feel their illness is real/warrants treatment	[39-42, 46-48, 50]
	Connecting	Experiences with others and/or settings which leave the individual feeling understood, believed and that their condition is recognised as valid and deserving of care/treatment	[39, 41-43, 45, 48, 50]
	White coat effect	The environmental influences described above are amplified when medical professionals and settings are involved, allowing a	[40, 41, 44, 50]

		mixture of very positive or very negative outcomes	
"…one of the hardest things I have ever gone through"	Fighting body for control	The more physical aspects of the HG experience, including nausea, vomiting, sensory changes, dehydration, fatigue, incontinence	[41, 42, 44, 47]
	Vicious emotional cocktail	The myriad emotional impact of HG including depressed mood, anxiety, guilt, shame, fear, disappointment, anger, resentment, and confusion	[39-44, 46-50]
	Cut off from life	The various ways in which one can become isolated; because it's hard to move/go out, not wanting to worsen nausea, and feeling cut off from others (including services) who can't seem to relate/understand – can lead to loss of roles/identity	[39-48, 50]
	How bond with baby is affected	The impact HG has on relationship with the unborn child and assumption of the maternal role after birth	[41, 42, 44, 49]

Two circles and a larger oval were used to represent the themes emergent from the line-of-argument synthesis diagrammatically (Fig 2). Within each theme shape can be found the respective sub-themes, themselves having been positioned in such a way as to try to represent the way they relate to each other. For example, the 'White coat effect' was made larger and positioned between the other two sub-themes as it can amplify either, demonstrating how influential healthcare professionals (HCPs) can be in this context. Arrows have also been used to illustrate the presence and direction of the key influences across and within themes.

Fig 2: Line of argument synthesis **(diagram)**



Trying to make sense

'Trying to make sense' (see right circle, Figure 2) refers to the process of developing understanding of the HG experience all sufferers go through. Most studies emphasised at least one facet of how their participants tried to make sense, with papers like Munch [39] focusing on this more explicitly.

The context one arrives with

The synthesis illuminated events, beliefs, expectations, and attitudes which shaped the lens through which individuals viewed their HG experiences [39-41, 43, 44, 46, 48-50].

> "I didn't envision this about pregnancy…I always thought that pregnancy could be one of the most beautiful moments that happen. Especially when you're all well in your head, you have a good entourage, you don't have any problems, no health problems, but…since then I've realised that's not necessarily true." [48]

Several synthesised papers mention the HG experience differing markedly from expectations of pregnancy. As the quote above demonstrates, individuals may feel hopeful of a positive experience by having done what they can to prepare. Such confidence can lead some to make "…this great plan to do yoga, Pilates, you know all these beautiful things, sit on the mat with your bump, that was off the menu" [41]. This mismatch between expectations and reality leads to feelings of disappointment, self-blame, and difficulty being in the company of others with seemingly smoother pregnancies. Comments such as, "there's so much that we're not allowed to say, we're not allowed to feel when we're pregnant" [46] suggest individuals feel pressure to be a certain way throughout pregnancy. Internalised norms of what is expected within pregnancy could inform some of the social hardships associated with HG.

> "My mother told me when she was pregnant with me—she told me she had exactly the same thing, she was even hospitalized the last 4 months of her pregnancy. I saw in

> Cameroon people who vomited a lot, they weren't exaggerating either. I received a lot of support from my family." [48]

The above quote highlights the benefit of possessing HG awareness, or what Groleau and colleagues [48] call an 'illness prototype' for HG, for setting one's expectations and those of others. On individual expectations, "…I find it's a problem with me that when I get pregnant and that will pass after that. After the 9 months, it will go and I won't have it anymore" [48]. An illness prototype seemingly provides a helpful foundation for sense-making. Prototypes could come from others, media coverage, or direct experience, though the level of detail will vary with each source. Direct experience allows for informed decisions about moving forward; "If we were to have another baby, my mom has to be involved with this decision…I just wouldn't be able to do it without the constant minding." [41]. Some choose not to have more children due to high reoccurrence rates of HG alongside childcare responsibility.

Is this real or is it just me?

How much one conceptualises their symptoms as resulting from a medical condition, or what O'Brien and colleagues [43] call 'internal recognition' is referred to variously in the other papers [39, 43, 46, 48, 50].

> "…that feeling of it not being a real illness because you know it's going to finish and you're going to have a baby at the end" [46]

For some, HG emerging in the context of pregnancy made it hard to regard as an illness. This could be internalised unsympathetic attitudes some experienced from individuals viewing pregnancy-related difficulties as self-inflicted. Being hospitalised without knowledge of the condition can lead to thinking, "…well, that's stupid. I should be able to eat but I can't. I thought they [caregivers] must think that I am crazy or something…" [43]. This individual seems to find their own predicament bizarre and is concerned others will think so too.

> "I felt that because I was not in labour that it wasn't important. I was really sick and feeling crappy and I didn't understand why I was kind of just put into a corner…and I just didn't feel like it [severe nausea and vomiting] was important." [43]

This illustrates someone's internal recognition being influenced by others, concluding their suffering isn't important based on being neglected. Stating 'I just didn't feel', rather than, 'they didn't seem to feel' once again suggests internalisation. Feeling dismissed led some to feel, "Enough people tell you it is all in your head, you almost start to believe it yourself…" [39]. These communications complicate the internal acknowledgement of HG, as "…people would say 'it's quite normal' and I don't know if that was helpful or not because for me it felt excessive." [43]. This likely confuses how to think about and react to what's happening, and in turn what to expect from oneself.

Why is this happening?

Several of the papers discussed and highlighted participants' comments on attribution and the effects of thinking about causation in different ways [39, 40, 43, 44, 48, 49].

> "[I felt] sad and like a failure because I was back in the hospital. I thought there was something more that I could have done. Even though I know I couldn't have done more than what I did, but…" [43]

These comments allude to a belief that their symptoms were preventable had they behaved differently, bringing on self-blame. Attributions like this and, "Why can't I get over this? Maybe it is psychological; women get pregnant every day" [39] show how harsh individuals can be towards themselves when unaware of HG and still holding themselves to 'typical' pregnancy standards. Without obvious cause, psychogenic explanations arise; "Nobody that I know of has had this until me…I even asked the doctor if this was nerve related…if it's in my head I want to see a

psychiatrist" [44], again related to comparisons and wondering what it is about themselves which has led to greater struggles.

> "It was a month before I got pregnant that my father died…I think I had a lot of stress…my father…[the] new environment and [being] away from my family…[if they were here] maybe it would be easier for me." [48]

Evidence here of curiosity about the contribution of stress and missing practical support from family who still lived in their country of origin. Comments such as "…I think the more stress you're under, the worse you feel, the more scared you are. But I still think most of it is physical." [40] propose a stress interaction, but a predominantly physical basis. The role of preserving occupational function emerges as a participant theorises about why she's suffered more during a subsequent pregnancy; "I think I had less time to concentrate on how sick I felt, and this time I was completely at home" [44].

> "(I imagine) there is a disagreement -hormonal or another kind- between my body and the baby. And therefore, hyperemesis happens. Maybe the baby damages my chemical and physiological balance." [49]

This illustrates those who suspect a physiological cause, perhaps related to hormonal or chemical imbalance. Others reason "…I know it wasn't in my head because it goes away eventually. Nothing changed other than that I'm further along and that I know it's the hormones." [40]. As attributions shift from psychogenic to physiological the degree to which the individual feels responsible for their illness changes, with the former being more associated with self-blame.

Key considerations emergent from this synthesis include the difficulties those without an HG illness prototype have in trying to make sense of what's happening. Lacking a prototype leaves individuals more vulnerable to outside influence when considering the degree to which HG is

recognised as an illness and what to attribute the condition to. Sense-making evolves over the course of and over repeated experiences of HG, and is likely to influence how an individual feels, reacts to and what they expect of themselves over the course of their experience.

What does and doesn't help?

This theme (see left circle, Figure 2) refers to external influence on individuals' experiences of HG. Most studies highlighted some aspect of how participants were affected by others' communication and behaviour, with some focusing on medical environments. The review identified a range of influences conveyed and experienced via a range of overt, less overt and symbolic means.

Pushing away

The synthesis highlighted external factors which exacerbate HG, often reinforcing isolation. The reviewed papers suggested many felt poorly understood [39-43, 46-48], things had to worsen before being believed [39-41, 47, 48, 50] and processes and environments were poorly designed for HG patients [41, 47, 50].

> "…his family [caused the most stress] because my housework suffered and I wasn't taking care of my husband…They didn't understand why I couldn't do those things. And we didn't get any help from them." [40]

Due to low awareness, many haven't heard of HG before encountering it personally, leaving some feeling, "I don't really feel like I was ever heard. And I really felt like people didn't get it" [46]. Just as those with lower illness recognition expect more of themselves, the quote shows this was also the case here with in-laws' expectations of the individual. A lack of what O'Brien and colleagues [43] termed, 'external recognition' from others sat in parallel with the internal equivalent. As morning sickness is a phenomenon more are familiar with, many equivocate, but "To say HG is similar to morning sickness would be like calling the hurricane a little rain" [42]. Interactions

demonstrating a lack of understanding left some feeling, “When you are feeling sick and want somebody to help you, it is hard to ask for that help when you know it is going to come back to you, ‘oh, all you need to do is sleep it off.’” [43].

> “But if I wasn’t dehydrated, they sent me home, although I knew I would be back within a few days, because it wasn’t a solution. (…) They let me go for so long, that I lost so much weight and was dehydrated in such way, that it went too far. (…) Waiting till I was dehydrated, only then they were willing to take action.” [47]

A pattern emerged of individuals not being taken at their word when they tried to impress on others how unwell they were, in the case above being left to deteriorate before worthy of intervention. Being treated this way symbolises to individuals that they’re not unwell enough or worth taking seriously. This also emerged occupationally; “…if I wanted my job I better get back to the office. I came in the next day, and I spent almost all day in the bathroom; and they finally understood that I was not lying.” [40]. The ruptures in relationships and ill-feelings individuals are left with when others treat them this way adds further burden. It relates to what others require to accommodate novel conditions, even at home; “…Also, my husband sometimes doesn’t believe me. Like last time I was hospitalized he said ‘It’s nothing’… and when I was admitted for long term stay, that’s when he realized ‘Ah ok.’” [48].

> “…I called and said ‘I can’t manage any more, I can’t even walk to the toilet without fainting’. They said ‘alright, then I want you to come to our practice’. So I said ‘how will I get there?’ (…) Driving by car with HG is a nightmare. I was vomiting all the way to the practice, and in the waiting room too, with people all around me.” [47]

When one manages to overcome fear of a negative response, they can be faced with systems designed in such a way that they can exacerbate HG. Awareness of HG would have facilitated appreciation of how unreasonable the example was, but understanding levels were experienced as mixed even in medical environments. The setups of inpatient settings were similarly

aggravating at times; “I noticed that light really causes an extremely intense impulse to vomit. On the other side of the room a girl was admitted, and she had the television on during half the night…” [47]. Additional to exacerbating nausea, “…because of time restraints…they were just trying to get them [IV fluids] into you as quickly as possible…” [41]. Health systems being under-resourced makes providing person-centred care challenging and leaves individuals wondering, “’Am I an inconvenience’?” [50].

Connecting

There were accounts of positive interactions which relieved burden. Various helpful experiences were highlighted, including feeling understood [42, 43, 45, 46, 50], acknowledging HG as real [39, 42, 47, 50] and support networks [41, 42, 43, 44, 47, 48, 50].

> “I accessed the online resources, joined the Facebook group where I was able to connect with other pregnant women experiencing the same condition and was paired with a peer support survivor who contacted me regularly during my pregnancy and offered support. This was a turning point for me, as I was no longer suffering alone.” [42]

Connecting with an HG peer was a valuable experience for those who had it. Knowing, “…I am not the only one.” [43] seems an ideal salve when feeling alone in one’s experience. Online communities such as Hyperemesis Gravidarum Australia (HGA) spread supportive messages like, “Hang tight. You’re never ever ALONE and I for one, along with this HGA community, will walk in the darkness with you until it becomes light once more!” [42] as peers know how isolating it can be and seek to instil hope. Some provided examples of powerful symbolic acts of connection; “I started to sleep in the bathroom. It’s just easier to stay still and not move…my husband started to sleep next to me, so I wasn’t alone” [42]. Some sufferers were believed because “…she knows that I don’t have a tendency to exaggerate…she was there for me the whole time…” [48], showing the benefit of support from someone with knowledge of someone’s pre-illness disposition; something most healthcare professionals (HCPs) are unlikely to have.

> "If I had known earlier about foundation ZEHG… I found a lot of information there, and I shared that with my boyfriend, my parents and his parents, who all didn't understand…These were the people from whom I hoped to receive help, and from whom I eventually did, but only after all the information, because they just didn't understand it at first, they just couldn't imagine it." [47]

This quote highlights how valuable HG-focused organisations, in this case the Dutch foundation ZEHG, and good quality HG information can be as it can mobilise a support network. Support can include helping cover responsibilities the individual cannot manage, such as, "…my friends made a roster to bring food around as even though I couldn't eat it (or smell it!) my family still needed to eat." [42]. Being informed enough about HG provided some with enough knowledge to give a firm push to seek help; "It was my mother who forced me, mainly because I'm very obstinate and thought that I could manage that by myself if I just lie down and cry hidden away…" [45]. Factors such as trying to maintain control, fear of dismissal, and self-blame could help understand the reluctance to seek help. Doherty and colleagues [50] discussed patients' experiences of an HG-informed day-clinic, which incorporates some of the above positives; "…We got chatting every week and it was lovely actually to go in and see familiar faces…there's a sense of camaraderie in a sense that we're going through the same thing" [50]. Benefitting from peer-support whilst receiving treatment avoided the unfavourable comparisons to those without HG on generic wards. A dedicated clinic powerfully acknowledges HG symbolically; "I don't think I could have gotten to this point without completely falling apart if it wasn't for the fact that it was a lot more recognised during this pregnancy and the fact that there was a support there" [50].

White coat effect

Authors described a mixture of positive and negative encounters with healthcare professionals (HCPs). Medical professionals' views carry extra weight as they are relied upon to help understand ailments, and so the impact of those encounters was amplified and had more

influence on participants. Examples included formal recognition of HG and its wider impact [39, 40, 42, 43, 45, 47, 48, 50], shared belief in aetiology [39, 40, 44, 48], lack of HG awareness [39, 41-43, 46-48], and dismissive communication [39, 41, 42, 47, 48].

> "The most helpful thing was just acknowledging that I was sick enough to be admitted to the hospital, that I couldn't go on any more at home…And that I wasn't making it up. I knew I wasn't [making it up] but [it helped] that someone believed me." [39]

The power of medical opinion is evident here; being admitted allowed for removal of expectations on self, that "…you don't have the requirement to do something." [45] and symbolised there was a real illness they couldn't control, that, "I didn't have to fight anymore, and they were going to take care of me. I think I cried my eyes out." [42]. The culturally agreed credibility assigned to HCPs rendering opinions on these matters gave previously conflicted individuals permission to "…feel that it's OK to feel bad…" [45]. Formal external recognition also influences internal recognition; "[It was helpful] for the doctor to say it's not in your head…I knew it wasn't…But it's just nice to have that reaffirmation…" [39]. The existence of specialists also symbolised a sense of legitimacy; "because of [Dietitian], you felt like this is a real thing, that there is support for people" [41].

> "I couldn't even keep a mouthful of water down. If a GP then still says: 'most pregnant women feel sick…' I thought: 'yes, 3 times in the morning or 30 times, the whole day long vomiting, and not being able to leave the toilet, because you can't even get on your feet any more, I think that's quite different'." [47]

Here, a GP provides an opinion similar to what many experience when speaking to non-medics; confabulation with morning sickness and minimisation of symptoms. When HCPs say "…'You're grand, it's just part of pregnancy'" [50] it's unsurprising individuals don't feel taken seriously. Being dismissed can impact internal recognition of HG; "He made me feel that there was really nothing wrong and that it was in my mind. And it was like I shouldn't call him or bother him for

such a minor thing'' [39]. Sense of worthiness of professional care can also be affected, “When they brush it off you just feel, ‘Oh, God, I’m wasting everyone’s time’. You feel like I shouldn’t be here or something” [41]. Published 23 years apart but conveying similar sentiments demonstrates the relevance of these papers and this review [39, 42].

> “…he would be very supportive in the fact that it was mentally draining and that there was help available if I needed someone to talk to, help relieve some of the depression caused by hyperemesis…he was very supportive and understanding, and recognized things that even I was slow to bring up.” [40]

This demonstrates how effective an engaged clinician can be as a key support and acknowledging wider HG impact. Comments such as, “When the doctor is working for you, you feel good about yourself. And I think when you feel good about yourself, you're maybe going to get better quicker.'' [39] suggest an HCP could be integral within a support network due to their amplified influence. Key HCP support could come from various professionals (e.g. dieticians and nurses) perceived as medically authoritative; “I just found it very comforting to know that there was someone there that was telling me that that’s okay, or ’can you try this’, or, you know, she was a voice of experience of what works" [50].

External influences play a significant role within the HG experience, notably related to isolation based on the capacity to leave someone feeling connected to others or with a desire to withdraw from them. Internal recognition of HG is also influenced by external factors; an effect likely to be more pronounced in those lacking an illness prototype. Possession of a prototype can shield from some of the negative environmental effects described. The synthesis suggested HCPs wield amplified influence, potentially playing a significantly positive or negative role within any HG experience.

"...one of the hardest things I have ever gone through"

The theme "One of the hardest things I have ever gone through" [42] (see large oval, Figure 2) refers to the biopsychosocial and attachment related features of the HG experience which emerged from the synthesis.

> "So it has been pretty bad...it just takes a toll on your family, your mental being, your physical being, marriage, everything." [43]

As this quote demonstrates, HG is a multifaceted and complex experience, with specific details varying greatly depending on individual circumstances. Each study mentioned at least some of the aspects which make up this experience; the focus shifting depending on the research question.

Fighting body for control

A general sense of losing control [41-46] was reported across the studies. This included struggles managing hypersensitivity [42, 45-47], lacking energy for routines or coping strategies [43, 45], and relentless nausea and vomiting [40-45, 48-50].

> "If I hadn't felt so bad I would have managed in another way...I feel that I can't cope...if I've had a shower I'm so tired that I just sit or lie down and take the chance to go to bed because I don't have the energy...If it had been normal then I would have been out walking or doing things in the garden..." [45]

The intense fatigue comes through in this account which describes feeling drained of energy after the act of having a wash. There's also the awareness that outside of the context of feeling so unwell, there's various coping actions the individual would have been engaging in that would usually help them feel better. The lack of energy is not surprising when "It's a daily basis kinda thing. I was pretty much throwing up day and night and nothing would stop it." [44]. Accounts

confirmed that as the length of time individuals went on without nourishment, fatigue made even simple actions feel increasingly out of reach.

> "...everything becomes much stronger...things you haven't felt earlier suddenly occur...just pinpricks in your nose when you get close to something...perfume and suchlike...the dog smells awful (laughs)...poor things...I can hardly pat her anymore because she smells so bad." [45]

Trying to manage nausea is made harder due to hypersensitivity, demonstrated in this account in the olfactory form, but discussed by others as affecting other senses too. When fundamentals such as our senses and the ability not to reject food and drink can no longer be relied upon, "...you feel totally out of control of your own body..." [46].

Vicious emotional cocktail

The HG experience often includes a complex mixture of painful feelings which adds burden. This includes feeling depressed [40-42, 46-48, 50], fear and anxiety [40-45, 47, 50] and guilt [40-43, 45-47, 50]. Whilst there were some accounts of HG exacerbating pre-existing mental health difficulties [40], the synthesis seemed to reflect that emotional difficulties developed secondarily to physical symptoms, then became involved in the maintenance of suffering.

> "I could hardly talk on the phone, hardly do anything ... I got very anxious during that time about everything. Things that...I shouldn't have been anxious about...I had the support I needed from everyone, but one night I remember at the hospital I stayed awake wondering if there's a fire in the hospital and would I have enough energy to get out." [48]

Such is the level of functional impact on this individual that their anxiety seems to have generalised beyond pregnancy or HG. Questioning whether they'd be able to save themselves communicates how vulnerable they feel, which understandably leads to fear. Other sources of anxiety include the antiemetic medications some are prescribed; "Half the time I was worried I'd

see you come out with an extra or less of something because of the drugs I had to take." [42] and survival; "It still haunts me to this day hearing my children ask my husband if mummy was going to die. And all I could think was, will I?" [42].

> "It was very depressing. You almost thought the pregnancy wasn't worth going through because it was a sacrifice…It was my last hospitalization and I said if it doesn't stop…I'm terminating the pregnancy." [44]

"…It's an overwhelming experience if you are so nauseous…" [47] so considering means of escape emerged often throughout the synthesis and "…once thoughts of termination or suicide enter your mind, they tend to linger" [42]. The fact that there were so many recorded accounts of individuals with wanted pregnancies finding their experiences so intolerable that they considered, and in some cases went through with, these options underlines how profoundly torturous HG can be.

> "…I felt guilty about work, I felt guilty towards my child, I felt guilty towards my husband…and I felt angry with myself: 'why can't I do this?' (…) Yes, it would have been very nice if I could have spoken to someone other than my direct family. It doesn't have to be solved, but it helps to talk about how you can deal with it." [47]

This quote demonstrates that individuals blamed themselves for being unable to fulfil roles despite HG rendering them so unwell. The painful emotions described above compounded difficulties for the participants alongside the physical hardships already discussed.

Cut off from life

Isolation is a common feature of the HG experience for many. Contributing factors include withdrawing to manage nausea [41-45, 47, 48, 50] and to avoid painful interactions [40, 42-44, 46-48]. Isolation can progress to the point that individuals describe 'loss of self', which seems linked to progressive loss of roles linked to identity [40, 41, 43, 45, 48, 50]. O'Brien et al.'s [43]

paper describes a process by which HG impact can become the only thing the individual can focus on.

> "I'm always telling my husband, 'We can't do that because I'm not feeling good.' [I am telling] my little boy, 'I can't play with you right now because I am not feeling good enough.' I always feel like I'm disappointing people all the time." [43]

This demonstrates a common dynamic of having to repeatedly turn down invitations or suggestions due to level of illness, resulting in additional emotional pain. Having to step back from caring responsibilities generated family strain and more painful emotions; "I had a 3-year-old who was missing his mummy and worrying that there was something seriously wrong. I…couldn't be the mummy my boy so desperately needed. So also had the heartbreak to go with it" [42]. Some suspected their "…family is tired of it…and there is no end in sight" [43].

> "It is a kind of loneliness. You look around and you see all these other women with babies and you know there are smiles on their faces. I couldn't even stand for anyone to be in the room, I was just so sick that [I] just wanted to pull a blanket over [my] head…" [43]

Happiness visualised in the faces of other women seems to sit in stark contrast to the reported internal experience of HG. It potentially alludes to societal beliefs of what pregnancy and early motherhood is *supposed* to be and even imagining proximity to that provides motivation to avoid others. Some expressed doubts about others' ability to relate to their experiences; "When you've got your head stuck down the toilet bowl with cyclical vomiting and your whole life stops for months on end, there are very few people in our day-to-day life who understand." [42].

> "It takes over your life…you care less and less about everything else…one's work, one's family…finally all that is left is myself and my nausea." [45]

As demonstrated within the quote, when focus on nausea has become absolute, accounts increasingly include similar language such as, "I want my life back; I am dying; I felt really not

alive. It's almost like I really don't exist anymore, and I am hyperemesis" [43]. Many described feeling they needed to isolate themselves from as much sensory stimulation as possible to keep nausea to a minimum. The absence of other roles leads some to experience a sense of fusion with HG. Hyperemesis can last the whole pregnancy. If someone reaches this extent of loss of identity it becomes easier to understand why consideration of desperate means of escape arise.

How bond with baby is affected

Accounts of HG experiences often discuss how the relationship with the unborn child is affected [41-44, 46-49].

> "All you think about is how you are feeling. You don't think about what you are going to do with your child. You are just thinking about feeling sick…It sort of takes priority over anything else." [43]

Attention can become focused on daily survival, thus not available for the unborn child. Comments such as, "I don't feel like a future mother. All the movie stuff about picking names, talking to the baby, daydreaming, etc., are not in my routine." [49] show an awareness of a glamorised version of pregnancy including headspace to consider the baby. Rather, they "…ceased to be a human being and instead was an incubator. It took me until my daughter was almost 10 months old to say that she was worth it." [42], which in turn meant they "felt numb and guilty for not enjoying her daughter." [42]. A sense of what a mother-to-be should feel produces further emotional pain and obstructs the bonding process. The influence of attribution is also evident as some came to view their child as responsible, which led to being "…worried that I was going to hate this little baby once she was born and that terrified me." [42].

> "I cried…she was here…she actually survived. After that, I didn't want anybody to mess with her. I felt very protective. Right after I had her, I didn't even want to go to sleep. I

wanted to be right there with her, I wanted to be holding her. I can remember my husband saying, "Wait, it's my turn."" [44]

Some found that they were so relieved to meet their baby after a difficult pregnancy that they became possessive. There was a quality of making up for lost bonding time in some accounts; "When my son arrived, I knew instantly that everything I had suffered through was worth it…" [42]. Some found motivation to persevere when they "…saw the baby on the display, I thought 'this is what I'm doing it for, for you'." [47] while others "…had numerous ultrasounds…I didn't care…" [44]. Maintaining a bond with the unborn child is complicated by an HG pregnancy, yet many feel intensely pressured to, or else experience guilt and shame.

The physical and emotional toll of HG grows to the extent that it can overwhelm and consume the individual. Psychological and social drivers lead to feelings of isolation and losses of roles, which can lead to loss of identity. These factors obstruct connecting with the expectant child. This theme demonstrates that the HG experience is complex, multifaceted, and idiosyncratic, thus requiring careful attention to individual circumstances to understand any presentation.

Discussion

Summary of findings

This meta-ethnography sought to improve understanding of the HG experience by synthesising research exploring those experiences, additionally hoping to discover what adds to or reduces burden. The review included twelve papers from which three main themes emerged: 'Trying to make sense', 'What does and doesn't help', and "…one of the hardest things I have ever gone through" [42].

'Trying to make sense' of HG experiences elaborated more on the internal relationship with the condition and was a central theme subdivided into 'The context one arrives with'; 'Is this real or is it just me?'; and 'Why is this happening?' Culturally informed expectations and standards for what a pregnancy should be contrast strongly with experiences of HG and can become a further source of emotional pain, mimicking findings from an interpretative phenomenological analysis (IPA) on mental health during pregnancy [51]. Insights can also be gleaned from the literature on chronic pain, which has highlighted that presence of a condition which interferes with one's ability to fulfil their goals can impact on their mental health and overall sense of identity, as appears to have been the case with many whose expectations of what they'd do throughout pregnancy were ruined by the presence of HG [52]. Whether or not an individual possesses an illness prototype [48] for HG seems to dictate the extent that someone will look externally for answers, which highlights the need for timely and accurate differential diagnosis by healthcare professionals (HCPs). The prototype appears to serve as a shield against negative experiences with others. Whether this shield is present influences whether individuals can conceive of HG as an illness rather than a personal failing. Parallels with other perinatal mental health conditions are present, such as in the case of postpartum psychosis where the point at which individuals realise they are not alone in their experiences has been found to be a key stage of recovery [53].

A range of attributions were discussed within the review, showing that participants considered degrees of psychogenic and physiological influence as having led to HG. The exploration of the internal relationship interestingly highlighted the link between psychogenic attribution and self-blame, perhaps due to ongoing stigma regarding psychosomatic conditions and mental health generally. The increased vulnerability of individuals without an illness prototype or effective social support was clear.

The interaction between 'What Does and Doesn't Help' and "...one of the hardest things I have ever gone through" [42] in the diagrammatic representation of the synthesis (Figure 2) illustrates that HG brings individuals into contact with others as it arises in the context of pregnancy and because of the severity of its impact. The results highlighted that external influences can be experienced as 'Pushing away' or 'Connecting' to the individual with HG. These influences seem amplified within a healthcare context suggesting the presence of the 'White coat effect'. Healthcare professionals wield a higher degree of influence on internal recognition, attribution, and access to treatment. Whether in a healthcare context or not, feeling dismissed and poorly understood were common experiences which then contributed to emotional burden and led to individuals feeling reluctant to engage others again, thus contributing to isolation. Action research by Power and colleagues [25] highlights that participants felt unpopular with HCPs and that feeling was reflected in HCPs who voiced scepticism of the validity of most HG presentations. The comments from HCPs ironically acknowledged various social and psychological dimensions to HG but used this as justification for it being less appropriate for hospital treatment than other conditions. This might reflect a bias towards a more traditional medical model compared to a holistic approach as well as the level of stress involved when resources are insufficient.

In terms of burden reducing experiences, access to peer-support and expert-by-experience informed HG information appeared of great benefit. At the non-specialised level, it might be more

practical for HCPs to be aware of reliable organisations they can signpost individuals to for access to these support and information, such as Pregnancy Sickness Support. Healthcare services being designed with the benefit of HG research and staffed with HG-informed HCPs also appeared very well received. Examples were also given of practical and symbolic gestures individuals made which resulted in someone feeling less isolated in their HG experience.

A key overarching component of the synthesis was exploring the most challenging aspects of the HG experience which combine to make it, "...one of the hardest things I have ever gone through" [42]. The aspects included: 'Fighting body for control'; 'Vicious emotional cocktail'; 'Cut off from life'; and 'How bond with baby is affected'. Struggling for control of senses, energy, nourishment, and access to coping strategies left participants desperate to regain agency. Nausea and vomiting were viewed as threatening so attention seemed to become preoccupied with the minimisation of each. A vicious cocktail of painful emotions resulted from the physical hardship as well as unhelpful external influences and self-critical internal dialogue. Feeling their own life and that of the unborn child was at risk, it would seem reasonable for a fight-or-flight response to be triggered, which would help to understand the preoccupation with the threat over other daily tasks. A small number of quotes from the review suggested an important role for self-monitoring and attention, in that if otherwise occupied with work or conversation, some experienced a temporary relief of symptoms. Further research exploring similarities to the maintaining role of self-monitoring in the case of panic disorder would be useful to understand more [54]. The observations made and data gathered by Agren and Berg [45] regarding participants feeling more able to receive a tactile intervention outside the home environment suggest more needs to be understood about the role of arousal, perhaps exploring means of regulation and drawing on concepts like the window of tolerance to understand why the threats posed by HG have someone feeling hyper-aroused [55]. The combination of feeling too physically depleted alongside the preoccupation led to feeling increasingly cut off from life as usual life roles ceased. Anticipation of, or actual, negative social experiences also led to withdrawal, thus contributing towards

isolation. A range of parallels, including the experience of isolation, can be found within the literature on mental health difficulties during pregnancy, as has been demonstrated in a recently published interpretative phenomenological analysis [51].

The results highlighted that it is common for individuals struggling greatly with HG to consider termination or suicide as a solution. Research examining this in more depth revealed risk factors for the former include being unable to look after existing children and seeing it as a choice between that and becoming suicidal [24]. Perinatal loss has been shown to increase rates of depression and anxiety, highlighting that those driven to termination are more likely to suffer yet more secondary mental health difficulties [56]. Some definitions of perinatal loss, such as the one used by Herbert and colleagues [56], do not include those left feeling the need to terminate due to complications of pregnancy, meaning those who terminated to end an HG pregnancy may face stigma and difficulties accessing perinatal loss support. Risk factors for suicide include two features the present review identified in the HG experience, those being isolation and pregnancy complications. Their analysis revealed struggles accessing medication and services being inaccessible in general due to inability to physically leave home, which left individuals without hope of improvement and feeling a need to resort to desperate measures. Individuals left prioritising daily survival by the challenges of HG are left with little or no time to think about their unborn child. The review highlighted that many find it difficult to think positively about the child, especially if they are thought to be responsible for the HG. Quantitative HG literature provides a reassuring follow-up to these difficulties with bonding, suggesting there wasn't a significant increase in bonding-related difficulties when compared to non-HG controls after birth [20]. The review does suggest it would be useful to understand more about how the difficulties with bonding affect decisions about termination of pregnancy. Almost half of the HG participants met threshold for probable depression during pregnancy (versus 6% of controls), dropping to 29% postnatally (versus 7% of controls), thus somewhat quantifying the additional degree of emotional impact HG entails [20].

The number of arrows in Figure 2 and how many mentions there are of themes influencing each other throughout the results highlight that trying to differentiate them is difficult due to the high level of interconnectedness, but doing so hopefully aids understanding. The findings would suggest that emotional symptoms increase shortly after physical HG symptoms develop, and then individuals go to others for help understanding if they don't recognise what's happening. If others communicate the impression there's something real happening, it feels valid to try and access care; if not, the individual may feel so ashamed that they're not coping that they hide and feel unworthy of care. That being the case, 1st time HG sufferers without an illness prototype are most vulnerable to the worst experiences as they are more influenced by problematic interactions with others, which negatively impacts on sense-making and mental health, and so more must be done to support those individuals and identify when additional support is indicated. The NVP (and potentially salivation issues and hypersensitivity) as well as some degree of emotional burden seem almost guaranteed with HG, as does some amount of role loss for duration of symptoms. Features like the isolation, bond with baby, reluctance to access services, and internal strife seem less guaranteed and quite workable with the right services and awareness available.

Strengths and limitations

This meta-ethnography included 12 papers, having benefited from a 2nd screener for a proportion of the papers returned from database searching. This methodology was adhered to as closely as possible, with Meta-ethnography Reporting Guidance (eMERGe) utilised to ensure findings are presented in an accessible format [28].

One limitation is a lack of homogeneity within the papers sampled in terms of stage of pregnancy and qualitative methodology. The 2nd screener had also planned to provide input for quality appraisal but was unable to due to time restrictions. Meta-ethnography guidelines recommend a team-based approach to analysis which was also not possible due to resource constraints. The

choice to exclusively review peer-reviewed published work could be viewed as a strength but does mean potentially insightful information from so-called 'grey literature' is absent. A similar observation applies regarding the choice to exclusively include solely qualitative papers in the name of seeking a more homogeneous sample but excluding data from mixed-methods studies.

Conclusions

This is the first meta-ethnography seeking to synthesise individuals' experiences of HG, to the best of the author's knowledge. It provides insights into the ways others, especially HCPs, can influence the sense-making process, and in turn the wider experience of HG. To ensure this influence reduces, rather than contributes to, the burden of HG, HCPs should be prepared to listen for signs an individual's experience might constitute difficulties beyond more common NVP. Clinicians in primary care and at booking appointments should be supported in the use of screening measures. Screening and diagnostic measures should also continue to be researched and refined as necessary. Formal diagnosis should be provided when HG is identified, and individuals should be provided with or signposted to means by which they can access peer-support as well as information for themselves and their support network to learn more about HG to reduce uncertainty and help plan for the rest of the pregnancy. This could come from organisations like Pregnancy Sickness Support in the UK, for example.

Other clinical recommendations following from the findings of this review include adopting a tailored, person-centred approach due to the highly idiosyncratic configurations of the factors seen to make up the HG experience as it is difficult to imagine a one-size-fits-all approach to HG management based on this review. This can facilitate a positive therapeutic relationship and the patient feeling able to access care rather than ashamed and unworthy of it. Professionals trained in psychological therapies to facilitate adjustment to illness, such as clinical psychologists, would seem well-placed to support individuals to understand their HG experiences during or

after pregnancy. There is a demand for more mental health support, but efficacy and viability of options would seem a fertile area for further research. The day-clinic model described by Doherty and colleagues [50] included many HG-informed features which should be incorporated in other sites and subject to ongoing evaluation and refinement. These include low-stimulation ward environments with other individuals with HG to achieve a peer-support effect, continuity of input from an HG-informed multidisciplinary team, and pre-bookable regular appointments when required. More efforts at raising awareness of this condition in the general public are required to increase detection of HG and compassionate support from friends and family whilst reducing equivocation with milder NVP.

Further research into the roles of attention and whether managing to maintain or regain occupational function can reduce or suspend nausea and vomiting symptoms would be helpful in better understanding some of the findings from the synthesis. An exploration of the role of different cultures on informing expectations of pregnancy and influencing attribution for complications of pregnancy would also be welcome. We should also seek a better understanding of whether HG rates differ internationally now that a consensus definition has been established. If rates are higher in some nations, it would be interesting to note whether those cultures and medical systems are better equipped to support HG sufferers and to learn from how this is achieved. Syntheses should also be carried out to better understand other perspectives relevant to the HG experience, such as those of partners and HCPs.

The findings of this meta-ethnography will hopefully improve understanding of HG, inform further research, and provide guidance to clinicians leading to improved experiences for patients and their families in the future.

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Journal Article 2: Original Research Project

How do first time sufferers of Hyperemesis Gravidarum make sense of their experience and the way others communicate with them? An Interpretative Phenomenological Analysis

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Abstract

Background: Hyperemesis gravidarum (HG) is a rare complication of pregnancy characterised by severe nausea and/or vomiting. Past research indicates prior awareness of HG helps individuals recognise it and seek appropriate support. The profound physical, psychological, and social impact is frequently not understood or acknowledged by others, which adds further burden to severe illness. Those encountering HG for the first time are therefore vulnerable and at risk of not receiving appropriate support.

Aim: The present study sought to explore individuals' first experiences of HG, and interactions throughout, using an interpretative phenomenological analysis (IPA) approach.

Methods: Lived experiences of HG were explored using IPA. Eight women were recruited via social media. Video interviews were performed remotely and transcribed verbatim.

Results: An overarching group experiential theme, 'Journey to understanding' encapsulated four other group experiential themes, adding an evolving chronological element to HG experiences as they progressed. The other group experiential themes were: "What's wrong with me?", '(How) Can we get through this?', 'What others bring to the HG experience', and 'Looking back, looking ahead'.

Conclusions: This IPA deepens understanding of HG and provides further support that first experiences are especially difficult due to a lack of awareness and knowledge on how to cope. Findings also suggested first-time sufferers are more influenced by external factors, meaning uninformed care can be especially harmful. Despite psychologically informed guidance being available in the UK from as early as 2016, participants still had experiences in the NHS which reflect a lack of HG awareness and therefore added burden rather than relieved it. Suggestions of improvements from patient perspectives is included as well as ways clinical psychologists can support improved HG care.

Keywords: Hyperemesis gravidarum, HG, Nausea and vomiting of pregnancy, Interpretative phenomenological analysis, Women's experiences, Qualitative, IPA, Pregnancy sickness, Perinatal mental health, Women's health, Complications of pregnancy

Introduction

Hyperemesis Gravidarum (HG) is a severe form of Nausea and Vomiting of Pregnancy (NVP), which affects 0.3-3.6% of pregnancies [1]. To move towards a globally accepted diagnostic definition of HG, an international collaboration produced the Windsor Definition, which states that illness must have started before 16 weeks gestation, severe nausea and/or vomiting is present, inability to eat and/or drink normally and strongly limiting of daily activities [2]. Research has linked HG to increased risk of numerous short and long-term physical health issues and psychosocial outcomes for the pregnant individual and the child exposed to HG. These include potentially fatal secondary impact on the pregnant individual from Wernicke's encephalopathy due to thiamine deficiency [3] and refeeding syndrome caused by less careful reintroduction of nutrition following malnourishment [4, 5]. Evidence on the child exposed to HG during pregnancy varies, but some suggest increased risk of low birth weight, children being born small for gestational age, and prematurity [4]; any of which could impact development and later life outcomes [6]. A recent review highlighted slight increases in neurodevelopmental disorders, testicular cancer, and mental health disorders, though the authors urged caution due to poor evidence quality [7].

Active contemporary theories on HG aetiology include genetic, hormonal, immunological and infective factors [8-10]. Historically, HG had been contextualised as a neurotic conversion disorder [11] or linked to hysteria [12]. Reviews inspecting the empirical rigour of the research supporting psychogenic aetiology found it to be lacking [13, 14]. Poursharif and colleagues' [15] qualitative study provided evidence indicating the aetiological evidence shift is not uniformly reflected within medical practice or lay awareness. This could be understood via work highlighted by Munch [16] suggesting that once psychogenic causation is concluded, it persists due to gender bias in women's health research [17].

Management of NVP and HG guidance was recently updated by the Royal College of Obstetrics and Gynaecology [18]. These guidelines recommend psychologically informed support and, where indicated, stand-alone input should be offered. Support could include referral to specialist services or signposting to peer support. The guidance describes mental health difficulties as arising secondarily to HG. Recommendations cited research highlighting HG sufferers having higher levels of somatisation, overall psychological distress, and depression compared to non-HG expectant mothers [19] and more post-traumatic stress symptoms [20]. Depression and anxiety is found to be higher in those with HG [21]; and evidence suggests psychological sequelae continue postnatally [22].

Perinatal mental health needs have been acknowledged by the Scottish Government [23] via strategies linked to funding in addition to updated guidelines from the National Institute for Health and Care Excellence [24]. A UK impact study on HG specifically has not been published, however the national economic impact of NVP more broadly was estimated at over £62m [25]. Figures for HG patients are not provided, but as it is a severe form of NVP, HG likely requires increased use of medical services and has disproportionately high economic impact relative to those with less severe NVP. Negative experiences engaging with healthcare providers has been shown to increase probability of poor outcomes related to HG, such as suicidal ideation, anxiety, depression and termination of pregnancy [15, 26]. Views from healthcare providers and HG patients revealed that medical staff questioned the validity of hospitalisation, attributed psychosocial causation to symptoms, and voiced scepticism regarding severity of symptoms[27]. The views from patients included feeling they weren't deserving of medical care and feeling unpopular with medical staff.

A systematic review of qualitative research on NVP highlighted a need for more high quality qualitative research on this topic [28]. Qualitative research transparent about the views of the author(s) would be welcome. Emergent psychosocial themes included difficulties caring for self

and others; social isolation; a sense of dying, suicidal ideation and termination of pregnancy; and psychological difficulties (including depression, anxiety, guilt, and loss of self). Subthemes included changing plans for more children and a need to take time off work [28]. For some within Poursharif and colleagues' [15] sample, relationship difficulties resulted in divorce and occupational difficulties led to job loss. Nana and colleagues [29] found that rates of suicidal ideation and termination of wanted pregnancies were higher if not offered medication to manage HG symptoms and for those with poorer experiences of medical care.

Canadian research on the experiences of immigrants with HG underlined the impact of lacking cultural knowledge to understand symptoms as it was linked to greater levels of criticism from families, higher levels of stress, anxiety and self-doubt [30]. These findings highlight the influence others can have on meaning-making for HG sufferers, which then impacts how HG is experienced. Lived experience is shown to be especially important in Power and colleagues' [27] action research with medical staff as the three medical professionals with personal experience of HG held more sympathetic views, contrasting with their peers [27]. Having everyone delivering HG care experience the condition personally to illicit more compassionate care is not a viable option. Short of that, well disseminated qualitative research could invoke more humane, less sceptical responses by illuminating HG experiences.

This study aims to explore how understanding of the condition evolves throughout the experience as well as the influence of degree of prior knowledge and others' communication on the experience of HG. One aim is to explore whether the increased availability of evidence-based guidance results in fewer accounts indicating healthcare providers contributed to distress by communicating scepticism, implying psychogenic causation, or denying access to treatment.

Methodology

Design

Interpretative Phenomenological Analysis (IPA) was utilised to elucidate the complex experience of HG as it is a psychologically informed analytic approach well established as a qualitative methodology in healthcare research which acknowledges what the researcher brings to the process [31, 32]. The more deliberate attention to bracketing of researcher bias and the IPA methodology having been designed to understand personal experience made it the preferred choice over thematic analysis. As there is an existing grounded theory of HG [33], a grounded theory approach in this case seemed less appropriate. Smith and colleagues' [34] updated IPA procedure was utilised for this research. Remote semi-structured video interviews were used to collect data. Feedback on aims and study design was sought and implemented from a panel of experts by experience via Pregnancy Sickness Support (PSS).

Ethics

The University of Edinburgh's Clinical Psychology Ethics Committee have granted full ethical approval to this study (Appendix C). The University of Edinburgh's School of Health in Social Sciences Office also agreed to act as sponsor (Appendix D).

Recruitment

Recruitment began on 13th April 2023 via the Facebook, Twitter and Instagram accounts of PSS. Pregnancy Sickness Support were involved as the UK's leading charity for supporting individuals affected by HG. Individuals were invited to participate if they live in the UK, are over the age of 18, had experienced HG for the first time within the last 8 years and had not given birth within the last 6 weeks. UK-wide recruitment was utilised due to the rarity of HG and concerns about a large enough sample not being available locally. First experiences of HG were targeted to explore what

characterised the experience and what contributed to meaning making without prior first-hand experience. The specified recruitment timeframe sought to balance not being so distant that recollection would be hard, but not so recent that they were still recovering from birth and prioritising bonding with their child. Participants also had to be able to provide informed consent, understand spoken and written English (or agree to the use of interpretation and translation to do so), and have access to the internet and equipment necessary to participate in a video or phone call.

The study advert (Appendix F) distributed by PSS linked to a Qualtrics page. Individuals who visited the page viewed the Participant Information Sheet (Appendix E). Those interested in participating proceeded to the Consent Form (Appendix G), which also gave the options of providing feedback about emergent group experiential themes and receiving a summary of the final report. Providing consent took participants to a Contact Details Form (Appendix H), then a Pre-Interview Questionnaire (Appendix I). Microsoft Teams was used to carry out and record all eight video interviews.

The PSS panel of experts by experience also highlighted the male gender of the researcher negatively impacted their sense of trust and safety to be honest about their HG experiences. However, this was offset following the researcher's disclosure of exposure to HG during both of his wife's pregnancies. After discussion with the wider research team, the panel's recommendation to inform interviewees of the researcher's gender and their personal relationship to HG was implemented to facilitate an informed decision about participation.

Participants

Of 153 online form completers, the first 11 to respond were offered an interview via email. Three did not respond to the invitation or became unresponsive, leaving a sample of 8 whose contributions were transcribed. The level of interest greatly exceeded what was anticipated,

meaning the majority (n=141) of respondents weren't offered an interview. Those who were not offered an interview were sent an initial email thank them for their interest, highlighting the overwhelming level of interest and that they would be contacted separately if they were to be offered an interview. After 8 interviews had been conducted, the group of 141 were sent a further email thanking them again for their interest but informing them that on this occasion they will not be asked to contribute further to this study, once again citing the higher-than-expected level of interest. All participants identified as having experienced HG for the first time within the last 8 years. Smith et al. [34] recommend recruiting between 6-10 individuals for an IPA conducted as a requirement of a professional doctorate, which guided the present study. Information gathered via the pre-interview questionnaire is presented below; including demographic details, details relating to the context of their HG experience, and a modified version of the Pregnancy-Unique Quantification of Emesis (PUQE) Index. The PUQE is a measure frequently used to quickly assess severity of nausea and vomiting of pregnancy presentations clinically [35]. This modified version asked individuals to complete the measure in retrospect, thinking of a typical day during the period they were experiencing HG symptoms.

Table 6 contains a summary of demographic information participants provided. Aliases have been used to preserve anonymity. All eight had a minimum of an undergraduate degree and all but two falling in the 35-44 age range, with the others aged 25-34. Aside from one full-time parent and another who is self-employed, the participants were employed on either a full- or part-time basis. All interviewees were married and aside from two residing in Scotland and Wales respectively, they all live in England. Two of the participants have 2 children, with the others all reporting having a single child at time of interview. All but one participant had prior experience of a non-HG pregnancy and all births following HG took place within the last 8 years, meaning most pregnancies were affected in some way by the Covid-19 pandemic.

Table 6: Demographic Information

Alias	Age	Education Level	Working Status	Marital Status	Nation	No. Children	Non-HG Past Pregnancies	Year(s) of HG Birth(s)
Jane	35-44	Postgraduate	Full-time	Married	England	2	Yes	2023
Mary	25-34	Undergraduate	Full-time	Married	Scotland	1	Yes	2022
Amy	35-44	Postgraduate	Full-time	Married	England	1	Yes	2021
Nadine	35-44	Undergraduate	Part-time	Married	Wales	1	Yes	2021
Claire	35-44	Undergraduate	Part-time	Married	England	1	Yes	2021
Brenda	25-34	Doctorate	Part-time	Married	England	2	No	2019, 2022
Sally	35-44	Postgraduate	Full-time parent	Married	England	1	Yes	2020
Holly	35-44	Undergraduate	Self employed	Married	England	1	Yes	2020, 2023

Table 7 summarises responses relating to experiences of participants' first HG pregnancies. Based on responses to items relating to diagnostic criteria for HG based on the Windsor Definition, all eight participants would seem to satisfy diagnostic requirements, though one participant reported not receiving a formal diagnosis. The diagnostic criteria state illness must: have started before 16 weeks gestation; be characterised by severe nausea and/or vomiting; an inability to eat and/or drink normally, and strongly limit daily activities [2]. Two participants sought out mental health support during pregnancy, at least one of whom was privately funded. Three of the eight participants had prior mental health diagnoses, those being Complex Post-Traumatic Stress Disorder, Anxiety and Depression respectively. Six participants were prescribed more than one antiemetic medication, one was prescribed a single antiemetic, and the other participant was not prescribed any antiemetic medication. Scores on the modified Pregnancy Unique Quantification of Emesis (PUQE) Index ranged from 8-15 out of a maximum of 15. Three of the PUQE scores fell within the moderate severity NVP range, whilst the other five fell within the severe range based on HG diagnostic criteria predating the Windsor Definition. Alongside average hours slept, participants reported various comments on sleep including exhaustion as a side-effect of medication, struggling to sleep despite being tired, and poor quality sleep due to nausea. Finally, participants were asked to rate their wellbeing on a typical day during their HG pregnancy from 0 (worst possible) to 10 (best possible). All scores ranged from 0-3 with one response missing.

Table 7: 1st HG Pregnancy Information

Alias	Met HG Criteria*	Formal HG Diagnosis	Mental Health Support Sought during Pregnancy	Prior Mental Health Diagnosis	Prescribed Antiemetic Medication	PUQE Score**	Average Daily Sleep (hours)	Wellbeing Rating (0 (worst) - 10)
Jane	Yes	Yes	No	No	Yes (more than one)	15	18-20	3
Mary	Yes	Yes	No	No	Yes (more than one)	15	12	0
Amy	Yes	Yes	Yes (private psychotherapist)	Yes (CPTSD)	Yes (more than one)	13	10	2
Nadine	Yes	No	No	No	No	8	9	1
Claire	Yes	Yes	No	Yes (Anxiety)	Yes (more than one)	13	12	0
Brenda	Yes	Yes	No	No	Yes (more than one)	12	6	3
Sally	Yes	Yes	Yes (psychologist)	Yes (Depression)	Yes (one)	12	Can't Remember	3
Holly	Yes	Yes	No	No	Yes (more than one)	13	16-20	Missing

**HG Diagnostic Criteria as proposed by the Windsor Definition [2], **The Pregnancy Unique Quantification of Emesis (PUQE) Score comprises responses to 3 items rated out of 5 relating to NVP symptoms, with higher scores indicating greater severity (Appendix I)*

Data collection

Data was gathered during May and June 2023 using semi-structured video interviews on Microsoft Teams. Interviews were recorded and automatically transcribed using Microsoft Teams, then transcripts were manually checked for accuracy and corrected using the original recording. Interviews ranged from 80 to 112 minutes in length with an average of 91 minutes. Participants were supported to describe their experiences and evolving understanding related to HG using an interview schedule (see Appendix J) designed with IPA methodological principles in mind [34]. When interviews were complete, participants were thanked for their time and provided opportunity for a short verbal debrief before being sent a standard Debrief document (Appendix K). Disclosing my own exposure to HG appeared to have the desired effect of eliciting personal events and emotions quickly, though there was still the occasional allusion to the limits of what I could comprehend as a male individual. Questions such as, "How was your experience of communicating with health professionals regarding your HG?" and prompts like, "Can you talk me through who the main involved professionals were?" were used. Feedback was sought and

implemented in relation to this schedule from a panel of experts by experience organised by PSS, particularly with respect to accessibility and appropriateness of language. This included being reminded that individuals who do not identify as women but were born biologically female can still suffer from HG, and so to try to utilise gender-neutral language in materials where possible.

Reflexivity

I am completing a doctorate to become a clinical psychologist. Prior to this I was a clinical associate in applied psychology for over four years. I primarily used cognitive behavioural therapy to help individuals with a range of physical, emotional, and social difficulties appreciate the interconnectedness of our thoughts, emotions, physiological sensations, and behaviour. Since beginning to study psychology in 2005 and over my years of clinical practice I have learned about various models I have brought to bear in the present study to try to better understand and analyse the experiences described. I am also a father of two children, my wife having endured HG during both pregnancies. It was her experiences, and our experiences as a family, which brought me to this topic. I have tried to be aware of the ways my own experiences have influenced my perception of HG as a phenomenon and have hopefully arrived at a transparently reasoned set of conclusions and recommendations. A reflective log was kept throughout as a space to continually explore and record noteworthy reflections in accordance with IPA guidance (Appendix M) [34]. An initial bracketing exercise was conducted prior to data collection to try to increase conscious awareness of what biases in interpretations might be more likely due to personal exposure to HG.

Analysis

Smith et al. [34] outline seven steps for analysing data for IPA. The first involved the researcher immersing in the data by reading each transcript at least twice and rewatching the original recordings. Detailed notes were made relating to each transcript, commenting on language used,

concepts present and descriptions of what was said. The next step involved using the notes to identify experiential statements present for each individual transcript (for an example, see Appendix N). The example demonstrates how the coding and annotation functions on NVivo were utilised to record experiential statements and help develop personal experiential themes. Once personal experiential themes had been extracted for all transcripts, they were compared to look for convergence and divergence across the sample, which helped develop group experiential themes (hereafter referred to as 'themes') and subthemes. If themes and subthemes were present in half or more of the transcripts they were included [34].

In accordance with recommended best practice in qualitative research [36], all participants were asked whether they would like the opportunity to provide feedback on the themes and subthemes extracted from the data. A summary of themes and subthemes was prepared (Appendix O) and sent out to those participants who opted in to this process. Feedback from those who provided it was incorporated into the final report.

Results

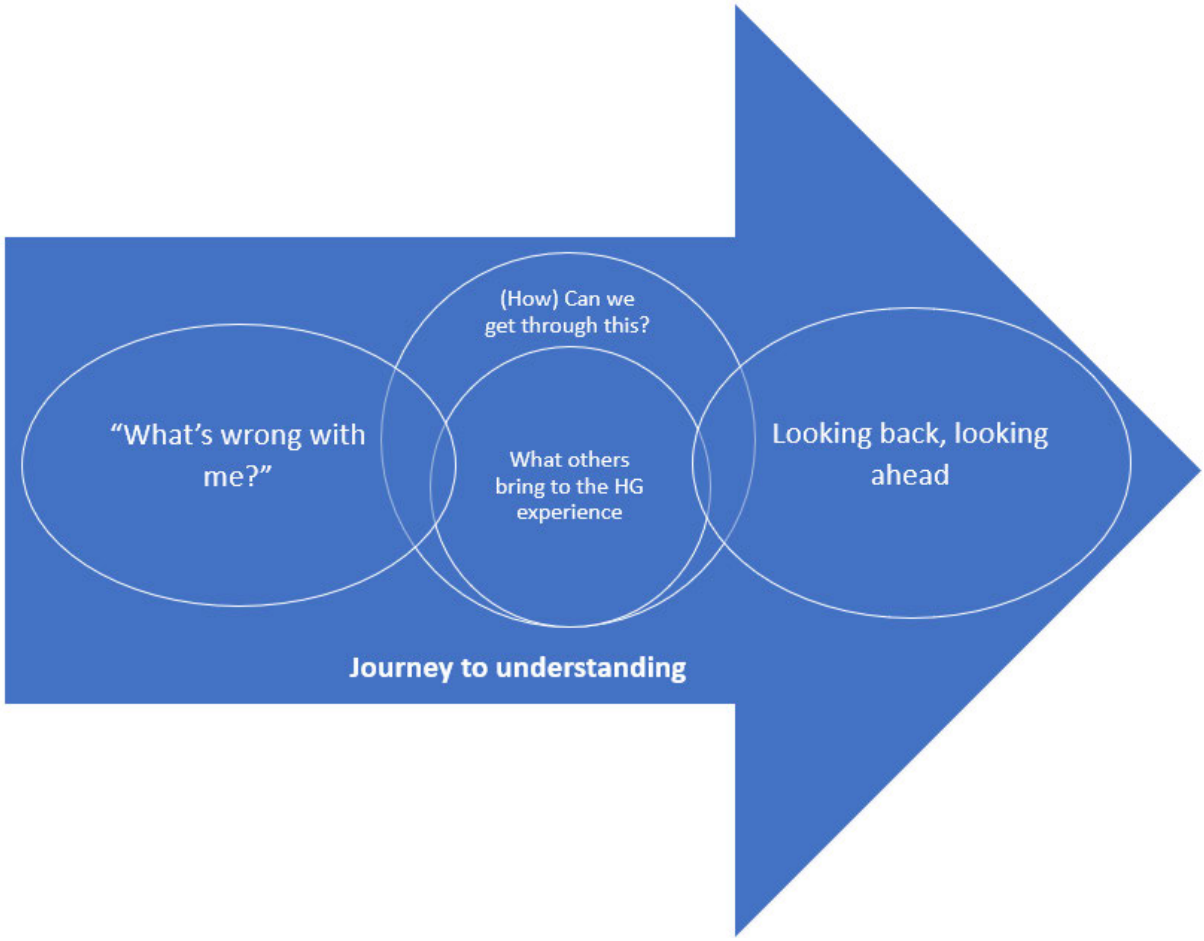
Summary of themes

An overarching theme of 'Journey to understanding' served as a throughline to the experiences. Four other themes were identified; "'What's wrong with me?"', 'What others bring to the HG experience', '(How) Can we get through this?', and 'Looking back, looking ahead'. Each theme had a set of related subthemes (Table 8). See Figure 3 for a visual representation of themes and subthemes and how they relate to one another which shows them flow into one another as opposed to being separate, as well as understanding building over time.

Table 8: Summary table representing themes and subthemes

Group Experiential Themes	**Subthemes**
Journey to understanding	
"What's wrong with me?"	Completely overwhelming Living with uncertainty "Extraordinarily isolating"
What others bring to the HG experience	Being believed and understood Tip of the iceberg "They wanna get you out of there ASAP"
(How) Can we get through this?	HG peers and allies Torn about medication Desperate measures
Looking back, looking ahead	Wanting to block out, but often can't The prospect of doing it again

Figure 3: Overarching theme and themes



Journey to understanding

This overarching theme serves as a throughline representing the understanding of first HG experiences evolving throughout and beyond pregnancy.

> "...sense-making kind of creeped in, I think after that point of being given this label that even with that it was still a kind of journey of figuring out 'cause no one actually explains what that means. It's just, it's something called HG." [Brenda, line 647-649].

Here we can see mention of the iterative process of interviewees making sense over time. There is also an indication of limited professional explanation, as Brenda was not alone in receiving little information beyond diagnosis. Each journey was unique but included HG fluctuating throughout pregnancy, with the physical, psychological, and social impact compromising function and being acknowledged and understood to varying degrees by others.

“What’s wrong with me?”

Expectations of pregnancy typically suggest individuals will be able to continue functioning as usual, perhaps with some discomfort during the first trimester due to ‘morning sickness’. What individuals encountering HG for the 1st time experience violates those expectations, as some describe being too unwell to continue usual routines. They find themselves negotiating the role transition from usual level of function to significantly disabled for some or all of pregnancy. The unexpected magnitude of illness and speed of onset presents the individual with a situation that is hard to make sense of.

> “…I don't think that helps feeling that…you've been weak and you're just not coping well…you're so down as well…it's just knackering…you're physically exhausted, mentally exhausted and…you should be excited and happy…It all just impacts…and just like grows, it's like a big weight on you…you do, just feel like an absolute, like failure like this is something you should be able to do. It's natural…and you're just struggling day-to-day to see it through to the next day, you're considering termination…embarrassing as well…because it's you.” [Mary, line 568-596]

This quote exemplifies the shock at the beginning of many first HG experiences including violation of prior expectations of what pregnancy was supposed to be and what Mary felt she should be capable of. This stage typically predates awareness of HG or consideration that it could apply as it’s “something over there and that's really extreme and really, really rare. So that can't be what I was experiencing” [Brenda, line 349-350]. She may have assumed she was experiencing ‘morning sickness’ which many continue to function through. Interviewees questioned being strong enough to be pregnant without knowledge of a more serious condition. Some feel ashamed associated with feeling they’ve failed to fulfil a natural function. This quote also illustrates the physical defining symptoms at the core, then exhaustion and the mental and emotional impact that grows. The collective impact of HG can be so significant that termination

of an otherwise wanted pregnancy is considered. The upcoming subthemes explore the components which layer upon each other to make the early weeks and months of a first encounter with HG especially difficult.

Completely overwhelming

Descriptions the sample gave of their realities throughout pregnancy were analysed to gain insight into the physical impact of HG.

> "...the sort of narrative that society or movies put out there that in your first trimester, you might be a bit sick...like once or something in the morning or whatever, as the name suggests. But I was so sick, like I felt absolutely rubbish. People talking about these glowy pregnancies where they look amazing and their hair's gorgeous...this was not my experience...the vomiting...was so consistent throughout the entire day and night...only respite I had was when I was asleep...that constant nauseous feeling...it just gets you down..." [Sally, line 813-857]

The mismatch between expectation and reality comes through here alongside frustrations about the term 'morning sickness', which has been described as, "a very invalidating and unhelpful term" [Brenda, line 180]. The term implies vomiting is restricted to mornings and doesn't mention persistent nausea. Contrary to what morning sickness would imply, what is described is a relentless physical experience which left Sally and others feeling awful, including mood being negatively impacted, and only experiencing relief when unconscious. Various participants reported a range of unpleasant sensory changes which made their bodies feel foreign to them and contributed to overwhelm as it felt like they were working against their own physiology; "I had such a strong aversion to water... just the thought...would make me feel sick...so challenging in terms of getting so dehydrated" [Brenda, line 971-978].

> "...I wasn't suicidal, but I didn't want to exist. I wanted to go on standby. That's the way I used to say to everyone. You know when you put your TV on standby? I just wanted to go on standby until it was over. I didn't wanna die...But every day when I woke up in the morning with it again, I didn't want to do the day." [Nadine, line 1896-1902]

Living with HG was so dreadful that Nadine suggests a desire to lose awareness for the duration. These quotes convey oppressiveness; at its worst, the illness is experienced in every waking moment. The sentiment is therefore understandable, though Nadine emphasised that she did not want to die, rather she wished there was a way for her to skip beyond HG.

Living with uncertainty

Individuals expressed uncertainty with respect to what was going on and duration of illness. Without a priori knowledge of HG, some hoped symptoms would cease within the 1st trimester based on awareness of 'morning sickness'.

> "...in your head there's this magic of like, 'Oh, I'm now in my second trimester it's going to subside, and it's gonna get better'...I was at the end of week 13, and there was just zero light at the end of the tunnel...this hadn't lifted...I had no diagnosis. I had no support at all because again, COVID...I couldn't understand why it was so bad. You have no context of how different that experience is from other people's morning sickness...to even be able to process that really and and so in a way that was kind of more challenging." [Jane, line 1960-2011]

Uncertainty regarding duration of NVP increases after passing the milestone transitioning from 1st to 2nd trimester without symptoms resolving. The longer HG lasted, the more it fed into other anxieties about preparedness as some wondered, "...how on Earth am I gonna get ready for this baby? Because I can't even look after myself right now" [Amy, line 1823-1824]. This extra violation of morning sickness expectations provided interviewees with further evidence something

atypical was happening. Jane highlighted lack of context for understanding her experience exacerbated difficulties with making sense. The coronavirus pandemic also made access to medical services and other forms of support more difficult. This reduced opportunity for formal diagnosis, which could have helped contextualise the experience. Reduced opportunities to speak to others knowledgeable or experienced in HG worsened isolation and maintained uncertainty.

"It was extraordinarily isolating..."

Interviewees described HG as a very isolating experience for various reasons.

> "...only my partner really because...I didn't want to tell anyone until 12 weeks...that's the other advice people used to be given...I couldn't even look at my phone...I was getting headaches and things...I think it was a bit of a shock; it was a very fast way to go downhill so there was no time to like, prepare and chat to people or ask for help...I just felt like I was in a pit of misery and better alone." [Nadine, line 677-700]

In her personal life, this participant only had her partner to speak to about her experience partly because of the societal practice of not announcing pregnancy within the first trimester. The practice isolates the pregnant individual (and possibly their partner) and discourages discussion of miscarriages. For our interviewees, it meant they felt obliged to keep their pregnancy and HG symptoms private, restricting access to support. Nadine's symptoms were also intensified by looking at communication devices, which made it harder to reach out. Hypersensitivity of one or more type aggravating nausea is common in HG and can motivate some to isolate; "...I couldn't go downstairs because...I could just smell the food in the kitchen, like it was awful" [Mary, line 1369-1370]. Nadine also spoke of symptom onset being so rapid that she couldn't establish a support network. The quote ends reminiscent of a depressed presentation, as she concludes she is "...better alone".

> "... it's only you that it's happening to...people can't understand, and there's only so many times you can...try and explain it...it did make me go into myself a lot...the more you're not...talking and sharing to people, the more you are...alone with your thoughts and trying to make sense and trying to desperately...make it better...feeding into all sorts of...unhelpful cycles." [Brenda, line 2030-2051]

This quote speaks to the internal aspects of HG experienced exclusively by the individual. Exasperation was expressed regarding repeated efforts to inform others of her experiences who struggled to understand what she was saying, which unfortunately led her and other interviewees to withdraw and stop trying to educate. Isolation provided time to internally make sense of and find solutions to what was happening, which Brenda came to realise in her case led her to push herself harder in ways that may have inadvertently worsened her symptoms.

> "I felt like I...needed to protect him from that a little bit I think...Because he had so much else to take on that I didn't want to add to that burden with just how frankly miserable I was...It was extraordinarily isolating." [Jane, line 3106-3131]

Even though partners were described as supportive, this demonstrates why some felt a need to deal with their emotional pain alone. It was reported that partners supported practically, including taking over the others' share of domestic tasks and childcare, researching HG, and caring for them when they were unable to themselves. Surmising how their partners were doing seemed to cultivate reluctance to add any further burden, which unfortunately led those individuals to greater emotional isolation.

What others bring to the HG experience

Accounts of our interviewees' interpersonal interactions revealed that others have the potential to add to or reduce the burden of HG. This included friends and family, employers and colleagues, and healthcare professionals (HCPs).

> "...they're like, 'Oh yeah, well, I had that and I took ginger and I was fine'. As if! Especially people who are not aware of HG kinda don't realise how bad it is and how serious it can get. So they are thinking back to their experience where they maybe had quite a bit of...pregnancy related sickness...but maybe not to the levels of HG. You can feel like...you're milking it or as if you're weak, sometimes you get that kind of judgement feeling as well." [Mary, line 605-615]

Here we have what has been experienced as a misguided attempt at being helpful from someone with experience of milder NVP. Equivocating this to HG frustrates as it communicates a lack of appreciation of magnitude of illness present. Individuals describe feeling judged in a way that echoes some of the early self-judgement during the initial phase of working out what's happening when they believed they were struggling more than most with 'morning sickness' before learning of HG. The quote ends highlighting how horrible one can feel when they fear someone else is repeating this appraisal.

> "...when someone loses weight I think society generally views that as a positive...I'm not an angry person...the impulse to hit someone is like, so far removed from me as a human, but...I had rage towards people who would say these things to me...there's just so much bottled up...It just showed...they clearly didn't have any comprehension of how unwell I had actually been" [Jane, line 1041-1085]

Jane's efforts to understand why her friends thought she'd welcome complements on her weight are evident, despite having said it was the result of illness. She alludes to a societal tendency to value weight loss regardless of means. She went on to mention, "some of it's my fault because I didn't give them the context, but...I had no emotional bandwidth for...anything other than putting one foot in front of the other..." [Jane, line 1114-1116], which shows an awareness within the interviewee that they were in "survival mode" [Amy, line 4348], so couldn't provide all of the information about what is happening. A combination of lacking the physical and emotional

capacity to communicate effectively at the height of HG symptoms will be touched on throughout this theme as difficulties self-advocating was spoken about often. There seems a progression of emotional responses to not feeling understood within the sample, often starting with feeling disappointed and questioning own perception. As interviewees became more certain of their experiences, others demonstrating a lack of understanding generated increasing frustration.

Without HG awareness, others seem to try to contextualise experiences as something they are already familiar with, rather than something new. This mirrors the starting point of individuals' first HG experience, who think it's morning sickness until they're faced with too much contradictory evidence. With access only to what can be observed or conveyed, the process of understanding seems slower for those communicating with the affected individual. Interviewees focused more on and brought higher expectations to healthcare contexts as they "...placed a lot of trust in medical professionals" [Brenda, line 1391].

Being believed and understood

As the interviewees approached their initial interactions with HCPs they were seeking support and validation that their experiences were more serious than typical NVP.

> "...We were both just so desperate (for) this appointment thinking like, 'you're so ill, someone's gonna be able to help us'. That did not happen...this is where the...'morning sickness'...label was just really, really unhelpful cause she was saying, 'Oh yeah morning sickness is difficult, isn't it?'...really dismissed and invalidated what I was going through...completely shut me down" [Brenda, line 1163-1194]

To have approached this appointment desperate for help only to come away feeling this way seems hugely disappointing. Brenda felt conflicted as to whether her experience was the result of a lack of strength on her part or because of a more serious condition. The midwife's language tipped her towards the former, leading her to persevere until she "...ended up in A&E" [Brenda,

line 1226]. The reverence with which people can view a HCP's words make them harder to ignore. Interactions like these impacted interviewees emotionally, influenced choices, and informed sense-making. Some participants "…read optimistically that 'oh, they think it's okay, you know, they would say something if it wasn't OK'" [Claire, line 806-809] if their HCPs didn't suggest something more serious might be present, but reassurance was short lived as symptoms maintained.

> "…that diagnosis said to me there's a very good chance that this is gonna last at least until 20 weeks…it has been identified as being an abnormal experience…from an emotional standpoint, that helped a lot." [Jane, line 2036-2054]

A different tone is clear, with a greater degree of validation and containment from Jane's experience being named as distinct from morning sickness. The act of diagnosis communicated to Jane that she was taken seriously, and her experience was legitimised officially. It also allowed some of the initial uncertainty to be addressed regarding what was happening, whether it was normal and duration. This appears to have been helpful emotionally, even if the physical experience continued.

> "…they sent me home with big, massive antibiotic tablets. When I say there's…no chance I'm keeping that tablet down they…just said, 'Oh just give it a try, it's just a bit of sickness'…ended up back in hospital…for three days…because I was so severely dehydrated…they were both quite dismissive…they just they didn't seem to take me seriously…as if I was a bit of a drama queen…I really didn't want to go back into hospital cause the way I was treated the day before…we really seriously considered termination." [Mary, line 632-694]

This quote demonstrates how treatments offered, and language used, can communicate poor understanding of HG and a refusal to take the patient seriously, leaving Mary feeling she was being perceived as overdramatic. This left she and her husband upset, frustrated and considering

whether a termination was going to be necessary, as those entrusted with her care and that of her child didn't believe her, leaving her reluctant to go back. She was left wondering if "...they realised...when you're already suffering so much mentally from HG, that their actions can then impact..." [Mary, line 921-922] how she feels.

Tip of the iceberg

For those who received an HG diagnosis, this was generally a helpful milestone which led to improved understanding. In terms of ongoing interactions though, it was commonly reported that others struggled to appreciate the wider impact beyond the observable physical symptoms of HG.

> "...it's like an iceberg and there's that focus on...vomiting you know, and everything else...It's like it doesn't exist, but actually...that's what impacts them...that's what they remember about it." [Amy, line 2960-2982]

An effective analogy is used to convey that most of what was contributing to Amy's experience of HG was not acknowledged. Emphasis seems typically on more observable symptoms like vomiting and dehydration. She described the medical focus as only on the tip of the iceberg, when for her it was, "more about the nausea and it's about the impact that it has...on your entire life and your ability to function" [Amy, line 2909-2910], which felt neglected below the surface. This typifies the dynamic between HCP and patient for most of this sample, in that women felt HCPs prioritised doing what was needed to continue the pregnancy but had less to offer for nausea and less observable secondary impact on things like mental health and functional capacity, leaving interviewees feeling partially understood at best.

> "...that really kind of stands out...throughout pregnancy...it kind of is...baby, then your pregnant body, then you are kind of somewhere in the background...Never really a

> question of, 'how is it impacting you and how are you feeling and how are you doing with all of this?'" [Brenda, line 2439-2467]

This quote conveys how fragmented Brenda felt because of what was and wasn't attended to. She felt her physical body and unborn child were prioritised, leaving the other aspects of her feeling forgotten. Others echoed this sentiment as "...I didn't get any help for my mental health because I was...concentrating on dealing with the HG..." [Claire, line 172-176]. Surviving the relentless daily impact of HG left little room for interviewees to attend to their mental health, and so support would have had to be offered from outwith.

> "...I opened the door...in every appointment...how hard it was physically, but I never really properly opened up about how hard it was mentally...It wouldn't have taken much because it was so close to the surface...in retrospect it had to have been pretty clear...anyone who would have thought about the situation I was in...would have gone, 'There's no way you're OK. There's absolutely no way that you're OK. There's no way to be that sick and for that long and be OK.'" [Jane, line 3537-3567]

This quote talks about the interviewee having provided the information required to surmise a mental health need, without explicitly stating it. Despite this, it wasn't enquired about or addressed. The mention of how clear she feels it would have been to someone considering her circumstances suggests she felt the HCP wasn't paying attention beyond the physical aspects she was focusing on. Similar accounts didn't attribute this to malice, instead suggesting "everyone's doing the best they can with the resources they have but they don't have enough" [Jane, line 3583-3584]. As interviewees attended appointments throughout their pregnancies, several felt "a bit like a number" [Claire, line 1582-1583], stemming from HCP appointments experienced as going through a "checklist" [Amy, line 3928] and being aware of "a line of people waiting" [Jane, line 3528].

“They wanna get you out of there ASAP”

The sense of resource scarcity left interviewees feeling rushed and that HCPs didn’t have capacity to think beyond their specific task. This alongside depleted physical and emotional bandwidth for most interviewees made for an unhelpful combination.

> “It's really hard to advocate for yourself…when I went into A&E, my sister came…cause I couldn't even talk and they sent her away…they're so busy and they wanna get you out of there as soon as possible…I'm 37…not 85 with a breathing difficulty and they're like, ‘alright, get her out of here because she doesn't need to be here’…just feel like you're this inconvenience…” [Holly, line 1039-1115]

The interviewee was left feeling like a nuisance despite being desperate for support. Holly rationalises her experience, surmising that the HCPs prioritise those with more life-threatening needs, which in a context of resource scarcity leaves her being rushed out. She and others mentioned difficulty speaking up for herself due to struggling “to think straight” [Amy, line 354], highlighting the cognitive impact of the bodily strain. Holly’s sister was sent away due to pandemic restrictions, which exacerbated self-advocacy difficulties associated with HG. The perception of the services being too overstretched to do anything about it seemed to inhibit participants’ appetites to disclose their struggles completely. Feeling an intense need for support, but that there isn’t enough available left some of our interviewees questioning how they could continue.

> “…the empathy was almost worse because it made me feel weak like, ‘Oh, I'm really sorry…you feel like this.’ …it just felt like lip service to get me out…it didn't help. Someone logical with a plan with some ideas…could help. ‘Have you tried this?’ and ‘Can we try this?’ and ‘If it doesn't work come back and this…might happen with the medication…’ just some sort of plan rather than someone just watching you cry and offering you a tissue.” [Nadine, line 1656-1678]

A sympathetic response from the doctor did not have the desired effect, but instead left Nadine feeling weak and unwelcome. Despite guidelines existing to guide medics [18], she appears not to have experienced the type of plan she described. Lacking a clear plan left her thinking, "...they thought I was going crazy" [Nadine, line 2695] as her condition felt unacknowledged and not worked with. This experience exemplifies that HCPs missing a key component of the HG experience, be it physical or emotional hardship, can be experienced negatively.

> "...she has the ability to write a script...without consulting with somebody else...access to the type of treatment that I needed and access to her was so readily available. But I always felt listened to; She no way diminished...the severity of how shit I felt or the illness so that was really lucky." [Sally, line 692-718]

Unfortunately, we must look to the individual in our sample who utilised private healthcare to find a care experience which attended to a fuller range of needs. Here we see Sally describe benefits of an obstetrician-led pregnancy, a single consultant involved throughout her experience and available as required. She felt heard and that the illness and the emotional impact were acknowledged. There are numerous ways others can add to the HG burden, but we end on a hopeful note, showing the potential to meet needs well enough. How and whether this can be delivered consistently in an NHS context is a key question.

(How) Can we get through this?

After the initial impact of HG and a sense of available support has been established our participants consider whether the pregnancy can be endured alongside their available adaptation resources.

> "...you don't want to admit how bad it is...I think there's a lot of lying to yourself during HG...I used to get like...really sorry for myself...and then like the next day just...like, 'Right,

> naw just need tae power on'...a lot of my coping mechanism was just pretending it wasn't as bad as it was or trying not to think about it too much." [Mary, line 1657-1680]

Several reported staying occupied in some fashion was helpful. This quote describes convincing oneself into thinking things are better to avoid the dire reality of circumstances, akin to a degree of dissociation from experience utilised to persevere. Some were frustrated as they wanted to more actively improve their situation but couldn't, so questioned, "...why am I not making it better?" [Brenda, line 2913]. Because "it was a big shock...no chance to adjust...no chance to plan...just survive" [Nadine, line 2006-2012], coping strategies were often improvised with what was available. The pandemic provided those who felt able with a way to continue jobs as remote working increased.

> "...there is no way that I could have done any of that without...just talking to someone about being so ill and dealing with the pregnancy and how it affected the pregnancy...how do you embrace this life giving...process that's happening...when you feel so crap?" [Sally, line 1870-1908]

Sally used private therapy to access emotional support which she experienced as helpful for reconnecting with why she was enduring such hardship. She represents a minority within the sample who accessed therapy during pregnancy, though others described similar benefits from discovering via forums that "There's other women out there going through what I'm going through" [Claire, line 1477]. Both examples allude to reducing the emotional toll of HG, with the latter achieved online for those who found helpful forums or social media accounts.

HG peers and allies

Those interviewees who encountered peers spoke positively about interactions with HG experienced and informed individuals.

> "...she's got that understanding, compassion, so...the first couple months where I was, you know getting a handle on it...she'd come round...help me try and find foods to...keep myself going...having someone there that understands...being able to chat with your friend once a week" [Amy, line 2692-2717]

Compared to interactions with less HG aware individuals, interviewees seemed to experience speaking with HG peers who just 'got it' as like finding water in the dessert as they felt recognition and acknowledgement of their experiences. Amy describes appreciating the support of an HG-experienced friend. Some interviewees accessed peer support through Pregnancy Sickness Support (PSS), but some weren't aware of this charity or chose not to as they didn't want to talk about their HG. Describing HG experiences and being met with compassion and relatability rather than confusion or scepticism was greatly valued within the sample. Some alluded to limitations of textbook-based HG information, stating that "...there's a difference to experiencing it versus...academic kind of understanding of it..." [Sally, line 1957-1963]. When it came to normalisation and reassurance, one interviewee reflected, "I recognise a lot of that needs to come from something like a forum...doesn't need to come from a midwife or a doctor" [Amy, line 2894-2897]. Based on other examples, if the recipient didn't feel reassured from a position of HG awareness, it was harder to take at face value. Personal experience of HG conveyed that awareness quickly and seems harder earned for most HCPs who will lack said experience.

> "...it was on the pregnancy sickness Instagram page that somebody had labelled it dry HG...that helped me...to think, 'Okay, So it is...' even though I already knew it was, even now I'm surprised that helped...rather than just, 'Oh well, I had HG without the sickness.' To say, 'Actually I had dry HG' was...made it more realistic...more...Accepted" [Nadine, line 2972-2988]

This highlights variety within HG, Nadine having experienced 'dry HG', with persistent nausea but little or no vomiting. Her experience produced uncertainty regarding identifying with an HG

diagnosis, but encountering this message via PSS was a reaffirming sign of acceptance by that community. Organisations like PSS also provide information on "...how to approach talking to a doctor which was fantastic..." [Claire, line 1468-1469] for navigating discussions about access to medication and other forms of treatment.

> "...the fact that his wife had gone through the same thing...it gave a sense of understanding and I wasn't having to constantly explain...I only needed to tell him and then he was...like, 'No, this is serious...this is what she needs' kind of thing." [Jane, line 891-894]

Benefit was also described from interactions with HG allies; individuals without first-hand experience, but knowledgeable such that little explanation is required before appreciation of needs and experiences of individuals with HG is achieved. The quote exemplifies what is valued from interacting with individuals with HG awareness, as Jane did not have to justify herself excessively to illicit a helpful level of understanding and support at work as her senior colleague's wife had experienced HG. Partners also often became HG allies as, "...I don't think that he ever questioned the legitimacy of it, because he was bearing witness to it." [Sally, line 3041-3045], bestowing greater insight than most into the extent of HG impact.

Torn about medication

Aside from rehydration via drip, antiemetic drugs seemed the main treatment offered for management of HG, however the decision whether to take medication was not an easy one.

> "...it's tricky because...I had...miscarriages...I don't know if I was a bit closed off to medication because I didn't want, you know, you you read the risks, don't you? I read the research studies and...there's always an unknown and I didn't want to have any part of that." [Nadine, line 1788-1815]

This demonstrates a significant source of anxiety throughout the sample; that being a lack of research on safety of antiemetics during pregnancy. Nadine highlights that miscarrying in the past led her to be especially cautious regarding potential risk to her unborn child, even though she was suffering greatly with HG. This resembles where most interviewees started when considering medication, feeling conflicted between possibly alleviating some personal discomfort against unknown impact on the new life they feel responsible for. Nadine's experience of pregnancy loss may have biased her decision making and interpretation of research, fearing the possibility of her actions contributing to future loss and guilt, thus motivating her to endure further suffering without medication. How HCPs spoke to interviewees influenced decisions; "I had one doctor who'd been through it herself…How she talked about it was just really, really helpful in removing any guilt or worries around it." [Brenda, line 3510-3514]. This demonstrates more support for the peer effect, Brenda attributing more credibility to this professional opinion as it came from someone who she felt could appreciate her dilemma more completely.

> "You just finally come to accept, like, I've got this thing…I need help with it and then the GPs…they're still kind of reluctant to prescribing things which made me really anxious…so I wouldn't take the medication…regularly and just…a real battle of actually accepting…cause every time it would be, 'Risks to baby'…" [Brenda, line 1269-1279]

Brenda's conflicted feelings regarding whether to take medication were exacerbated by how others interacted towards her. The quote conveys that several prescribers communicated varying comfort levels prescribing antiemetics during pregnancy, which she experienced as cause for worry, leading to an internalisation of prescriber anxiety. Anxiety about medication safety led her to feel "…they didn't really help, both because I don't think that they were strong enough, but also because I was too scared to…actually take them regularly." [Brenda, line 1294-1298]. Others experienced similar difficulties with prescribers or dispensing pharmacists, the hesitancy in each case communicating a sense of risk.

> "...it caused such extreme headaches and drowsiness I couldn't and plus the nausea...so I stopped taking that...I wasn't told, '...continue on and it might...improve or...headaches might stop.'...I didn't know that there was a...treatment plan on, 'If this doesn't work, try this or there's a stronger one...'" [Nadine, line 1593-1622]

Of those who tried medication, many encountered side-effects. The quote highlights that more information on side effects, including duration, could have led to different outcomes. For Nadine, adding headaches to her existing symptoms was intolerable so she ceased after 3 days, the lack of information about side-effects and alternatives leading her to disregard medication as a helpful option. Her language suggests she felt she didn't have enough information to make informed decisions. For those who did persevere with medication, a common sentiment was that "It stopped me actually physically vomiting, but it didn't take away the constant kind of nausea that I had" [Claire, line 319-320], suggesting benefits were restricted to reducing vomiting. This helped and restored some meaningful function to individuals, but several reported being more bothered by the nausea. Not being offered anything to manage nausea was frustrating and contributed to feeling partially understood and attended to.

Desperate measures

Some interviewees faced difficult choices as they reached what they experienced as the limits of available support, leading to consideration of desperate solutions.

> "...I had a lot of concern...about the nutrients for the baby, so one of the midwives in passing mentioned that if I can keep food down for at least an hour, the baby will get a lot of the nutrients that it will mostly need...So what I then, just had to do was when I was being sick, swallow my sickness, which was awful, absolutely awful. But I was obsessed with keeping food down for, like, an hour or so...I think that's what caused a lot of the long-term impacts with eating issues and stuff like that..." [Mary, line 1294-1312]

The quote describes why Mary resorted to swallowing her vomit to keep it in her system long enough to absorb nutrients for her child. Her GP had expressed that they were at the limit of primary care support and that referral to hospital could only be made by a midwife, who did not feel a referral was warranted. This left Mary feeling she had exhausted professional support options and that she would have to improvise solutions on the matter of nutrition for her child. This powerfully demonstrates the desperation some can feel and determination to ensure the wellbeing of the life they're responsible for when feeling additional professional support isn't available. It's also a poignant example of the power of language and the reverence with which the words of HCPs are treated.

> "...I went to the the darkest place I've ever been in my whole life...I had...dreams of, like, stabbing myself in the womb to kill the baby like...oh God...there just wasn't really the support with it...on the other side of this, I'm I'm trying to go well, 'I'm a mum and I need to look after my kid and I'm also self-employed, so if I don't work then I don't get paid anything'...and I was like, 'Well I'm in no fit state to go to work'." [Holly, line 1205-1231]

This vivid insight into Holly's internal world illustrates her struggle with HG whilst aware of her inability to provide for or parent her two-year-old. She experienced her disturbing dreams of self-mutilation as her body communicating that the pregnancy couldn't continue as sufficient support wasn't available. A subsequent HG pregnancy was so intense that she expressed, "...if the dehydration wouldn't kill me, I would have committed suicide..." [Holly, line 966-967], again demonstrating she was finding it unbearable and wanted it to stop. She faced a horrible choice; to return to supporting her child she was going to have to end a pregnancy.

> "I felt like HG's dirty little secret because I'd had two abortions. I'm not like the happy poster girl that...has been so brave...with the baby at the end. There's no baby for me...no one wants to hear 'cause it's like, 'Oh she did that, that's not nice.' But...because of all the

> circumstances and and all the experiences, I just didn't have any other option" [Holly, line 1372-1450]

Holly feared others in the wider HG community would judge her negatively for not having found a way through based on the choices she felt she had to make based on her circumstances. She imagines what others would say about her and compares herself unfavourably to 'the happy poster girl' of HG. This is something Holly has been able to explore in therapy, which has helped her to process the experiences and grieve for what was lost. She also highlighted how hard it is to endure all that HG involves, "once you've been through that one time and you know that there is that switch that will give you the release from the hell that it is" [Holly, line 867-868].

Looking back, looking ahead

Many felt they only found the opportunity to reflect and attempt to understand what had happened after their HG experience had concluded, which then influenced how interviewees moved forward.

> "It's really difficult to wrap your head around anything when your head's in a toilet…definitely there were quite a few layers of…psychological impacts going on which wouldn't have helped…with all of the physical symptoms…of the HG as well." [Sally, line 1787-1803]

Sally succinctly expresses why it can be difficult to reflect on what's happening during the HG experience. Daily survival can demand considerable attention during HG and so it's understandable that some of the secondary impact, such as the psychological factors, didn't become fully apparent to our interviewees until HG had resolved. Without constant nausea impacting cognition, "I feel like I was able to process it afterwards. Like after it was over, I felt like I was able to process what had happened and reflect on it, and everything." [Amy, line 3024-3033].

> "...it's probably gonna take me a good few years...my teeth won't recover...I used to walk 10,000 steps a day...by the time baby's here...I'll walk 10 minutes down the road and...I'm done...That's eight months of my life that I've not been able to do things...so rebuilding on all levels I think." [Amy, line 4779-4814]

Due to factors such as fatigue and nausea, several interviewees had reduced activity considerably, losing physical conditioning and social connections. This quote mentions common examples of some of the sacrifices participants made, including the dental toll excessive vomiting takes. Amy wasn't alone in feeling that during the pregnancy, "you kind of forget what normal actually feels like until all of a sudden...the veil lifts and you're like, 'Oh right, this is who I am.'" [Jane, line 4107-4111]. The pregnancy term was experienced as enough time to update participants' sense of normality, so it was after HG resolved that they could begin reconnecting with themselves and rebuilding physically, emotionally and socially.

Wanting to block out, but often can't

A commonly reported impulse was trying to block the HG experience out after symptoms had resolved. Reflecting on the HG experience likely wasn't an attractive prospect for our sample as resolution of pregnancy meant new parenting responsibilities or painful loss to negotiate alongside any lasting complications of pregnancy.

> "...eight months after, I had a massive panic attack...I knew it was my body telling me you haven't dealt with this...after I gave birth I was like, 'Right, that's it. It's over. I never have to do that ever again if I don't want to. Put it in a box, put it away.'" [Claire, line 1953-1957]

Claire's desire had been to put the HG experience behind her following delivery of her child, but she felt her body had other ideas, communicated via a panic attack. The reference to never having to go through the experience again could refer to future pregnancy or revisiting her HG experience. Various interviewees described experiencing HG as traumatic and sought to avoid it,

but ultimately found benefit from integrating the experience; "...therapy...has enabled me to...move towards finding a...way through it...I don't wanna say like moving on from it cause I don't think you do" [Holly, line 3576-3580]. Holly and others found benefit from professional support to safely revisit their HG experiences.

> "...it's really traumatic...there was times when I would just be so sick that I couldn't breathe...feeling like I was gonna die...it's just really hard when you just go from something so intense like that to just...having to kind of carry on...when I feel like ill or feel sick it takes me straight back to that place and that kind of panic of, 'It's not going to go away and it's gonna...feel like it did before'..." [Brenda, line 3019-3056]

This quote provides examples of what was experienced as traumatic; being sick with such frequency and intensity that it complicated breathing and caused fear for life. She explains how difficult it was to switch from such a terrifying context to suddenly having to function normally, potentially with limited opportunity to process what happened as "you're thrust into having a newborn...you can't massively look back" [Nadine, line 2311]. Other indications of trauma are evident as "...it is quite triggering talking about some things...and some smells...I do remember how strong things brought it back on...Everyone says, 'You never forget childbirth', but I actually think I remember the HG more..." [Nadine, line 2953-2963].

The prospect of doing it again

Following their HG ordeals interviewees reported reducing or completely ruling out the possibility of more children, even if a larger family had been hoped for previously. Knowledge and experience from first HG pregnancies influenced how individuals approached any subsequent HG pregnancies.

> "...even though I felt worse, I've managed to keep food and drink down more this time...I'm advocating for myself and prioritising what I need to survive...like, '...I'm going through

> something that's hell and that's what I need to focus on…not everything else for everyone else'…it's easier this time…but first time…you don't have that awareness" [Amy, line 2592-2634]

Despite HG feeling more intense during a subsequent pregnancy, Amy reported prioritising herself and managing the physical symptoms came more easily with the benefit of wisdom from her first pregnancy. Others also spoke of finding self-advocacy easier during subsequent pregnancies; "I felt more confident to kind of say, 'This is what I'm struggling with, this is what I need, which was not the case in my first pregnancy at all." [Brenda, line 240-242].

> "…my 5-year-old…he says to me, 'Mummy, where's the baby gone?' And I'm like, 'Yeah, I don't really know how to explain that to you just yet…the baby's not there anymore.' But what else do I say? …One day I'll be able to explain…he's not going to have a sibling because…because of this…in the bigger picture, it is what it is, but for…our lives…it's everything." [Holly, line 1945-1962]

Holly hadn't had HG with her 5-year-old, so was blindsided during subsequent pregnancies. She had also miscarried previously, so didn't take the decision to terminate lightly. The fact that she felt left with no other choice is testament to the devastating impact HG can have on an individual and their family circumstances, which in Holly's case included existing parenting responsibilities and being self-employed. Her first HG pregnancy also occurred as the Covid-19 pandemic began and her partner was a key worker, resulting in limited support and leading to the tragic situation described in our quote. Holly's words were full of regret for the lives that couldn't be realised. A commonly expressed sentiment following HG pregnancy was that "HG has had a limiting factor on my life choices about whether I want to do that again and we've had to seriously think about whether we want to…to have another child." [Claire, 2909-2932].

> "…when I was pregnant with Freddy, I was adamant… 'Definitely never doing this again'…if we hadn't lost Freddy, that probably would have been the case…but…They have said that

> I should have a much different experience in another pregnancy…I would be under the hospital care right from the beginning and…they would make sure they have a different plan in place…" [Mary, line 3246-3329]

In the late stages of Mary's pregnancy, signs appear to have been missed that she was dangerously unwell; tragically Freddy died two days after his birth. Mary relayed that a review concluded more could have been offered to help her manage HG. She conveyed that pending promised improvements to healthcare provision she is open to the possibility of future pregnancy. It is noteworthy that following a devastating outcome to a horrific experience, the promise of better-quality care elicits openness to the idea, even though "people say like it gets worse with each pregnancy" [Sally, line 1504]. Experiences like Mary's demonstrate the importance of external support and how influential it can be on the HG experience. It was striking that she managed to maintain hope after a family tragedy alongside ongoing difficulties with cyclical vomiting and refeeding syndrome.

Discussion

The current IPA sought to gain insight into individuals' first experiences of HG. The data indicated a 'Journey to understanding' occurred whereby interviewees spoke of what characterised their experiences and influenced sense making throughout and beyond pregnancy. Initially participants asked, "What's wrong with me?" at illness onset; then discovered, 'What others bring to the HG experience'; before asking '(How) Can we get through this?' to examine difficult decisions and coping strategies; then finally 'Looking back, looking ahead' for reflections on the experience and the future.

The question, "What's wrong with me?", took on a dual meaning as individuals wanted to know why they were feeling so unwell when unfamiliar with HG but also wondered, 'What's wrong with *me*?' related to violated pregnancy expectations and comparison to others. The former was a source of worry while the latter was associated with self-judgement and lowered mood as participants felt they were failing at something that should come naturally. Not having answers to their questions led to anxiety, while not being able to relate to others' pregnancy experiences left them feeling isolated. Although it wasn't always explicitly stated, seeking to understand the underlying psychological constructs associated with this early stage of the HG experience indicated a powerful sense of failure for struggling with something the participants expect themselves to perform naturally. A deep desire not to want to reveal this 'failure' to others and difficulty relating to them contributed to a felt need for isolation and subsequent experience of shame. Poursharif and colleagues' [15] mixed methods study also found participants mentioned social isolation, feeling like a failure, and missing out on the pregnancy experience they felt others were having. The magnitude of the experience left our participants feeling overwhelmed physically and mentally. This also featured as an overriding theme from patients' perspectives in previous research, emphasising relentless symptoms and the emotional impact of the ordeal [27]. Altered sensory experience such as sudden aversions to things and uncharacteristic

preferences for others also contributed to feeling overwhelmed. These findings provide insight into higher rates of anxiety and depression found in quantitative HG research [22] alongside sources of distress in later themes. The uncertainty resultant from first encounters with HG alongside isolation and relentless physical symptoms made for a vicious combination, helpfully captured in the present study to aid understanding of early HG pregnancy difficulties and choices.

This study sought to better understand the role others play in the overall HG experience as effective support is vital when someone is so unwell during pregnancy. The theme of 'What others bring to the HG experience' emerged as a significant topic, highlighting the potential to relieve or add to the HG burden, with healthcare experiences receiving particular attention. Interviewees often felt dismissed and that others did not appreciate or address the whole HG experience. These features helped identify a further underlying psychological factor occurring throughout the data; that being the impact of relationship ruptures as others not only failed to provide what was felt to be needed, but also communicated in such a way that actually reinforced the senses of failure and shame. These ruptures contributed to the profound sense of isolation and were pervasive in personal lives, work settings and in healthcare settings. This mirrored accounts of those who reported poorer healthcare experiences in previous studies, where individuals were doubted, dismissed at first, or assumed to be suffering from milder NVP, leaving them to get worse before action was taken [15, 37]. Individuals were left frustrated, doubting themselves, and feeling unseen. Van Vliet and colleagues [37] and members of our sample suggested improved HG awareness would reduce these upsetting, unhelpful experiences and emphasised how difficult it is to assert oneself when so unwell. Our analysis suggested first time HG sufferers are especially vulnerable to difficulties with self-advocacy as they're communicating whilst still trying to learn about the condition themselves. Those experiencing HG on subsequent occasions reported fewer difficulties speaking from an informed position and benefitting from HG wisdom. Interviewees feeling HCPs implied psychogenic causation or exaggeration echoed previous

research speaking of an extensive history of gender bias clinically and in research relating to women's health issues including HG [14]. This replicates the finding that despite the discrediting of research supporting psychogenic causation, evidence of it continues to pervade HG care experiences [15]. Our interviewees also felt frustrated and unsupported as they believed others lacked sufficient time or resources for them. This finding could be more present in the UK context due to current difficulties and narratives regarding the NHS. Parallels with previous research were identified in that length of relationship with physicians influenced how they responded to patient complaints; if they knew the patient as someone not to over-react, they'd respond more urgently to medical complaints [38]. One of our interviewees contrasted the reaction of her non-medical employers, who knew her not to take time off unnecessarily, against HCPs who only knew her in the context of an HG pregnancy and were dismissive and seemed quick to assume exaggeration. Another common finding is the positive impact of a consistent relationship throughout pregnancy with one doctor [38]. Where this occurred in our sample the result was positive, but most saw several clinicians so struggled to establish shared understanding sufficient to make honest disclosures feel safe. Power and colleagues' [27] action research included focus groups with HCPs which provides insight into our participants' healthcare experiences. Themes included questioning appropriateness of using hospital resources; belief in mostly psychosocial causation; doubting authenticity of severity; and feeling referrals from primary care were inappropriate [27].

One theme involved individuals questioning if and how they could endure their HG pregnancy. Psychologically, a strong sense of guilt seemed present as a powerful influence associated with consideration or completion of the decision to end pregnancy, difficulties holding the unborn child in mind with positive associations or having to assume responsibility for uncertain levels of risk linked to antiemetic medication. This highlighted how idiosyncratic circumstances are in terms of HG severity, duration and whether the family can withstand such an illness in their domestic, financial, and occupational context. The theme facilitated exploration of how certain

types of support were experienced, namely from those with HG experience and/or knowledge, and complexities around antiemetic medication. The former was experienced as helpful for addressing isolation, learning about HG, and for reducing guilt and anxiety. Participants within van Vliet and colleagues' [37] study described benefiting from HG information and peer connections within a Dutch context akin to our sample benefiting from UK-based equivalents like Pregnancy Sickness Support. Medication choices led to internal conflict and anxiety for several, but also became a staple of how some survived their HG experiences. Nana and colleagues' [29] study presented those reporting an 'extremely poor' or 'poor' primary and secondary care experience were less likely to have taken medication or to have received rehydration therapy, reflecting lower utilisation of medical support options in those groups. Their qualitative analysis exploring this finding suggested many were exposed to judgemental or anxiety provoking guidance regarding antiemetics, and so were put off taking them even if offered [29]. If individuals aren't confident in the treatments available, this could worsen mental health as some could feel lost as to what they can turn to that is safe. This echoes experiences within the present study alongside instances of side-effects worsening situations which also contributed to refusal or poor compliance. This theme also explored desperate measures several felt necessary because individuals felt they'd exhausted professional support or termination of pregnancy was necessary due to the impact an HG pregnancy would have on them and their family. The need to resort to these options can have further secondary mental health impact including trauma and loss related difficulties. Our findings are consistent with prior research highlighting that lack of support meeting existing childcare responsibilities and experiencing HCPs as indifferent led participants to consider or complete termination of wanted pregnancies [29].

The final theme arose from reflections on first HG experiences and their legacy. Individuals being further on in their 'Journey of Understanding' led to realisation that some initial questions were answered whilst others remained. Recognition of accumulated understanding and experience was bittersweet for some who wished they'd had access to the wisdom earlier on. Locock and

colleagues [39] observed that NVP shares common features with the notion of biographical disruption discussed in chronic illness literature. As our interviewees tried to prepare for biographical transition into motherhood or family expansion, they encountered biographical disruption relating to unexpected impact of HG [39]. Difficulty with the transition in our sample appeared associated with a strong sense of failure and subsequent shame. Participants described how they'd communicate with greater confidence and assertiveness with the benefit of their HG wisdom during subsequent HG pregnancies. Others expressed regret about deciding to reduce or eliminate future pregnancy plans. Previous mixed methods research also found that over 75% of the 808 sampled changed their childbearing plans, many expressing fears of pregnancy and grief for children they won't have [15]. It was noteworthy that several of our interviewees didn't want to speak about HG during or immediately after pregnancy, but then experienced their bodies communicating with them that there was something unresolved. Quantitative research has evidenced long-lasting psychological morbidity associated with HG, though limited formal diagnosis or referral to specialist perinatal services [21]. Poursharif and colleagues' [15] mixed methods study found that post-traumatic stress disorder was among serious psychological sequelae mentioned by a small proportion of their sample.

The present study contrasted in some areas with prior research which found a greater emphasis on occupational impact, including job loss [15]. This was possibly partially accounted for by the influence of the Covid-19 pandemic, with several participants remarking that increased adoption of remote working practices allowed them to continue working despite HG at points they couldn't have attended the office. The UK context of the present study also contrasts with US-based research which often describes friction with health insurance providers. However, US-based studies also more frequently mention freedom to switch healthcare providers to find better suited support [15]. This contrasts with our subtheme related to scarcity of NHS resources, which leads individuals to feel they are stuck with who they have, can't request a switch, and that they should be grateful even if the HCP isn't well-suited to provide the necessary support. Romantic

relationship strain was mentioned but did not appear to the extent reported in other research where relationships had ended [15]. Benefit of access to HG information and peers is briefly mentioned in previous research, but appeared more prominently in the present study [37].

Strengths and limitations

Design of the present study benefited from access to experts by experience facilitated by Pregnancy Sickness Support (PSS). This included the recommendation of thoughtful inclusion of self-disclosure of prior exposure to HG in the primary researcher's personal life. Based on feedback, this has had the effect of allowing our sample to feel more comfortable providing their experiences to a level of detail which felt safe for them and placed the researcher in the privileged position of having a rich dataset for analysis.

Whilst the sample had unique experiences, the present study lacked diversity on certain characteristics. Previous research suggests that certain non-white ethnicities are overrepresented in clinical HG populations [40]. All our participants were married, so we could not explore difficulties faced by single parents. As all participants were aged 25 years or older and educated to at least undergraduate level, it would be of interest to explore whether HG experiences resemble the present sample or differed markedly in younger individuals and/or those with lower educational attainment.

Conclusions and clinical implications

The present study has contributed to understanding of first HG experiences, especially the contribution of interpersonal factors. Experiencing others as lacking HG awareness left our sample vulnerable to various secondary difficulties, exacerbating an already harrowing condition. Knowing little or nothing about HG in advance, our sample had to try to adapt to and understand what was happening in parallel to a disabling illness and nurturing a developing life. This research aims to raise awareness to help people recognise and manage HG and to recognise

the condition in others. It also seeks to guide more informed HG service design, support and care.

Recently updated guidance regarding recognition and management of HG from the Royal College of Obstetrics and Gynaecology has been available in the UK since 2016, but NHS experiences in particular prompts questioning of the degree to which they are being utilised. The present research suggests the consequences of uninformed care adds to, rather than relieves from, an already considerable illness burden and can be fatal. The benefit of someone taking the time to help an individual with HG feel understood and validated was clear. A holistic biopsychosocial appreciation of HG potentially helps to address feelings of failure and shame and would be preferable to what was experienced as a focus on 'the tip of the iceberg'. The present study also highlighted value gained from access to peer support and reliable HG information, so making patients and their support networks aware of organisations like PSS and their function early could improve experiences and reduce relationship ruptures without additional NHS strain. Connecting with peers and learning more about HG would help to address the identified psychological factors of failure, shame, guilt, and isolation. Interviewees suggested developing an HG pathway, earlier recognition and access to antiemetic medication (accompanied by sufficient information for informed choices), and smoother referrals to secondary care where appropriate. Whilst HCPs require information from patients, the present study highlighted that communicating one's needs becomes very difficult during HG for various reasons. Consistent use of measures like the Pregnancy Unique Quantification of Emesis [35] and good record keeping and information sharing within staff teams reduces need for repetition from patients and facilitates timely diagnosis, which in turn would aim to help alleviate a personal sense of failure and subsequent shame. Greater transparency regarding treatment plans was desired, and a role for clinicians skilled in the use of psychological therapies was clear based on those who reported benefiting from processing work after their HG pregnancies. Psychological therapies could also

be utilised to support individuals develop insight into and manage the impact of the identified underlying psychological constructs of failure, shame, guilt, isolation and relationship ruptures.

Regarding causation and how HG relates to mental health, the present study was not designed to allow declarative statements to influence the argument. However, the data this IPA has produced has highlighted some plausible scenarios. Feeling anxious could be a reasonable reaction to being suddenly surprised by profound illness for indeterminate duration whilst responsible for a developing life. Feeling depressed to the point of suicidality could be an understandable reaction to being unable to perform the roles linked to one's sense of identity and purpose, feeling they're failing at something they feel is one of their main reasons for existing, and losing access to usually mood-bolstering people and strategies. Experiencing a trauma reaction to something which can be fatal to the pregnant individual and/or their unborn child could be a natural response. This provides useful context for understanding why poor mental health is frequently linked with HG but seems more likely a consequence of the condition.

The IPA methodology proved useful for focusing on individual experiences and appreciating the complexity of what makes it difficult to endure. Further IPAs could be conducted on more specific questions to better understand the individual experience, but it would also be valuable to gain insight into the experiences of others close to the experience, such as partners, GP's, midwives, or obstetricians. More formal piloting of a psychologically informed HG pathway within the NHS would also seem a considerable but valuable endeavour. In addition to the proposed means by which clinical psychologists could contribute to HG care, the present study demonstrates how the profession can contribute, alongside other valued professional groups, at a systemic level by eliciting and analysing in-depth accounts providing deeper insights into the phenomenon whilst mindful of researcher bias.

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Table of Appendices

Appendix A: Journal Submission Guidelines

Submission Guidelines

Related information for authors

- PLOS Writing Center
- Submission system
- Journal scope and publication criteria
- Getting started guide
- Guidelines for revisions
- Publication fees
- APC Support

Style and Format

File format	Manuscript files can be in the following formats: DOC, DOCX, or RTF. Microsoft Word documents should not be locked or protected. LaTeX manuscripts must be submitted as PDFs. Read the LaTeX guidelines.
Length	Manuscripts can be any length. There are no restrictions on word count, number of figures, or amount of supporting information. We encourage you to present and discuss your findings concisely.
Font	Use a standard font size and any standard font, except for the font named "Symbol". To add symbols to the manuscript, use the Insert → Symbol function in your word processor or paste in the appropriate Unicode character.
Headings	Limit manuscript sections and sub-sections to 3 heading levels. Make sure heading levels are clearly indicated in the manuscript text.
Layout and spacing	Manuscript text should be double-spaced. Do not format text in multiple columns.
Page and line numbers	Include page numbers and line numbers in the manuscript file. Use continuous line numbers (do not restart the numbering on each page).
Footnotes	Footnotes are not permitted. If your manuscript contains footnotes, move the information into the main text or the reference list, depending on the content.
Language	Manuscripts must be submitted in English. You may submit translations of the manuscript or abstract as supporting information. Read the supporting information guidelines.
Abbreviations	Define abbreviations upon first appearance in the text. Do not use non-standard abbreviations unless they appear at least three times in the text. Keep abbreviations to a minimum.
Reference style	PLOS uses "Vancouver" style, as outlined in the ICMJE sample references. See reference formatting examples and additional instructions below.

Equations

We recommend using MathType for display and inline equations, as it will provide the most reliable outcome. If this is not possible, Equation Editor or Microsoft's Insert→Equation function is acceptable.

Avoid using MathType, Equation Editor, or the Insert→Equation function to insert single variables (e.g., "$a^2 + b^2 = c^2$"), Greek or other symbols (e.g., β, Δ, or ′ [prime]), or mathematical operators (e.g., x, ≥, or ±) in running text. Wherever possible, insert single symbols as normal text with the correct Unicode (hex) values.

Do not use MathType, Equation Editor, or the Insert→Equation function for only a portion of an equation. Rather, ensure that the entire equation is included. Equations should not contain a mix of different equation tools. Avoid "hybrid" inline or display equations, in which part is text and part is MathType, or part is MathType and part is Equation Editor.

Nomenclature

Use correct and established nomenclature wherever possible.

Units of measurement	Use SI units. If you do not use these exclusively, provide the SI value in parentheses after each value. Read more about SI units.
Drugs	Provide the Recommended International Non-Proprietary Name (rINN).
Species names	Write in italics (e.g., *Homo sapiens*). Write out in full the genus and species, both in the title of the manuscript and at the first mention of an organism in a paper. After first mention, the first letter of the genus name followed by the full species name may be used (e.g., *H. sapiens*).
Genes, mutations, genotypes, and alleles	Write in italics. Use the recommended name by consulting the appropriate genetic nomenclature database (e.g., HGNC for human genes; we strongly recommend using this tool to check against previously approved names). It is sometimes advisable to indicate the synonyms for the gene the first time it appears in the text. Gene prefixes such as those used for oncogenes or cellular localization should be shown in roman typeface (e.g., v-fes, c-MYC).
Allergens	The systematic allergen nomenclature of the World Health Organization/International Union of Immunological Societies (WHO/IUIS) Allergen Nomenclature Sub-committee should be used for manuscripts that include the description or use of allergenic proteins. For manuscripts describing new allergens, the systematic name of the allergen should be approved by the WHO/IUIS Allergen Nomenclature Sub-Committee prior to manuscript publication. Examples of the systematic allergen nomenclature can be found at the WHO/IUIS Allergen Nomenclature site.

Copyediting manuscripts

Prior to submission, authors who believe their manuscripts would benefit from professional editing are encouraged to use language-editing and copyediting services. Obtaining this service is the responsibility of the author, and should be done before initial submission. These services can be found on the web using search terms like "scientific editing service" or "manuscript editing service."

Submissions are not copyedited before publication.

Submissions that do not meet the *PLOS ONE* publication criterion for language standards may be rejected.

Manuscript Organization

Manuscripts should be organized as follows. Instructions for each element appear below the list.

Beginning section	*The following elements are required, in order:* › Title page: List title, authors, and affiliations as first page of the manuscript › Abstract › Introduction
Middle section	*The following elements can be renamed as needed and presented in any order:* › Materials and Methods › Results › Discussion › Conclusions (optional)
Ending section	*The following elements are required, in order:* › Acknowledgments › References › Supporting information captions (if applicable)
Other elements	› Figure captions are inserted immediately after the first paragraph in which the figure is cited. Figure files are uploaded separately. › Tables are inserted immediately after the first paragraph in which they are cited. › Supporting information files are uploaded separately.

Refer to our downloadable sample files to ensure that your submission meets our formatting requirements:

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The compiled submission PDF includes low-resolution preview images of the figures after the reference list. The function of these previews is to allow you to download the entire submission as quickly as possible. Click the link at the top of each preview page to download a high-resolution version of each figure. Links to download Supporting Information files are also available after the reference list.

Parts of a Submission

Title

Include a full title and a short title for the manuscript.

Title	Length	Guidelines	Examples
Full title	250 characters	Specific, descriptive, concise, and comprehensible to readers outside the field	Impact of cigarette smoke exposure on innate immunity: A *Caenorhabditis elegans* model Solar drinking water disinfection (SODIS) to reduce childhood diarrhoea in rural Bolivia: A cluster-randomized, controlled trial
Short title	100 characters	State the topic of the study	Cigarette smoke exposure and innate immunity SODIS and childhood diarrhoea

Titles should be written in sentence case (only the first word of the text, proper nouns, and genus names are capitalized). Avoid specialist abbreviations if possible. For clinical trials, systematic reviews, or meta-analyses, the subtitle should include the study design.

Author list

Authorship requirements

All authors must meet the criteria for authorship as outlined in the authorship policy. Those who contributed to the work but do not meet the criteria for authorship can be mentioned in the Acknowledgments. Read more about Acknowledgments.

The corresponding author must provide an ORCID iD at the time of submission by entering it in the user profile in the submission system. Read more about ORCID.

Author names and affiliations

Enter author names on the title page of the manuscript and in the online submission system.

On the title page, write author names in the following order:

- First name (or initials, if used)
- Middle name (or initials, if used)
- Last name (surname, family name)

Each author on the list must have an affiliation. The affiliation includes department, university, or organizational affiliation and its location, including city, state/province (if applicable), and country. Authors have the option to include a current address in addition to the address of their affiliation at the time of the study. The current address should be listed in the byline and clearly labeled “current address.” At a minimum, the address must include the author’s current institution, city, and country.

If an author has multiple affiliations, enter all affiliations on the title page only. In the submission system, enter only the preferred or primary affiliation. Author affiliations will be listed in the typeset PDF article in the same order that authors are listed in the submission.

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Contributions will be published with the final article, and they should accurately reflect contributions to the work. The submitting author is responsible for completing this information at submission, and we expect that all authors will have reviewed, discussed, and agreed to their individual contributions ahead of this time.

PLOS ONE will contact all authors by email at submission to ensure that they are aware of the submission.

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Upload a cover letter as a separate file in the online system. The length limit is 1 page.

The cover letter should include the following information:

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- Relate the study to previously published work
- Specify the type of article (for example, research article, systematic review, meta-analysis, clinical trial)
- Describe any prior interactions with PLOS regarding the submitted manuscript
- Suggest appropriate Academic Editors to handle your manuscript (see the full list of Academic Editors)
- List any opposed reviewers

IMPORTANT: Do not include requests to reduce or waive publication fees in the cover letter. This information will be entered separately in the online submission system.

Read about publication fee assistance.

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The Abstract comes after the title page in the manuscript file. The abstract text is also entered in a separate field in the submission system.

The Abstract should:

- Describe the main objective(s) of the study
- Explain how the study was done, including any model organisms used, without methodological detail
- Summarize the most important results and their significance
- Not exceed 300 words

Abstracts should not include:

- Citations
- Abbreviations, if possible

Introduction

The introduction should:

- Provide background that puts the manuscript into context and allows readers outside the field to understand the purpose and significance of the study
- Define the problem addressed and why it is important
- Include a brief review of the key literature
- Note any relevant controversies or disagreements in the field
- Conclude with a brief statement of the overall aim of the work and a comment about whether that aim was achieved

Materials and Methods

The Materials and Methods section should provide enough detail to allow suitably skilled investigators to fully replicate your study. Specific information and/or protocols for new methods should be included in detail. If materials, methods, and protocols are well established, authors may cite articles where those protocols are described in detail, but the submission should include sufficient information to be understood independent of these references.

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PLOS ONE offers two options for publishing stand-alone protocol articles: Lab Protocols that describe reusable methodologies and Study Protocols that describe detailed plans and proposals for research projects. Specific guidelines apply to the submission of Lab Protocol and Study Protocol manuscripts. Read the detailed instructions for submitting Lab Protocols and Study Protocols.

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- Submitted research should not rely upon retracted research. You should avoid citing retracted articles unless you need to discuss retracted work to provide historical context for your submitted research. If it is necessary to discuss retracted work, state the article's retracted status in your article's text and reference list.

Ensure that your reference list includes full and current bibliography details for every cited work at the time of your article's submission (and publication, if accepted). If cited work is corrected, retracted, or marked with an expression of concern before your article is published, and if you feel it is appropriate to cite the work even in light of the post-publication notice, include in your manuscript citations and full references for both the affected article and the post-publication notice. Email the journal office if you have questions.

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Make sure the parts of the manuscript are in the correct order *before* ordering the citations.

Formatting references

Because all references will be linked electronically as much as possible to the papers they cite, proper formatting of references is crucial.

PLOS uses the reference style outlined by the International Committee of Medical Journal Editors (ICMJE), also referred to as the "Vancouver" style. Example formats are listed below. Additional examples are in the ICMJE sample references.

A reference management tool, EndNote, offers a current style file that can assist you with the formatting of your references. If you have problems with any reference management program, please contact the source company's technical support.

Journal name abbreviations should be those found in the National Center for Biotechnology Information (NCBI) databases.

Source	Format
Published articles	Hou WR, Hou YL, Wu GF, Song Y, Su XL, Sun B, et al. cDNA, genomic sequence cloning and overexpression of ribosomal protein gene L9 (rpL9) of the giant panda (Ailuropoda melanoleuca). Genet Mol Res. 2011;10: 1576-1588. Devaraju P, Gulati R, Antony PT, Mithun CB, Negi VS. Susceptibility to SLE in South Indian Tamils may be influenced by genetic selection pressure on TLR2 and TLR9 genes. Mol Immunol. 2014 Nov 22. pii: S0161-5890(14)00313-7. doi: 10.1016/j.molimm.2014.11.005. Note: A DOI number for the full-text article is acceptable as an alternative to or in addition to traditional volume and page numbers. When providing a DOI, adhere to the format in the example above with both the label and full DOI included at the end of the reference (doi: 10.1016/j.molimm.2014.11.005). Do not provide a shortened DOI or the URL.
Accepted, unpublished articles	Same as published articles, but substitute "Forthcoming" for page numbers or DOI.
Online articles	Huynen MMTE, Martens P, Hilderlink HBM. The health impacts of globalisation: a conceptual framework. Global Health. 2005;1: 14. Available from: http://www.globalizationandhealth.com/content/1/1/14
Books	Bates B. Bargaining for life: A social history of tuberculosis. 1st ed. Philadelphia: University of Pennsylvania Press; 1992.
Book chapters	Hansen B. New York City epidemics and history for the public. In: Harden VA, Risse GB, editors. AIDS and the historian. Bethesda: National Institutes of Health; 1991. pp. 21-28.
Deposited articles (preprints, e-prints, or arXiv)	Krick T, Shub DA, Verstraete N, Ferreiro DU, Alonso LG, Shub M, et al. Amino acid metabolism conflicts with protein diversity. arXiv:1403.3301v1 [Preprint]. 2014 [cited 2014 March 17]. Available from: https://128.84.21.199/abs/1403.3301v1 Kording KP, Mensh B. Ten simple rules for structuring papers. BioRxiv [Preprint]. 2016 bioRxiv 088278 [posted 2016 Nov 28; revised 2016 Dec 14; revised 2016 Dec 15; cited 2017 Feb 9]: [12 p.]. Available from: https://www.biorxiv.org/content/10.1101/088278v5 doi: 10.1101/088278
Published media (print or online newspapers and magazine articles)	Fountain H. For Already Vulnerable Penguins, Study Finds Climate Change Is Another Danger. The New York Times. 2014 Jan 29 [Cited 2014 March 17]. Available from: http://www.nytimes.com/2014/01/30/science/earth/climate-change-taking-toll-on-penguins-study-finds.html
New media (blogs, web sites, or other written works)	Allen L. Announcing PLOS Blogs. 2010 Sep 1 [cited 17 March 2014]. In: PLOS Blogs [Internet]. San Francisco: PLOS 2006 - . [about 2 screens]. Available from: http://blogs.plos.org/plos/2010/09/announcing-plos-blogs/.

Masters' theses or doctoral dissertations	Wells A. Exploring the development of the independent, electronic, scholarly journal. M.Sc. Thesis, The University of Sheffield. 1999. Available from: http://cumincad.scix.net/cgi-bin/works/Show?2e09
Databases and repositories (Figshare, arXiv)	Roberts SB. QPX Genome Browser Feature Tracks; 2013 [cited 2013 Oct 5]. Database: figshare [Internet]. Available from: http://figshare.com/articles/QPX_Genome_Browser_Feature_Tracks/701214
Multimedia (videos, movies, or TV shows)	Hitchcock A, producer and director. Rear Window [Film]; 1954. Los Angeles: MGM.

Supporting information

Authors can submit essential supporting files and multimedia files along with their manuscripts. All supporting information will be subject to peer review. All file types can be submitted, but files must be smaller than 20 MB in size.

Authors may use almost any description as the item name for a supporting information file as long as it contains an "S" and number. For example, "S1 Appendix" and "S2 Appendix," "S1 Table" and "S2 Table," and so forth.

Supporting information files are published exactly as provided, and are not copyedited.

Supporting information captions

List supporting information captions at the end of the manuscript file. Do not submit captions in a separate file.

The file number and name are required in a caption, and we highly recommend including a one-line title as well. You may also include a legend in your caption, but it is not required.

Example caption

S1 Text. Title is strongly recommended. Legend is optional.

In-text citations

We recommend that you cite supporting information in the manuscript text, but this is not a requirement. If you cite supporting information in the text, citations do not need to be in numerical order.

Read the supporting information guidelines for more details about submitting supporting information and multimedia files.

Figures and tables

Figures

Do not include figures in the main manuscript file. Each figure must be prepared and submitted as an individual file.

Cite figures in ascending numeric order at first appearance in the manuscript file.

Read the guidelines for figures and requirements for reporting blot and gel results.

Figure captions

Figure captions must be inserted in the text of the manuscript, immediately following the paragraph in which the figure is first cited (read order). Do not include captions as part of the figure files themselves or submit them in a separate document.

At a minimum, include the following in your figure captions:

- A figure label with Arabic numerals, and "Figure" abbreviated to "Fig" (e.g. Fig 1, Fig 2, Fig 3, etc). Match the label of your figure with the name of the file uploaded at submission (e.g. a figure citation of "Fig 1" must refer to a figure file named "Fig1.tif").
- A concise, descriptive title

The caption may also include a legend as needed.

Read more about figure captions.

Tables

Cite tables in ascending numeric order upon first appearance in the manuscript file.

Place each table in your manuscript file directly after the paragraph in which it is first cited (read order). Do not submit your tables in separate files.

Tables require a label (e.g., "Table 1") and brief descriptive title to be placed above the table. Place legends, footnotes, and other text below the table.

Read the guidelines for tables.

Statistical reporting

Manuscripts submitted to *PLOS ONE* are expected to report statistical methods in sufficient detail for others to replicate the analysis performed. Ensure that results are rigorously reported in accordance with community standards and that statistical methods employed are appropriate for the study design.

Consult the following resources for additional guidance:

- SAMPL guidelines, for general guidance on statistical reporting
- *PLOS ONE* guidelines, for clinical trials requirements
- *PLOS ONE* guidelines, for systematic review and meta-analysis requirements
- EQUATOR, for specific reporting guidelines for a range of other study types

Reporting of statistical methods

In the methods, include a section on statistical analysis that reports a detailed description of the statistical methods. In this section:

- List the name and version of any software package used, alongside any relevant references
- Describe technical details or procedures required to reproduce the analysis
- Provide the repository identifier for any code used in the analysis (See our code-sharing policy.)

Statistical reporting guidelines:

- Identify research design and independent variables as being between- or within-subjects
- For pre-processed data:
  - Describe any analysis carried out to confirm the data meets the assumptions of the analysis performed (e.g. linearity, co-linearity, normality of the distribution).
  - If data were transformed include this information, with a reason for doing so and a description of the transformation performed
- Provide details of how outliers were treated and your analysis, both with the full dataset and with the outliers removed
- If relevant, describe how missing/excluded data were handled
- Define the threshold for significance (alpha)
- If appropriate, provide sample sizes, along with a description of how they were determined. If a sample size calculation was performed, specify the inputs for power, effect size and alpha. Where relevant, report the number of independent replications for each experiment.
- For analyses of variance (ANOVAs), detail any post hoc tests that were performed
- Include details of any corrections applied to account for multiple comparisons. If corrections were not applied, include a justification for not doing so
- Describe all options for statistical procedures. For example, if t-tests were performed, state whether these were one- or two-tailed. Include details of the type of t-test conducted (e.g. one sample, within-/between-subjects).
- For step-wise multiple regression analyses:
  - Report the alpha level used
  - Discuss whether the variables were assessed for collinearity and interaction
  - Describe the variable selection process by which the final model was developed (e.g., forward-stepwise; best subset). See SAMPL guidelines.
- For Bayesian analysis explain the choice of prior trial probabilities and how they were selected. Markov chain Monte Carlo settings should be reported.

Reporting of statistical results

Results must be rigorously and appropriately reported, in keeping with community standards.

- **Units of measurement.** Clearly define measurement units in all tables and figures.
- **Properties of distribution.** It should be clear from the text which measures of variance (standard deviation, standard error of the mean, confidence intervals) and central tendency (mean, median) are being presented.
- **Regression analyses.** Include the full results of any regression analysis performed as a supplementary file. Include all estimated regression coefficients, their standard error, p-values, and confidence intervals, as well as the measures of goodness of fit.
- **Reporting parameters.** Test statistics (F/t/r) and associated degrees of freedom should be provided. Effect sizes and confidence intervals should be reported where appropriate. If percentages are provided, the numerator and denominator should also be given.
- **P-values.** Report exact p-values for all values greater than or equal to 0.001. P-values less than 0.001 may be expressed as $p < 0.001$, or as exponentials in studies of genetic associations.
- **Displaying data in plots.** Format plots so that they accurately depict the sample distribution. 3D effects in plots can bias and hinder interpretation of values, so avoid them in cases where regular plots are sufficient to display the data.
- **Open data.** As explained in PLOS's Data Policy, be sure to make individual data points, underlying graphs and summary statistics available at the time of publication. Data can be deposited in a repository or included within the Supporting Information files.

Data reporting

All data and related metadata underlying the findings reported in a submitted manuscript should be deposited in an appropriate public repository, unless already provided as part of the submitted article.

See instructions on providing underlying data to support blot and gel results.

Read our policy on data availability.

Repositories may be either subject-specific (where these exist) and accept specific types of structured data, or generalist repositories that accept multiple data types. We recommend that authors select repositories appropriate to their field. Repositories may be subject-specific (e.g., GenBank for sequences and PDB for structures), general, or institutional, as long as DOIs or accession numbers are provided and the data are at least as open as CC BY. Authors are encouraged to select repositories that meet accepted criteria as trustworthy digital repositories, such as criteria of the Centre for Research Libraries or Data Seal of Approval. Large, international databases are more likely to persist than small, local ones.

See our list of recommended repositories.

To support data sharing and author compliance of the PLOS data policy, we have integrated our submission process with a select set of data repositories. The list is neither representative nor exhaustive of the suitable repositories available to authors. Current repository integration partners include Dryad and FlowRepository. Please contact data@plos.org to make recommendations for further partnerships.

Instructions for PLOS submissions with data deposited in an integration partner repository:

- Deposit data in the integrated repository of choice.
- Once deposition is final and complete, the repository will provide you with a dataset DOI (provisional) and private URL for reviewers to gain access to the data.
- Enter the given data DOI into the full Data Availability Statement, which is requested in the Additional Information section of the PLOS submission form. Then provide the URL passcode in the Attach Files section.

If you have any questions, please email us.

Accession numbers

All appropriate data sets, images, and information should be deposited in an appropriate public repository. See our list of recommended repositories.

Accession numbers (and version numbers, if appropriate) should be provided in the Data Availability Statement. Accession numbers or a citation to the DOI should also be provided when the data set is mentioned within the manuscript.

In some cases authors may not be able to obtain accession numbers of DOIs until the manuscript is accepted; in these cases, the authors must provide these numbers at acceptance. In all other cases, these numbers must be provided at full submission.

Identifiers

As much as possible, please provide accession numbers or identifiers for all entities such as genes, proteins, mutants, diseases, etc., for which there is an entry in a public database, for example:

- Ensembl
- Entrez Gene
- FlyBase
- InterPro
- Mouse Genome Database (MGD)
- Online Mendelian Inheritance in Man (OMIM)
- PubChem

Identifiers should be provided in parentheses after the entity on first use.

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You can choose to upload a “Striking Image” that we may use to represent your article online in places like the journal homepage or in search results.

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If no striking image is uploaded, we will designate a figure from the submission as the striking image.

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Financial Disclosure Statement

This information should describe sources of funding that have supported the work. It is important to gather these details prior to submission because your financial disclosure statement cannot be changed after initial submission without journal approval. If your manuscript is published, your statement will appear in the Funding section of the article.

Enter this statement in the Financial Disclosure section of the submission form. Do not include it in your manuscript file.

The statement should include:

- Specific grant numbers
- Initials of authors who received each award
- Full names of commercial companies that funded the study or authors
- Initials of authors who received salary or other funding from commercial companies
- URLs to sponsors' websites

Also state whether any sponsors or funders (other than the named authors) played any role in:

- Study design
- Data collection and analysis
- Decision to publish
- Preparation of the manuscript

If they had no role in the research, include this sentence: “The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.”

If the study was unfunded, include this sentence as the Financial Disclosure statement: “The author(s) received no specific funding for this work."

Read our policy on disclosure of funding sources.

Competing interests

This information should not be in your manuscript file; you will provide it via our submission system.

All potential competing interests must be declared in full. If the submission is related to any patents, patent applications, or products in development or for market, these details, including patent numbers and titles, must be disclosed in full.

Read our policy on competing interests.

Manuscripts disputing published work

For manuscripts disputing previously published work, it is *PLOS ONE* policy to invite a signed review by the disputed author during the peer review process. This procedure is aimed at ensuring a thorough, transparent, and productive review process.

If the disputed author chooses to submit a review, it must be returned in a timely fashion and contain a full declaration of all competing interests. The Academic Editor will consider any such reviews in light of the competing interest.

Authors submitting manuscripts disputing previous work should explain the relationship between the manuscripts in their cover letter, and will be required to confirm that they accept the conditions of this review policy before the manuscript is considered further.

Related manuscripts

Upon submission, authors must confirm that the manuscript, or any related manuscript, is not currently under consideration or accepted elsewhere. If related work has been submitted to *PLOS ONE* or elsewhere, authors must include a copy with the submitted article. Reviewers will be asked to comment on the overlap between related submissions.

We strongly discourage the unnecessary division of related work into separate manuscripts, and we will not consider manuscripts that are divided into "parts." Each submission to *PLOS ONE* must be written as an independent unit and should not rely on any work that has not already been accepted for publication. If related manuscripts are submitted to *PLOS ONE*, the authors may be advised to combine them into a single manuscript at the editor's discretion.

Read our policies on related manuscripts.

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Appendix B: Quality Appraisal Tool

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

CASP
Critical Appraisal Skills Programme

Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

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4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

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6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

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8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

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Section C: Will the results help locally?

10. How valuable is the research?	HINT: Consider • If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature • If they identify new areas where research is necessary • If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:	

Appendix C: Ethics Form

School of Health in Social Science Research Ethics Application

The supervisor or primary investigator must complete and sign this form after checking that all relevant sections are completed, and relevant documents are attached. For all undergraduate (UG) and MSc student projects, it is the supervisor's responsibility to submit this form and all attachments. Please note that failure to do this will result in the application being returned (and not processed) causing your research to be delayed.

Supervisor (name and UUN): Dr Charlene Plunkett	
Primary Investigator (name and UUN): Navin Mistry s0675328	
List of all collaborators (with affiliated institutions in brackets): Dr Ashley Allan, Field Supervisor (NHS Grampian), Dr Caitlin Dean, Research Collaborator (Pregnancy Sickness Support)	
Student's programme of study (if applicable): Doctorate in Clinical Psychology	
Project Title: How do first time sufferers of Hyperemesis Gravidarum make sense of their experience and the way others communicate with them? An Interpretative Phenomenological Analysis	
Case Number (if known – assigned by Administrator at time of 1st submission):	
Proposed Project Start Date: 01/03/2023	**Proposed Project End Date: 01/08/2024**

Please indicate whether the primary investigator on this project is staff or student and select your subject area:

☐ Staff ☐ UG or MSc Student ☒ DClin Student ☐ PhD Student
☐ CPASS ☒ Clinical Psychology ☐ Nursing Studies

This is a:

☐ New application for ethical review – first submission
☐ Resubmission following reviewer comments
☒ Resubmission with requested amendments

Has been reviewed by an external ethical board, such as NHS IRAS or a UK HEI (multi-site studies only) with a favourable opinion? Level 1 *

☐ IRAS (NHS research ethics) ☐ Other: _____

Please tick one option that best describes your application:

☒ Collecting or generating new data involving other people: Level 2
☐ Extracting, re-coding and analysing existing data that contains sensitive information (i.e. identifiable information): Level 2
☐ Analysing secondary (archival) data that is routinely collected or is an existing anonymised dataset: Level 1
☐ Collecting new data BUT an external ethical review board (such as NHS IRAS; UK HEI – for multi-site studies; etc) has fully reviewed this project and generated a favourable opinion: Level 1

This application is complete with the following attachments (tick all that apply):

Advert/flyer ☒	Caldicott application stating what data was requested ☐	Caldicott signed approval ☐		Consent form/s ☒
Data collection tools (e.g. interview guides) ☒	Debrief with signposting ☒	IRAS application ☐	IRAS opinion letter ☐	NGO or local authority letters ☐
Participant Information	Participant Information Sheet	R&D	R&D	Researcher

**If your project has been reviewed and generated an opinion by an external agency with a full ethics board, for example IRAS approval from the NHS, you only need to complete the questions related to university regulations covered in the Level 1 section of this form to ensure you are following University policies and guidelines. Please also attach the externally reviewed application and decision letter. Please note that your project will not undergo a full additional ethical review by the School of Health in Social Sciences REC, however we need to ensure your project is adhering to university regulations before you begin collecting data.*

Sheet/s ☒	(young person version) ☐	application ☐	approval ☐	Checklist (C-19) ☐
Risk assessment ☒	Standardised recruitment email ☒	Sponsorship Letter OR Email to confirm no sponsorship needed / statement explaining why sponsorship is not needed. ☒		

Other attachments (please specify):

To be completed by primary investigator or project supervisor
By signing this front sheet, I confirm that I have prepared and/or reviewed this ethics application and related documents in accordance with ethical guidelines. I also confirm I have checked that all relevant sections of the application form are completed and relevant documents are attached. **Supervisor or/PI Signature:** **Student signature:** **Date: 15/11/22**

On completion, this Word document along with the relevant attachments should be submitted to ethics.hiss@ed.ac.uk.

Note: **Please note all undergraduate and MSc applications MUST been signed and submitted by the project supervisor.**

Contents

This section is to be completed after review only

ISSUES ARISING FROM THE PROPOSAL – to be completed by Ethics Reviewer

Thank you for your application. The review process has generated the following queries regarding your application. Please address the following items, and provide a note underneath each comment letting us know how you have addressed them:

Ethics Application

Q1 - In the recruitment process seems to be additional barriers and time placed on the potential participant i.e. need to contact lead researcher who then arranges an initial conversation, then video calling with the researcher, then they will be sent the consent form to complete etc. Is it not easier just to send them the link to consent before any contact is made and ask them to sign up to slots to take part and then take 5-10 mins before the actual interview to remind them of their participation and also if they have any questions and also build rapport?

I have streamlined the recruitment process somewhat based on some of your suggestions. The PIS has now been added to the beginning of the Qualtrics forms, and so instead of receiving it as an attachment in the initial recruitment email, they will receive a link to the Qualtrics page for the study. I have adjusted Standard Recruitment Email 1 accordingly to reflect this change. There is no longer a need for Standard Recruitment Email 2. Now, potential participants will be able to read the whole PIS and complete the Consent Form, Contact Details Form, and Pre-Interview Questionnaire online prior to having had any contact with me. I have requested an email address as a part of the consent process, which I will use to reach out to organise interview times and offer some time prior to the interview to test technology setup. I have invited potential participants to contact me via email if they have any questions about any of the initial pre-interview process including consent.

You say video calls will only be offered – is this right? You won't accept telephone interviews? This may limit participants who are from poor ses backgrounds and also those who may have anxiety related disorders (even though you offer to have the video off this may still be anxiety evoking for those participants). Have you considered this?

I have added the option of telephone interviews and adjusted all paperwork accordingly. The plan for those who opt for this option would be to record the phone call electronically using an encrypted recording device, then transcribe manually using that recording.

You will wait 48 hours to send the link to the consent form – will you also include the participant info sheet again? 48 hours is a long time to remember all details of a study.

This is no longer a factor as potential participants are receiving access to the Consent form as a part of the initial recruitment email.

How will interviews be arranged? Will the participants indicate via the qualtrics system their availability? Will the researcher then contact them via telephone or email?

As mentioned above, the researcher will contact potential participants via email using the address they provided as part of the consent process.

Q7 – What about if participants provide potentially identifying information? How will this be dealt with?

Any specific details about third parties that could be regarded as identifying information will be removed. The following statement has been added to Q7: " Likewise, any references made to third parties during participants' accounts will be removed in order to avoid the inclusion of identifiable data about others."

Q16 – Can you confirm that the research collaborator from the third sector will not have access to the raw data?

I can confirm my research collaborator will not have access to the raw data and have added this clarification to Q16.

Q21 – will you be making sure the emergency contact is someone within close proximity to the participant? So if they do become distressed they will be able to get to them quickly on the day of the interview?

Have added the following statement to the Participant Information Sheet: "When selecting an emergency contact, please try to list someone close enough to reach you quickly in case of emergency." This is in the section, "What happens if I agree to take part?"

Q32 – need to cite reference that supports your participant number (over and under recruitment is an ethical issue).

I have added references to Q32 including a chapter from a book on qualitative research methodology, a published IPA journal article showing precedent and made reference to having discussed this with my academic supervisor.

PIS

In this you say that participants will have up to 2 weeks to withdraw their data and after this it will be anonymised however in the application form q1 – you mention 'Original interview recordings will be deleted following transcription within a month of the interview having taken place,' q46 you mention 'participants will be informed that the original audio and video recording of their interview will be deleted 2 weeks after transcription.' Need to be consistent which one this is and what the time frame is (please also amend ethics application as appropriate). Think you need a statement in here saying that their audio recordings will be transcribed and deleted after 2 weeks to make this clear.

Informing participants that they have 2 weeks after their interview to withdraw their data and stating that interviews will be transcribed within a month are deliberately distinct. This was based on the advice of my academic supervisor, who has stated that it is important to allow plenty of time for transcription as it is a time-consuming process, and she is aware I have special measures in place due to disability and so will benefit from the additional time. She also stated that if participants are given longer than 2 weeks, she has experienced situations involving participants having requested their data be withdrawn after drafts have been written and sent to supervisors. I have, however, adjusted the statement in Q46 to say that participants will be informed that their original recording will be deleted immediately following transcription has been verified for accuracy.

You say 'You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have if you withdraw after 2 weeks of your interview'. This is conflating withdrawing participation with withdrawing data. Instead need separate statements such as –

'You can withdraw your participation at any point by stopping the interview without any negative repercussions. Following participation you are still able to withdraw your data up until 2 weeks after your interview. After this point your interview will be anonymised.'

I have made the changes to wording as suggested, as well as note that potential participants are free to cancel participation by cancelling their interview prior to the interview having taken place.

The complaints process is addressed to the head of school only – not the college governance team.

I have removed the contact details for the college governance team from the bottom of the PIS.

Consent

Would change your statements slightly to be in line with the participant information sheet (please see edits below in red) and the additional statement.

3. I understand that my participation is voluntary and that I can ask to withdraw my participation by stopping the interview at any time and without giving a reason.

Add another statement – 'I understand that I can withdraw my data up until 2 weeks following the interview. After this time my interview will be transcribed and anonymised.'

I would combine the statements around the recording and say that the interview will be audio and/or video recorded to streamline that a bit.

I have made all of the above suggested changes to the consent form.

Debrief

You have to outline what they need to do if they want to withdraw their data here i.e. contact you within 2 weeks of their interview.

I have added a reminder of the 2 week period following the interview, during which they can request their data be withdrawn by emailing me.

You also have to remind them of the main contacts again i.e. independent person and head of school for complaints.

I have added in the contact details of the independent person and the head of school for complaints.

Also be clear about how they can get a summary of the findings if they wish.

I have added a statement to say that if a participant did not opt in to the feedback process or request a summary of findings during the consent process, they can do so by emailing me after the interview instead.

I have also modified various other documents to include references to the added option of telephone interviews and the changes to the recruitment process. I have highlighted the parts I have changed in all altered documents. These include the Advert, the Pre-Interview Questionnaire, the Risk Assessment, and the GP Letter.

Signature: K Gillespie-Smith (sig)

Position: Senior Lecturer in Applied Psychology/Ethics and Integrity Lead

Date: 5/1/23

APPLICANT'S SIGNATURE FOLLOWING REVISIONS – to be completed by applicant

I confirm that I have addressed all of the queries generated during the ethical review process of my application. I have outlined in the box above underneath each comment how each request was addressed and/or provided further clarification.

Supervisor/PI Signature: Navin Mistry

Student signature: Navin Mistry

Date: 10/02/2023

CONCLUSION TO ETHICAL REVIEW – to be completed by Ethics Lead

The applicant's response to our request for further clarification or changes has now satisfied the requirements for ethical practice and the application has therefore been given a favourable opinion.

Signature: K Gillespie-Smith

Position: Senior Lecturer in Applied Psychology

Date: 20/02/23

NOTE: Once reviewed please include the page on which this box appears as a formal document demonstrating that favourable opinion has been provided for this project (for example as an attachment to MSc dissertations).

If you are applying for amendments to a previously reviewed and processed project, please use the below form to detail the amendments you wish to make:

This section is to be completed for amendments only
AMENDMENT/S: REQUEST FOR APPROVAL – to be completed by applicant
I would like to apply for the following amendments to this previously processed project which had generated a favourable opinion: • Extending the end date of the study to 01/08/2024 **Supervisor/PI Signature: Navin Mistry** **Student signature: Navin Mistry** **Date: 08/05/2024**
CONCLUSION TO ETHICAL REVIEW OF AMENDMENT – to be completed by Ethics Lead
The requested amendment satisfies the requirements for ethical practice and it has therefore received a favourable opinion. **Signature: Zsofia Garai-Takacs (sig)** **Position: Clinical & Health Psychology Ethics & Integrity Lead** **Date: 09/05/2024** NOTE: Once reviewed please include the page on which this box appears as a formal document demonstrating that favourable opinion has been provided for this project (for example as an attachment to MSc dissertations).

LEVEL 1 and 2 – Confidentiality and Handling of Data

Section 1: Introduction

External Research Ethics Approval:

Does your research project require the approval of any other institution and/or ethics committee, nationally or internationally?

Note: It is each researcher's responsibility to check whether their project requires Sponsorship, Caldicott Approval, R&D approval, and/or IRAS (see https://www.ed.ac.uk/health/research/ethics/sponsorship-and-governance). The principal investigator is responsible for ensuring compliance with any additional ethical requirements that might apply, and/or for compliance with any additional requirements for review by external bodies.

☒ This research project does not require external ethics approval.
OR

If you require external approval, please state the name of the review body:
☐ IRAS (NHS research ethics) ☐ Local Authority ☐ Other: _____

NB: If you require external approval from IRAS/NHS/Caldicott, **you must have external approval before submitting your application for School of Health in Social Science Research Ethics approval**. You can only submit your application to us once external approval has been obtained, and you must include all documentation including your application to and approval of external approval as an attachment.

If you require approval from a **local authority**, you must first receive ethics approval from the School of Health in Social Science Research Ethics Committee, before submitting your application to the local authority.

Q1. Project summary

Please provide a brief summary of your proposed study. Do not exceed 1366/1500 words. Our interest is in areas of your methodology where ethical issues may arise so please focus your detail on areas such as recruitment, consent, describing your participants and the nature of their involvement, and data handling.

Introduction

Hyperemesis Gravidarum is a severe form of Nausea and Vomiting of Pregnancy (NVP), which affects 0.3-3.6% of pregnancies. In an effort to move towards a globally accepted diagnostic definition of HG, a recent international collaboration produced the Windsor Definition, which states that the illness must have started before gestational age of 16 weeks, is characterised by severe nausea and/or vomiting, inability to eat and/or drink normally and strongly limited daily activities. Research has linked HG to increased risk of numerous short and long-term physical health issues for the pregnant individual and the child exposed to HG as well as various psychosocial outcomes.

Because HG is quite rare, it is often confabulated with common NVP, which can put great strain on relationships as the HG sufferer is not receiving the understanding or support they require. More recent research on HG describes support for various aetiological theories relating to HG including immunological, hormonal, genetic and infective factors. However, earlier literature framed HG as a primarily psychosomatic condition. Reviews of the research in support of psychogenic aetiology found the evidence to be lacking in empirical rigour. Qualitative evidence captured more recently suggest understanding amongst health professionals and the wider public has not been uniformly updated.

The present study takes place following publication of improved guidelines by the Royal College of Obstetrics and Gynaecology (2016) and perinatal mental health having been prioritized more by UK Governments in recent years.

Principle Research Question

- How did individuals who suffered with HG for the first time make sense of their experience throughout pregnancy and what role (if any) did others play in this?

Secondary Research Questions

- How does degree of prior knowledge of HG influence the way it is experienced?
- Are individuals experiencing mental health difficulties during and/or after an HG pregnancy being signposted appropriately and/or being referred for appropriate support?

Design
A qualitative design using Interpretative Phenomenological Analysis (IPA) has been chosen to explore how participants have made sense of their first experience of Hyperemesis Gravidarum, with a particular interest in the influence of others. Data will be collected using semi-structured interviews remotely via video-call using Microsoft Teams or telephone.

Participants
6-10 individuals who self-report having experienced HG for the first time during a pregnancy within the last 8 years will be invited to participate. Access to the sample will be facilitated by Pregnancy Sickness Support (PSS); the UK's leading charity supporting individuals affected by HG, who received over 3000 calls for help throughout 2021. Purposive selection of participants will be utilised to recruit a sample of individuals for whom the research question has significance.

Procedure
Recruitment will be facilitated by Dr Caitlin Dean, Chair Trustee of PSS. An advert (see Attachment B) will be distributed by PSS via their social media platforms (Instagram, Facebook and Twitter). Interested individuals will be encouraged to view the Participant Information Sheet (see Attachment A) on Qualtrics and contains more detailed information on the study, the link to which is included in the initial recruitment advert. Interested participants are encouraged to proceed beyond the Participant Information Sheet and on to the Consent Form (see Attachment D), also hosted on Qualtrics. It will also be made clear that the researcher is available to answer queries relating to consent via email or video-call (maximum 10 minutes) should there be any. The Consent Form will include an option to be contacted for feedback about key emergent themes and/or a summary of findings, refusal of which will not preclude individuals from participating in the research.

Those who give consent will be required to provide a contact email address, which will be used by the lead researcher to contact participants to organise an interview time and date. Those who complete the Consent Form will be directed to a Contact Details Form (see Attachment E), also hosted on Qualtrics, which asks for their name, address, contact number, registered GP practice, and a name and contact number for an emergency contact. This information is for use in situations involving the disclosure of information suggesting the individual is at imminent risk themselves or that there is a child protection risk identified. Participants' GP surgeries will be sent a standard letter informing their GP of the participant's involvement (see Attachment J). This is also explained in the Participant Information Sheet and the Consent Form, and the data is destroyed immediately after the interview if it is not required or immediately after any and all concerns have been actioned if the information has to be used. A Risk Assessment (see Attachment I) is included with this application detailing various disclosure scenarios and their responses as well as an estimate of likelihood.

Following completion of the Contact Details form, participants will be directed to the pre-interview questionnaire (see Attachment F), which is also hosted on Qualtrics. This questionnaire contains demographic questions, items about experience of HG and mental health. It ends with a modified version of the Pregnancy-Unique Quantification of Emesis (PUQE-24); a brief self-report measure containing 3 items related to frequency of nausea, vomiting and dry heaving over the 24 hours prior to completing the questionnaire and extra items related to sleep and quality of life. As the PUQE-24 is being used retrospectively on this occasion, participants will be asked how they would have completed the questionnaire when their HG symptoms were active. Some of the HG-related questions are designed to investigate whether they would appear to have met diagnostic criteria for HG based on the Windsor Definition.

The interviews are expected to last up to 1.5 hours and will start with a short review of what to expect and the aims of the study. Participants will be reminded that they may withdraw from the study at any point, up until transcription and anonymisation of interviews. Participants will be made aware that if the call ends abruptly in an unplanned manner for any reason, the interviewer will attempt to contact the participant using the contact number they provided to ascertain whether they wish to continue the interview and assist with re-establishing the video

call.

Wording of all participant-facing materials (Attachments A-G) and a semi-structured interview schedule consisting of up to 12 open questions (see Attachment H) has been agreed upon in collaboration with PSS's Patient and Public Involvement panel. Flexible use of the interview schedule will be utilised with the aim of facilitating exploration of elements of experience which are meaningful to the participant and provide enough data to address the research questions. Most of the video or phone call will consist of a semi-structured interview, which will be followed by a debrief including discussing support options if required. A written debrief will be sent containing this information as well (see Attachment G). As recruitment is intended to be UK-wide and it would not be feasible to be aware of all local options, signposting for support is likely to consist of nationally available choices. Video-call interviews will be digitally recorded via Microsoft Teams and stored securely via password-protection and encryption in accordance with the University of Edinburgh's procedures for secure data storage. Phone calls will be recorded digitally using a dedicated encrypted device and the file stored securely in the same fashion as the video interviews. The speech within the interviews will be transcribed and stored anonymously using a pseudonym for each participant. The University of Edinburgh's Datastore will be used to store transcripts and questionnaire responses for a minimum of 5 years. Original interview recordings will be deleted following transcription within a month of the interview having taken place.

Analysis
Anonymised transcripts will be analysed and coded to search for common themes. The primary researcher will oscillate between their own meaning making of the transcripts and the meaning making of the interviewees themselves in order to arrive at a final psychological analysis of the whole dataset that remains faithful to the source material, in accordance with the Interpretative Phenomenological Analysis methodology.

Q2. Will you collect or use NHS data?

☐ Yes ☒ No

If "yes" – what NHS data will you collect or use?

Q3. What information about participants/data subjects will you collect and/or use?

The following information will be collected:

- Information collected via Qualtrics in the Contact Details Form (Attachment E). This includes name, address, contact number, registered GP practice, emergency contact name and phone number
- E-mail address in order to send e-mails to organise interviews, answer queries, and provide the Advert, and link to the Qualtrics resources including Participant Information Sheet and Consent Forms as well as provide information on how to access Microsoft Teams calls
- The pre-interview questionnaire (Attachment F) gathers demographic information as well as information on HG and non-HG pregnancies, and mental health. Completed questionnaires will be gathered on Qualtrics then stored on University of Edinburgh's Datastore
- Audio and/or video recordings of interviews will be stored on the University of Edinburgh's Datastore in a password-protected folder and will be deleted within one month of the interview
- Anonymised interview transcripts will be stored on the University of Edinburgh's Datastore. This system requires user logins to access
- Email address if the participant chooses to receive a copy of the themes to comment and provide feedback on; and/or if the participant chooses to receive a summary of the final report. This will be optional and information about these processes are included in the Participant Information Sheet and Consent Form

Q4. What training will staff who have access to the data receive on their responsibilities for its safe handling? Have all staff and students who have access completed the mandatory data protection training on the self-enrolment page of Learn?

The researcher has undertaken the "MANTRA" Training Online and has access to the University of Edinburgh pages on data protection guidance and is aware of appropriate contacts should anything arise

Q5. Will the information include special categories of personal data (health data, data relating to race or ethnicity, to political opinions or religious beliefs, trade union membership, criminal convictions, sexual orientations, genetic data and biometric data)?

☒ Yes ☐ No

If "yes" – Explain what safeguards e.g. technical or organisational you have in place; including any detailed protocols if this requires special and/or external processing, storage, and analysis.

The pre-interview questionnaire contains questions about the participant's experience of pregnancies including with and without HG in addition to enquiring about mental health diagnoses and support sought. Responses will be held securely in the University of Edinburgh's Datastore

Q6. Please indicate how your research is in the public interest:

☒ Your research is proportionate
☐ Your research is subject to a governance framework
☐ Research Ethics Committee (REC) review (does not have to be a European REC)
☐ Peer review from a funder
☐ Confidentiality Advisory Group (CAG) recommendation for support in England and Wales or support by the Public Benefit and Privacy Panel (PBPP) for Health and Social Care in Scotland
☐ Other

Q7. It is essential that you identify, and list all risks to the privacy of research participants. You will then need to consider the likelihood of the risks actually manifesting and the severity of harm if the risks actually manifest.

Risk	Likelihood of risk manifesting			Severity of harm		
	Remote	Possible	Probable	Minimal	Significant	Severe
Identifiable due to data linkage	☐	☒	☐	☒	☐	☐
Identifiable due to low participant numbers	☒	☐	☐	☒	☐	☐
Identifiable due to geographical location	☒	☐	☐	☒	☐	☐
Identifiable due to transfer of data	☒	☐	☐	☒	☐	☐
Identifiable due to access of data	☒	☐	☐	☒	☐	☐
Insert more rows as appropriate	☐	☐	☐	☐	☐	☐

Please use this text box to record any other risks and the likelihood of them occurring, along with the severity of harm. Please also use this when dealing with secondary data.

Please identify measures you could take to reduce or eliminate risks identified as possible/significant or probable/severe.

On transcribing interviews, participants accounts will be attributed to a pseudonym, reducing likelihood of data linkage. Likewise, any references made to third parties during participants' accounts will be removed in order to avoid the inclusion of identifiable data about others. Intention is not to be any more specific than country of residence within the UK, thus reducing likelihood of identification due to geographical location. Risk due to transfer or access of data is reduced greatly by using the University of Edinburgh's Datastore for storage of sensitive data

Q8. Will information containing personal, identifiable data be transferred to, shared with, supported by, or otherwise available to third parties outside the University?

☒ Yes ☐ No

If "yes" - Please explain why this necessary and how the transfer of the information will be made secure. If the third party is based outside the European Economic Area please obtain guidance from the Data Protection Officer.

Information such as name, address, contact number and registered GP practice may be shared with emergency services, the GP surgery or social work departments only in the event of a disclosure suggesting a high level of risk of harm to the participant or someone else, including a child or children and/or disclosure of child abuse. The information will only be shared on an emergency as needed basis

The consent form, contact details sheet, and pre-interview questionnaire are all hosted on Qualtrics, and therefore the integrity and trustworthiness of that platform must be considered

Q9. Other than the use by third parties, will the data be used, accessed or stored away from University premises?

☐ Yes ☒ No

If "yes" - Describe the arrangements you have put in place to safeguard the data from accidental or deliberate access, amendment or deletion when it is not on University premises, including when it is in transit, and (where applicable) it is transferred outside the EEA.

It should be noted that the University of Edinburgh's Datastore will be accessed remotely via VPN, and so virtually still on the premises

Q10. Will feedback of findings be given to your research project participants or data subjects?

☒ Yes ☐ No

If "yes" - How and when will this feedback be provided?

Participants will have the option to receive a summary of key themes emergent from their transcript, which will be sent to them via email if they noted an interest in receiving this on their consent form. Participants will have a period of two weeks to provide feedback on these themes via email. Participants will also have the option to be sent a summary of the final write-up of the project

If "no" - Please provide rationale for this.

Q11. How do you intend to use/disseminate the results of your research project?

This research will form one half of a thesis completed as a requirement of the Doctorate in Clinical Psychology with the University of Edinburgh, the other half being a systematic review. The intention is to submit both halves of the thesis for publication in peer-reviewed journals individually following the Viva process.

A lay summary of the study findings and a poster will also be prepared and offered alongside the published research article to participants, the research collaborator (for distribution via PSS), and to members of the PSS PPI panel who were consulted throughout. A lay summary of the systematic review and a poster will also be prepared and offered alongside the published systematic review article to the research collaborator, again for distribution via PSS.

It is hoped there will be opportunities to present findings at one or more conferences and at a local level within NHS Grampian.

Section 2: Security-sensitive material

The Terrorism Act (2006) outlaws the dissemination of records, statements and other documents that can be interpreted as promoting or endorsing terrorist acts.

Q12. Does your research involve the storage on a computer of any such records, statements or other documents?

☐ Yes ☒ No (if you answered no to this question please jump to section 3)

If "yes" - Please type 'Yes' to indicate that you agree to store all documents on that file store

Q13. Might your research involve the electronic transmission (for example, as an email attachment) of such records or statements?

☐ Yes ☒ No

If "yes" - Please type 'Yes' to indicate that you agree not to transmit electronically to any third party documents stored in the file store

Q14. Will your research involve visits to websites that might be associated with extremist, or terrorist, organisations?

☐ Yes ☒ No

If "no", please proceed to Question 15.

If "yes" - You are advised that such sites may be subject to surveillance by the police. Accessing those sites from University IP addresses might lead to police enquiries. Please type 'Yes' to acknowledge that you understand this risk

By submitting to the ethics process, you accept that your School Research Ethics Officer and the convener of the University's Compliance Group will have access to a list of titles of documents (but not the contents of documents) in your document store. *Please type 'Yes' to acknowledge that you accept this.*

Yes

Please confirm that you have contacted your School Research Ethics Officer to discuss security-sensitive material by ticking 'Yes'

☐ Yes, I have contacted my School's Research Ethics Officer

☒ No, I have not contacted my School's Research Ethics Officer

Section 3: Copyright

Q15. Does your project require use of copyrighted material?

☐ Yes ☒ No

If "yes" please give further details

Section 4: Good conduct in collaborative research

Q16. Does your project involve working collaboratively with other academic partners?

☒ Yes ☐ No (if you answered no to this question please jump to section 5)

If "yes" - Is there a formal agreement in place regarding a collaborative relationship with the academic partner(s)?

Yes, a research agreement is in place between all parties. This includes myself, Dr Charlene Plunkett (academic supervisor), Dr Ashley Allan (clinical supervisor), and Dr Caitlin Dean (research collaborator). It should be noted that Dr Dean will not have access to the raw data as she works outside of both the university and the NHS in the her third sector role.

If "no" - Please explain why there is no formal agreement in place

Q17. Does your project involve working collaboratively with other non-academic partners?

☐ Yes ☒ No

If "yes" - Is there a formal agreement in place regarding a collaborative relationship with the non-academic partner(s)?

If "no" - Please explain why there is no formal agreement in place.

Q18. Does your project involve employing local field assistants (including guides/translators)?

☐ Yes ☒ No

If "yes" - Is there a formal agreement in place regarding the employment of local field assistants (including guides and translators)?

If "no" - Please explain why there is no formal agreement in place

Q19. Will care be taken to ensure that all individuals involved in implementing the research adhere to the ethical and research integrity standards set by the University of Edinburgh?

☒ Yes ☐ No

If "no" - Please explain why care will not be taken

Q20. Have you reached agreement relating to intellectual property?

☒ Yes ☐ No

If "no" - Please explain why you have not reached agreement

Section 5: Good conduct in publication practice

In publication and authorship, as in all other aspects of research, researchers are expected to follow the University's guidance on integrity. https://www.ed.ac.uk/governance-strategic-planning/content-to-be-removed/research-integrity. By ticking yes, you confirm that full consideration of the items described in this Section will be addressed as applicable

☒ Yes ☐ No

If you intend to collect new data, please continue completing the Level 2 application in the next page.

If you are NOT collecting any new data, you have now completed the Level 1 application. Please submit this document alongside all attachments to ethics.hiss@ed.ac.uk .

LEVEL 2 ONLY – Participant Risk and Information

The following Sections are to be completed if you are collecting new data. Please do not complete it if you are using existing data.

Section 6: Potential risks to participants and researchers

Q21. Is your research project likely or possible to induce any psychological stress or discomfort in the participants or others, indirectly associated with the research?

☒ Yes ☐ No

If "yes" state the types of risk and what measures will be taken to deal with such problems

Discussion of distressing subject matter could lead to emotional distress. In the event of significant distress, participants will be offered the opportunity to take a break or stop the interview completely if they feel they can no longer continue. If a participant is distressed and the call drops, an attempt will be made to contact the participant via the contact number they provided to check how they are and offer signposting advice if appropriate, whether they'd like to try to re-establish the call to continue; take a break or reschedule the call; and whether they'd like to continue participating in the study. Depending on level of concern regarding the welfare of the participant and whether they had disclosed an intention to harm themselves or someone else, inability to reach the participant via their contact number will then be followed by follow up via email to invite back to continue the interview or confirm they no longer wish to continue (low/no perceptible risk), contacting their emergency contact to ensure the safety of the individual or to prompt them to check in (medium risk), or contacting emergency services and GP surgery (high risk). Debrief will include checking in on distress and signposting to appropriate sources of support if necessary. If the participant discloses information that indicates they are a significant risk to themselves, the emergency contact or emergency services will be made aware (depending on imminence of harm). The participant would be made aware that these actions were to take place.

Q22. Does your research project require any physically-invasive or potentially physically harmful procedures?

☐ Yes ☒ No

If "yes" give details and outline procedures to be put in place to deal with potential problems.

Q23. Does your research project require the use of privacy-invasive technology, such as CCTV, biometrics, facial recognition, vehicle tracking software?

☐ Yes ☒ No

If "yes" - Give details and outline procedures to be put in place to deal with potential problems.

Q24. Does your research project involve the investigation of any illegal behaviour or activities?

☐ Yes ☒ No

If "yes" - Give details of any illegal behavior or activities you may investigate

Q25. Is it possible that your research project will lead to awareness or the disclosure of information about child abuse or neglect?

☒ Yes ☐ No

If "yes" - Indicate the likelihood of disclosure and the procedures to be followed if you become aware that a child has been or may be at risk of harm

It is possible I might be told about a child being neglected due to ill health of the pregnant individual feeling unable to continue their usual caring responsibilities. Should a significant concern by identified, the relevant social work department of the local authority, based on the address given by the participant, will be contacted to make them aware and take further action if they deem it necessary. The participant will be made aware that this disclosure is to take place

Q26. Is it likely that dissemination of research findings or data could adversely affect participants or others indirectly associated with the research?

☐ Yes ☒ No

If "yes" - Describe the potential risk for participants/data subjects of this use of the data. Outline any steps that will be taken to protect participants.

Q27. Could participation in this research adversely affect participants and others associated with the research in any other way?

☒ Yes ☐ No

If "yes" - Describe the possible adverse effects and the procedures to be put in place to protect against them.

It is possible that discussion of emotive subject matter relating to a difficult time in the past could bring that subject back into the present awareness of the individual for longer than the duration of the interview. It is hoped that the debrief discussion, the individual's existing support network and the support options covered in the debrief sheet will be sufficient to address any distress brought on by the discussion

Q28. Is this research expected to benefit the participants, directly or indirectly?

☒ Yes ☐ No

If "yes" - Give details of how this research is expected to benefit the participants.

The research is hoped to improve understanding of the experience of HG in a general sense as well as contribute to insight on the impact others have on individuals suffering with HG. Following effective dissemination, it is hoped there will be information that can be utilised by healthcare professionals to improve the quality of care provided to sufferers of HG in the future, which could include the participants of this study, for whom the likelihood of a future HG pregnancy is increased based on having had it once before. Information from this study could also contribute to more general public awareness campaigns which could mean suffers are met with a greater rate of understanding from others regarding HG.

Q29. Will the true purpose of the research be concealed from the participants/data subjects?

☐ Yes ☒ No

If "yes" - Explain what information will be concealed and why.

Q30. Will participants/data subjects be debriefed at the conclusion of the study?

☒ Yes ☐ No

If "no" – Why will participants / data subjects not be debriefed?

Q31. At any stage in this research could researchers' safety be compromised, or could the research induce emotional distress in the researchers?

☒ Yes ☐ No

If "yes" - Give details and outline procedures to be put in place to deal with potential problems.

My wife endured 2 HG pregnancies, which impacted her directly and myself indirectly in a significant way in both cases. It is possible that hearing similar accounts of difficulties could induce some emotional distress, and so I would plan to make use of my own means of support outside of the interviews in any such instances. This will also be monitored via supervision processes.

Please tick to confirm you agree with the following:

I will adhere to School guidance on risk assessment and health and safety and will seek advice on project and travel insurance prior to project commencement.

☒ I agree

☐ I do not agree

☐ Not applicable

Section 7: Participants and data subjects.

Q32. How many participants or data subjects are expected to be included in your research project?

The figure of 6-10 was arrived at via a combination of guidance related to the chosen methodology of Interpretative Phenomenological Analysis (IPA) (Smith and Osborn, 2015), precedence in published perinatal IPA research (Hall, 2006) and discussion of what a reasonable expectation would be of a clinical psychology doctoral student with my academic supervisor in terms of the time and resources available.

References

Hall P. Mothers' experiences of postnatal depression: an interpretative phenomenological analysis. Community Pract. 2006 Aug;79(8):256-60. PMID: 16922035.
Smith, J., & Osborn, M. (2015). Interpretive phenomenological analysis. In J. A. Smith (Ed.), Qualitative psychology: A practical guide to research methods (3rd ed., pp. 51-80). Sage.

Q33. What criteria will be used in deciding on the inclusion and exclusion of participants/data subjects in your research project?

Dr Caitlin Dean was consulted on appropriate inclusion criteria considering a balance of what criteria would be most likely to provide a homogenous enough sample to be able to extract themes from the analysis, but not so stringent that it would be hard to recruit the desired number of participants.

Inclusion Criteria

- Individuals who self-identify as having experienced HG for the first time within the last 8 years
- Pregnancy or birth occurred no less than 6 weeks prior to interview in order to allow the individual time to recover
- Over 18
- UK-based
- Able to provide informed consent
- Ability to comprehend and use written and spoken English or have access to translation and interpretation services
- Access to the internet and equipment necessary to video-call or telephone call

Exclusion Criteria

- Nausea and/or vomiting are accounted for by another condition

Q34. Are any of the participants or data subjects likely to be under 16 years of age?

☐ Yes ☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q35. Are any of the participants or data subjects likely to be children in the care of a Local Authority?

☐ Yes ☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q36. Are any of the participants or data subjects likely to be known to have additional support needs?

☐ Yes ☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q37. In the case of participants with additional support needs, will arrangements be made to ensure informed consent?

☐ Yes ☐ No ☒ N/A

If "yes" – What arrangements will be made?

If "no" – Please explain why not

Q38. Are any of the participants or data subjects likely to be physically or mentally ill?

☒ Yes ☐ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Possibility participants will still be recovering from the effects of HG and/or childbirth. This could include physical difficulties or any post-natal mental health difficulties. Efforts will be made during the recruitment process, when discussing the study and what it asks of participants, to identify whether the individual is struggling with any physical or mental health difficulties and the impact this may have on their ability to take part in the research

Q39. Are any of the participants or data subjects likely to be vulnerable or likely exposed to harm in other ways?

☐ Yes ☒ No

If "yes" - Explain and describe the nature of the vulnerability and the measures that will be used to protect and/or inform participants/data subjects.

Q40. Are any of the participants or data subjects likely to be unable to communicate in the language in which the research is conducted?

☐ Yes ☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q41. Are any of the participants or data subjects likely to be in a relationship (i.e., professional, student-teacher, other dependent relationship) with the researchers?

☐ Yes ☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q42. Are any of the participants or data subjects likely to have difficulty in reading and/or comprehending any printed material distributed as part of the study?

☐ Yes ☒ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q43. Describe how the sample will be recruited.

Recruitment will be facilitated by Dr Caitlin Dean, Chair Trustee of PSS. An advert (see Attachment B) will be distributed by PSS via their social media platforms (Instagram, Facebook and Twitter). Individuals interested in taking part in the study will be encouraged to click the link in the advert, which will take them to the study Qualtrics page, which begins with the Participant Information Sheet (see Attachment A). If, after reading the Participant Information Sheet, the potential participant is motivated to take part in the study, access to an online Consent Form (see Attachment D) can be gained by proceeding to the next page after the Information Sheet on Qualtrics. The researcher will email potential participants using the address they provided on the Consent Form to organise an interview date and time. It will also be made clear that the researcher is available to answer queries relating to consent via email or video-call should there be any. The Consent Form will include an option to be contacted about key emergent themes and/or be provided with a summary of final findings, refusal of which will not preclude individuals from participating in the research.

Q44. Will participants receive any financial or other material benefits as a result of participation?

☐ Yes ☒ No

If "yes" - What benefits will be offered to participants and why?

Section 8: Participant or data subject information and consent

Q45. Will written or oral consent be obtained from all participants or data subjects?

☒ Yes ☐ No

If "yes" – attach participant information sheet and consent form and detail the process you will follow.

If "no" – explain why not and what process you will follow regarding consent, or if consent cannot or should not be sought for some reason, please provide a clear case and rationale for this (e.g. in international contexts where speaking to foreign researchers is prohibited).

Potential participants will be sent an email with a link to the Participant Information Sheet attached, which leads on to the Consent Form for those interested in taking part based on what they have read. The consent form includes acknowledgement that the participant has read and understood the Participant Information Sheet

Q46. Have you made arrangements to tell participants what information you will hold about them and for how long?

☒ Yes ☐ No

If "yes" - what arrangements have been made?

Participants will be informed that their anonymised interview transcript and anonymised information gathered in their questionnaire will be stored for a minimum of 5 years and may be used in future ethically approved research.

Participants will be informed that their own contact details and the emergency contact details they provide will be deleted immediately following the interview or immediately following disclosure to relevant services (e.g. social work or emergency service) where necessary.

Participants will be informed that the original audio and video recording of their interview will be deleted immediately following transcription accuracy has been ensured, which will be carried out within a month of the interview.

Participants will be informed that if they agree to be contacted by the researcher for feedback about key themes that have emerged from the content of their interview, or have requested a summary of the final written report, their contact details will be stored securely and destroyed 6-12 months after the study is completed.

If "no" – why not?

Q47. Have you made arrangements to tell participants whether you will disclose the information to other organisations?

☒ Yes ☐ No ☐ N/A

If "yes" - What arrangements have been made?

Participants will be made aware via the Patient Information Sheet that their contact details can be shared with relevant services (e.g. social work or emergency services) should there be a disclosure of child neglect or abuse, or serious risk of harm to the participant.

If "no" – why not?

Q48. Have you made arrangements to tell participants whether you will combine that information with other data?

☒ Yes ☐ No ☐ N/A

If "yes" - What arrangements have been made?

Participants will be informed that their data will be combined with other participants' data after having been anonymised in order to provide opportunities for analysis and comparison of similarities and differences

Q49. In the case of children participating in the research, will the consent or assent of parents be obtained?

☐ Yes ☐ No ☒ N/A

If "yes" - Explain how this consent or assent will be obtained

If "no" – Please explain why you won't be obtaining consent

Q50. Will the consent or assent of children participating in the research be obtained?

☐ Yes ☐ No ☒ N/A

If "yes" - Explain how this consent or assent will be obtained

If "no" – Please explain why not

Q51. In the case of participants who are not proficient in the language in which the research is conducted, will arrangements be made to ensure informed consent?

☒ Yes ☐ No ☐ N/A

If "yes" – What arrangements will be made?

Translation and interpretation services will be utilised in order to ensure the content of the consent form is understood to the individual

If "no" – Please explain why not

Q52. Does the activity involve using cookies or tracking individual's activity on a website or the Internet in general?

☐ Yes ☒ No

If "yes" – Describe the arrangements you have put in place to obtain informed consent for the use of these tools

You have now completed the Level 2 application. Please submit this document alongside all attachments to ethics.hiss@ed.ac.uk .

Appendix D: Sponsorship Form

University of Edinburgh
College of Arts, Humanities and Social Sciences
Research Governance Office
55 George Square
Edinburgh
EH8 9JU

9th November 2022

Navin Mistry
c/o School of Health in Social Science
University of Edinburgh

Dear Navin

Study Title: How do first time sufferers of Hyperemesis Gravidarum make sense of their experience and the way others communicate with them? An Interpretative Phenomenological Analysis

Sponsor number: CAHSS 2210/05

Under the requirements of the UK policy framework for health and social care research, the University of Edinburgh agrees in principle to act as Sponsor for this project. Sponsorship is subject to you obtaining institutional ethics for the project.

As Chief Investigator, you must ensure that the study does not commence until all applicable approvals have been obtained. Following receipt of all relevant approvals, you should ensure that any amendments to the project are notified to the Sponsor (including an extension to the study end date). Please note that there is a requirement to notify the sponsor once the study has ended.

Yours sincerely

Charlotte Smith

Research Governance Coordinator

Appendix E: Participant Information Sheet

Participant Information Sheet

Study Title: How do first time sufferers of Hyperemesis Gravidarum make sense of their experience and the way others communicate with them? An Interpretative Phenomenological Analysis

Before you decide whether you would like to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information.

Take time to decide whether or not you wish to take part.

What is the study about?

There is currently not enough research on, or awareness of, the medical condition Hyperemesis Gravidarum. Hyperemesis Gravidarum (HG) is a severe form of Nausea and Vomiting of Pregnancy or 'Morning Sickness'. It is defined as starting within the first 16 weeks of pregnancy, and consists of severe nausea and/or vomiting, being unable to eat and/or drink normally and being strongly limited in ability to perform daily activities.

This study aims to explore the lived experiences of individuals who have had HG using a method called Interpretative Phenomenological Analysis. This is a style that involves focusing on how an individual experiences something, then analysing their account of their experience from a psychological perspective. This study has a particular interest in the influence interacting with other people had in that process. Similarities and differences between individuals' accounts will be explored. The researcher will achieve this by speaking with individuals who have experience of their first HG pregnancy within the last 8 years.

It is hoped that a deeper exploration of the experience of HG will provide insight into stages of the experience which are particularly important, things which are helpful and unhelpful about the way others interact with people with HG, and how beliefs about HG change. These findings have the potential to help improve awareness, guide psychologically informed practice, contribute to the HG literature and inspire more research into the area via effective distribution and promotion of the work.

Who are we inviting to take part?

We are seeking individuals who:

- Have had their pregnancy experience no less than 6 weeks ago, but no more than 8 years ago and experienced Hyperemesis Gravidarum during their pregnancy
- Are over the age of 18
- Live in the UK
- Are able and willing to complete a short questionnaire and participate in a 60-90 minute video or phone call about their experience of Hyperemesis Gravidarum

Do I have to take part?

No, it is entirely up to you. If you do decide to take part, you will be asked to complete an online consent form to show you understand your rights in relation to the research, and that you are happy to participate. If you do decide to take part, you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect you or your

medical care in any way. Please note it will only be possible to withdraw your data up to 2 weeks following your interview as it will be anonymised after this date and it will not be possible to identify your data to remove it.

I am interested in taking part, what do I do?

If you are interested in taking part, proceed to the Participant Consent Form by clicking the button with arrows pointing to the right at the bottom of this page. If you have any questions about the study, this sheet or the Participant Consent Form, please email the lead researcher, Navin, on s0675328@ed.ac.uk.

At the bottom of the Participant Consent Form, you will be asked for your email address to indicate you wish to take part. This is so that the lead researcher can email you to organise an interview time that suits you. Please look for an email from the lead researcher within a week of completing your form and remember to check junk mail folders.

What happens if I agree to take part?

- Providing consent via the online form will lead you to a form asking for contact details. You will be asked for the address from which you are taking part, your GP details and an emergency contact number. This is in case the researcher becomes worried about a risk to yourself or others. When selecting an emergency contact, please try to list someone close enough to reach you quickly in case of emergency. Contact information will be deleted immediately following the interview, or immediately following disclosure to the relevant service if necessary.
- Following completion of the contact details form, you will be invited to complete a pre-interview questionnaire. This includes questions relating to you, your experience of Hyperemesis Gravidarum and your mental health.
- The interview will take place over video using Microsoft Teams or telephone. You will need to be able to do this from a private space.
- The researcher will begin by asking questions about your experiences of Hyperemesis Gravidarum and will then move on to explore your experiences of interacting with others in relation to it. The conversation will take between 60-90 minutes.
- With your consent, video interviews will be audio and video recorded and transcribed (written up) at the same time. You may turn your camera off if you would prefer or are required to for cultural reasons. If the interview takes place via telephone, the transcription will be completed manually based on the recording of the phone call. The researcher will check the transcript against the recording and delete the recording after accuracy has been ensured. The researcher will ensure that any information that may identify you or other third parties is removed.
- The recording and transcript will be stored in a secure place.
- The lead researcher and a second coder will explore the transcripts for key themes that emerge from the content of the interview.
- If you wish, the researcher can email you with a summary of the key themes and ask you to give feedback via email on how well they fit with your experience. If you choose to do this, your email address will be stored securely and deleted 6-12 months after the study is completed.

What are the possible benefits of taking part?

We do not anticipate any direct benefits to you of taking part in this study. However, it is hoped that the results of this study can be used to improve the quality of healthcare services provided to those with Hyperemesis Gravidarum in the future, improve understanding of the current experience of Hyperemesis Gravidarum, and raise awareness of the condition.

What are the possible disadvantages of taking part?

We do not anticipate any significant risks associated with participation. You may find it distressing speaking about your experiences of Hyperemesis Gravidarum. If this happens, the interview can be paused to give you a break or stopped altogether. You will also be provided with information that gives you an idea of where to go for some support if you wish it.

The section below on confidentiality explains our duty of care and how it compels us to act on information suggesting risk of harm to yourself or someone else. We will only contact individuals or services if it is necessary due to imminent risk of harm and/or disclosure of child abuse or neglect. In cases where this is not clear, the researcher will attempt to clarify the situation with you to reduce the chance of unnecessary disclosures.

Will my taking part be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. The information you share is confidential, but this confidentiality has limits. Your GP Surgery will be informed that you are taking part in the study and sent a copy of this information sheet if you consent to take part. They will only be contacted again if it is necessary as part of a response to the disclosure of imminent risk to yourself. We have a duty of care to contact relevant services (for example, Social Work or Emergency Services) if there is a disclosure of child abuse or neglect, as well as disclosures of risk of harm to you. If we are worried about you but believe there is no immediate risk, then we will either contact your emergency contact. If the risk is immediate, then we will contact the emergency services. The researcher will discuss this with you before doing anything where possible.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Address
- Contact Number
- Email address
- Emergency Contact Name
- Emergency Contact Number
- GP Surgery

People will use this information to do the research or to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

If you consent to being audio recorded and video recorded, all recordings will be destroyed once they have been transcribed and accuracy ensured. Your data will only be viewed by the researcher/research team. If interviewed via video call, your data will be transcribed via the transcribe function on Microsoft Teams and then checked for accuracy by the lead researcher. If interviewed via telephone, your interview will be transcribed manually by the lead researcher listening to an electronic recording of the interview. All electronic data will be stored on a password-protected computer file and all paper records will be stored in a locked filing cabinet. Your consent information will be kept separately from your responses to minimise risk.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can withdraw your participation at any point by cancelling or stopping the interview without any negative repercussions.
- Following participation, you are still able to withdraw your data up until 2 weeks after your interview. After this point your interview will be anonymised.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information at

- https://www.ed.ac.uk/records-management/privacy-notice-research
- by asking one of the research team
- by sending an email to the University of Edinburgh Data Protection Officer at dpo@ed.ac.uk

The University of Edinburgh is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Edinburgh will keep identifiable information about you up to 1 year after the study has finished and your anonymised data for a minimum of 5 years. Your anonymised data may be used in future ethically approved research.

Transcripts and anonymised information gathered in questionnaires will be stored for a minimum of 5 years and may be used in future ethically approved research. Consent forms will be destroyed 6-12 months after the study is completed.

For general information about how we use your data go to: https://www.ed.ac.uk/records-management/privacy-notice-research

What will happen to the results of the study?

The study will be written up as one half of a thesis as part of the Doctorate in Clinical Psychology at University of Edinburgh. The final write-up will be submitted for publication in a relevant research journal. Anonymised quotes from interviews will be within the final written report. It is possible that the results of the study will be presented at relevant Hyperemesis Gravidarum, or more general pregnancy-related conditions, conferences. You will not be identified in any reporting of the data gathered. A summary of the findings from the study will be made available to participants who indicate they would like to receive this. This summary will be sent to participants by email.

Who has reviewed the study?

The study proposal has been reviewed by University of Edinburgh, School of Health in Social Science Research Ethics Committee.

Who can I contact?

- If you have any further questions about the study, please contact the lead researcher, Navin Mistry (Trainee Clinical Psychologist) on s0675328@ed.ac.uk
- If you would like to discuss the study with someone independent of the study, please contact Tim Bird (Research Director, University of Edinburgh) on timothy.bird@ed.ac.uk
- If you wish to make a complaint about the study, please contact Dr Matthias Schwannauer (Head of School of Health and Social Science) on headofschool.health@ed.ac.uk

Thank you for taking the time to read this information sheet and for your interest in this study.

If you meet the inclusion criteria and are interested in taking part, please proceed to the next page to review the Participant Consent Form.

If you have any questions before deciding to take part, please contact the lead researcher, Navin Mistry on s0675328@ed.ac.uk

Please keep a copy of this sheet for your records.

Appendix F: Study Advert

Were you so sick or nauseous during pregnancy that it was hard to eat or drink? Was it hard for you to go about your usual day?

We are conducting a study looking at how first-time Hyperemesis Gravidarum sufferers made sense of their experience and the way others communicated with them

Hyperemesis Gravidarum (HG) is a severe form of Nausea and Vomiting of Pregnancy or 'Morning Sickness'. It is defined as starting within the first 16 weeks of pregnancy, and consists of severe nausea and/or vomiting, being unable to eat and/or drink normally and being strongly limited in ability to perform daily activities.

My name is Navin Mistry and I am a Trainee Clinical Psychologist conducting a piece of research on individuals' experience of HG as a part of my Doctorate in Clinical Psychology with the University of Edinburgh. I am interested in finding out what it is like to have HG, especially what it's like trying to understand what is going on and about how others within and outside of healthcare influence that experience.

You can take part if you:

- Have experienced your first HG pregnancy within the last 8 years (and it is at least 6 weeks since pregnancy)
- Are over 18 years of age and live in the United Kingdom
- Can provide informed consent (making sure you understand enough about what the study involves and how your data will be used before deciding to take part)
- Can understand and use written and spoken English, or we can organise access to translation and interpretation services
- Have access to the internet and equipment necessary to participate in a video-call or phone call

What will taking part involve?

If you consent to take part in the study after hearing more about it, then you will be asked to complete a brief questionnaire about yourself and your HG experience, then you will take part in a 60-90 minute interview via video-call or telephone about your experience of HG. The interview will include questions about your overall experience of HG and the impact it had on your life, and what it was like talking to healthcare professionals and others in your life about HG.

Interested?

Please click the link to the more detailed Patient Information Sheet you should also have received. If you do not have it or have other questions about the study, please email me at s0675328@ed.ac.uk

Thank you for reading!

Navin Mistry, Trainee Clinical Psychologist, School of Health in Social Science, University of Edinburgh

Appendix G: Consent Form

Participant Consent Form

PLEASE TAKE A SCREENSHOT OF THIS FORM FOR YOUR RECORDS

Study Title: How do first time sufferers of Hyperemesis Gravidarum make sense of their experience and the way others communicate with them? An Interpretative Phenomenological Analysis

Researcher Name: Navin Mistry (Trainee Clinical Psychologist)

Contact Details: s0675328@ed.ac.uk

Participant ID:

1) I confirm that I have read and understood the Participant Information Sheet (version no. 3, 03/02/2023) for the above study ☐

2) I have been given the opportunity to consider the information provided, ask questions and have had any questions answered to my satisfaction ☐

3) I understand that my participation is voluntary and that I can ask to withdraw my participation by stopping the interview at any time and without giving a reason ☐

4) I understand that I can withdraw my data up until 2 weeks following the interview. After this time my interview will be transcribed and anonymised ☐

5) I understand that my anonymised data will be stored for a minimum of 5 years and may be used in future ethically approved research ☐

6) I understand that relevant sections of my data collected during the study may be looked at by individuals from the Sponsor (University of Edinburgh) where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data ☐

7) I agree to my interview being audio recorded and/or video recorded ☐

8) I understand that my interview will be transcribed via the transcribe function on Microsoft Teams or manually if interviewed via telephone ☐

9) I understand that anonymised quotes from my interview may be within the final written report ☐

10) By providing my email address below I am confirming that I agree to take part in the above study. The lead researcher will email you to organise an interview time that suits you

_____

11) [Optional] I would like to be contacted via the email address above by the researcher for feedback about key themes that have emerged from the content of the interviews. I understand that my contact details will be stored securely and destroyed 6-12 months after the study is completed

Yes ☐
No ☐

12) [Optional] I would like the researcher to provide a summary of the final work via the email address above. I understand that my contact details will be stored securely and destroyed 6-12 months after the study is completed

Yes ☐
No ☐

Appendix H: Contact Details Form

How do first time sufferers of Hyperemesis Gravidarum make sense of their experience and the way others communicate with them? An Interpretative Phenomenological Analysis

Contact Details in Case of Emergency

These details will only be used in the event that information is disclosed about a serious risk of harm to yourself or to someone else, including a child or children. If no such disclosures are made during your interview, these details will be destroyed. If disclosures to a service or services are required, these details will be destroyed immediately after all necessary disclosures have taken place.

Your Name:

Your Address (including postcode):

Contact Number:

Your Registered GP Practice:

Name of Emergency Contact:

Emergency Contact Phone Number:

Appendix I: Pre-Interview Questionnaire

Study Title: How do first time sufferers of Hyperemesis Gravidarum make sense of their experience and the way others communicate with them? An Interpretative Phenomenological Analysis

Information about you

Please answer the following questions by ticking the most appropriate answer. If there are any questions you would prefer not to answer, please leave them blank.

1) **What age are you?** 18-24; 25-34; 35-44; 45-54; 55+
2) **What is your highest level of education?** Primary school; Standard Grade or equivalent; Highers or equivalent; University undergraduate programme; University postgraduate programme; other…
3) **What is your employment status?** Unemployed; retired; part-time employment; full-time employment; care giver; student; other…
4) **What is your relationship status?** Single; married or domestic partnership; widowed; divorced; separated
5) **Which country do you live in?** Scotland; England; Northern Ireland; Wales
6) **How many children do you have?** 1; 2; 3; 4; Other _____
7) **Have you experienced one or more non-HG pregnancies in the past? (Hyperemesis Gravidarum is defined as starting within the first 16 weeks of pregnancy, and consists of severe nausea and/or vomiting, being unable to eat and/or drink normally and being strongly limited in ability to perform daily activities)** Yes; No
8) **In what year/s have you given birth following HG?** 2018; 2019; 2020; 2021; 2022; 2023

Your Experience of Hyperemesis Gravidarum

The next set of questions relate to your first experience of Hyperemesis Gravidarum. If there are any questions you would prefer not to answer, please leave them blank.

9) **When did you first experience nausea and/or vomiting during your pregnancy?** 0-16 weeks; 16-26 weeks; 26-40 weeks
10) **Were you able to eat normally?** Yes; No
11) **Were you able to drink normally?** Yes; No
12) **Were you able to continue with your usual daily activities?** Yes; Yes with difficulty; No
13) **Did you receive a diagnosis related to your nausea and/or vomiting during your pregnancy?** Yes (What was it?.....); No
14) **Did you seek mental health support during your pregnancy?** Yes (What kind?.....); No
15) **Had you received a mental health diagnosis before your pregnancy?** Yes (Please specify.....); No
16) **Were you prescribed any antiemetic medication (medicine for sickness and/or nausea) during your pregnancy?** Yes; No

Modified Pregnancy-Unique Quantification of Emesis Index

The next set of statements relate to your first experience of Hyperemesis Gravidarum. Please think back to the period during which you experienced symptoms of Hyperemesis Gravidarum and answer in relation to an average day:

1) On average in a day, for how long did you feel nauseated or sick to your stomach?

Not at all </=1 hr 2-3 hr 4-6 hr >6 hr

1 ..... 2 ..... 3 ..... 4 5

2) On average in a day, how many times did you vomit or throw up?

>/=7 times 5-6 times 3-4 times 1-2 times I did not throw up

5 ..... 4 ..... 3 ..... 2 1

3) On average in a day, how many times did you have retching or dry heaves without bringing anything up?

None 1-2 times 3-4 times 5-6 times >/= 7 times

1 ..... 2 ..... 3 ..... 4 5

How many hours would you sleep in a typical 24 hours? _____
Why?_____

On a scale of 0 – 10 how would you have rated your wellbeing during that time? ____ 0 (worst possible) -> 10 (best possible)

Thank you for completing these questions, I look forward to hopefully speaking with you during the interview. I will contact you via the email address you have provided to arrange a time and date that suits you for the interview, but if you would like to get in touch about anything else, please get in touch via email: s0675328@sms.ed.ac.uk

Appendix J: Semi-Structured Interview Schedule

Interview Questions

In line with Interpretative Phenomenological Analysis methodological guidance, this will be a semi-structured interview. The below topic areas and prompt questions will be used as a guide, but it will be used flexibly to allow each participant to explore the areas of meaning that are important to them. Questions may be added or amended based on feedback from interviewees. This list of questions and prompts will not be shared with participants before or during the interview, though can be shared on request after the interview has taken place.

The interview will be primarily focused on individuals' first experience of HG, but if a participant has had further HG experiences since, efforts will be made to provide space to discuss similarities and differences if time permits.

Introduction

Thank you for agreeing to take part in this research. We are interested in your experience of Hyperemesis Gravidarum throughout your pregnancy. We are also interested in what it was like communicating with others about your experience during your pregnancy.

We expect the interview to last between 60 and 90 minutes, but we can stop to take a break at any point, and you can finish the interview at any time without giving an explanation.

[If participant has consented to be recorded, switch on the recorder]

May I double-check that you are happy for this interview to be recorded?

[Continue recording, if participant has confirmed their consent.]

Experience of HG

1. What was your overall experience of Hyperemesis Gravidarum (HG)?
    a. Prompts
        i. Can you tell me about when you first started to be sick/feel nauseous?
        ii. What, if anything, helped you cope?
        iii. Would you say COVID-19 impacted on your experience at all?
        iv. Were there any other significant challenges during the pregnancy?
        v. How did HG impact your usual day-to-day life?
        vi. What adjustments, if any, did you have to make throughout your pregnancy due to HG?

Knowledge of HG

1. What was your awareness and understanding of HG before your first HG pregnancy?
    a. Was there a family history of HG? (if yes, ask to expand)
    b. Had you gained an awareness of HG from anywhere else?
2. When the nausea and/or vomiting started, how did you understand what was going on?
    a. How did understanding of your nausea/vomiting symptoms change throughout the pregnancy?

Medical Communication

1. How was your experience of communicating with health professionals regarding your HG?
    a. Prompts

i. Can you talk me through who the main involved professionals were?
ii. Did your experience vary at all with different professionals?
iii. Did you feel listened to?
    1. If not, how did that affect you?
iv. How did it compare to your expectations?
v. What treatments, if any, were you offered to help manage your HG symptoms?
    1. How effective were they?
vi. Were enquiries made about HG affecting your mental health?
    1. If HG did impact negatively on your mental health, what support or treatment options were you offered or made aware of?

2. How do you think the way you were communicated with by health professionals affected you?
    a. Prompts
        i. Do you feel it influenced how you thought about your HG?

Non-Medical Communication

1. How was your experience of communicating with those in your personal life regarding your HG?
    a. Prompts
        i. E.g. Partner, Parents, In-laws, Friends
        ii. Colleagues, Managers (if relevant)
        iii. Anyone else (PSS?)?
        iv. Did you feel listened to?
            1. If not, how did that affect you?
2. How do you feel your contact with these individuals in your personal (and professional) life affected you?
    a. Prompts
        i. Do you feel it influenced how you thought about your HG?
        ii. Do you feel it influenced your decision about whether to seek medical advice specific to nausea and/or vomiting?

Reflecting Back and Ongoing Impact

1. Considering all you've been through, what is your understanding of your experience of HG now?
    a. Prompts
        i. What, if anything, do you wish you'd known sooner?
2. How has your experience of Hyperemesis Gravidarum affected you on an ongoing basis?
    a. Prompts
        i. Any lasting impact on personal relationships? Occupational relationships? Career-wise? With medical professionals?
        ii. Attitude towards future pregnancy?
3. Is there anything I haven't asked you about that you think would be important or helpful to discuss?
4. Do you have any questions for me?

Closing question

1. Is there anything else you would like to discuss that has not already been covered?

Thank you very much for taking part in this interview

Appendix K: Debrief

Debrief

How do first time sufferers of Hyperemesis Gravidarum make sense of their experience and the way others communicate with them? An Interpretative Phenomenological Analysis

Many thanks for having given your time to take part in this study relating to your experience of Hyperemesis Gravidarum.

It is appreciated that discussing what was likely a very difficult time in your life may have a negative impact on you, and so below is a list of supports available:

- Pregnancy Sickness Support – Aiming to improve the experience and alleviate the suffering of people affected by pregnancy sickness: including hyperemesis gravidarum (HG) - www.pregnancysicknesssupport.org.uk
- PaNDAS – Post-Natal Depression Awareness and Support – www.pandasfoundation.org.uk
- Mind – Mental Health Support - www.mind.org.uk
- Citizen's Advice – Confidential advice on a wide range of issues - www.citizensadvice.org.uk
- Sands – Support for individuals following the death of a baby - www.sands.org.uk

This is not an exhaustive list, but as this study has recruited from across the whole of the UK, it would not be possible to list all of your available local options for support. Approach your GP, health visitor and other local healthcare services to discover additional options available specifically within your region.

If you decide you would like to have your data removed from the study within 2 weeks of your interview, please email the lead researcher on s0675328@ed.ac.uk. It will not be possible to remove your data from the study after this time. If you would like to opt in to receiving and having the opportunity to provide feedback about the key themes from the interviews, or would like to receive a summary of the final findings, but did not opt in during the consent process, you can request either or both of these via the lead researcher email address, s0675328@ed.ac.uk

If you have any further questions or complaints relating to the study, please use the following contact details:

- For further questions about the study, please contact the lead researcher, Navin Mistry (Trainee Clinical Psychologist) on s0675328@ed.ac.uk
- If you would like to discuss the study with someone independent of the study, please contact Tim Bird (Research Director, University of Edinburgh) on
- If you wish to make a complaint about the study, please contact Dr Matthias Schwannauer (Head of School of Health and Social Science) on headofschool.health@ed.ac.uk

Navin Mistry

Trainee Clinical Psychologist

University of Edinburgh

Appendix L: GP Letter

Date:

Dr [xxx]
[Address]

Dear Dr [xxx]

Re: How do first time sufferers of Hyperemesis Gravidarum make sense of their experience and the way others communicate with them? An Interpretative Phenomenological Analysis
School of Health in Social Science, The University of Edinburgh
[Patient name and address]

The above patient has kindly agreed to take part in a research study entitled: How do first time sufferers of Hyperemesis Gravidarum make sense of their experience and the way others communicate with them? An Interpretative Phenomenological Analysis.

This is a piece of qualitative research investigating Hyperemesis Gravidarum. The study, approved by the Research Ethics Committee of the School of Health in Social Science of the University of Edinburgh is being conducted by Navin Mistry, Trainee Clinical Psychologist.

The purpose of the study is to gather information about the participant's experience of Hyperemesis Gravidarum via a questionnaire and an interview conducted online via Microsoft Teams or telephone.

A copy of the participant information sheet is enclosed for your information. Should you have any questions regarding this study, please do not hesitate to contact me by email s0675328@sms.ed.ac.uk or telephone 07788724675.

Yours sincerely,

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Appendix M: Reflective Log Excerpt

conclusions and recommendations.

- Thinking of recommendations, it seems one of the most curative things about the hospital environment is the relief from the expectations of home. It's likely a lot to ask of certain family units, but one of the most effective things short of hospital admission would likely therefore be some way by which it could be communicated to the woman that she is allowed to be unwell and that she has been relieved of expectations. This is a little in tension with the benefits of having something to do to distract, but could be something there
- The fear-avoidance model seems relevant to bring to bear to understand how the NVP takes hold; certainly the cycle bit of it
- Wonder if Penny's research on the changing ways we come by knowledge in the wake of the internet boom will change the HG situation. The review is suggesting that those without an illness prototype/cultural context are more vulnerable to self-blame/victim-blaming. But those people were dependent on their parent or someone they knew having suffered HG, so that they'd have a concept of what it was to recognise it. Surely easier now to find countless people to relate to on the web via various social media and blogs etc. Will newer generations be less vulnerable to self-blame?
- Thinking more generally to other women's health experiences, I bet there's a very similar emergent literature on severity of menstruation related pain, in that many will be dismissed or assumed to be being dramatic because there's an assumption that everybody experiences the same level of pain, and that because others work through it, so should you. Society only seems to be willing to conceptualise a one-size fits all type understanding of these types of issue, and struggles to appreciate that there might in fact be a spectrum of severities of experience, leaving those at the more severe end feeling poorly understood and judged as dramatic/overreacting, etc.
- Trust emerging as such a key concept – in a state of feeling extremely vulnerable and like going to have to depend on others to get through, whether a patient feels they can trust HCP's and be trusted themselves is going to influence how likely they are to request care
- The line of argument synthesis revealed a hidden factor which relates to internal and external validation/recognition as well as isolation/connectedness – the data would seem to suggest an interaction between all 3 main themes such that if an individual receives too many communications which leave them feeling that they aren't well understood, there can get to be an increasingly wide gap between the level of internal recognition and external recognition, leaving the individual feeling nobody understands, but feeling too depleted to educate/fight, so isolates from/avoids others instead, which in turn impacts negatively psychologically. Someone is left with a feeling of experiential isolation/of relatedness.

Appendix N: NVivo Coding Excerpt

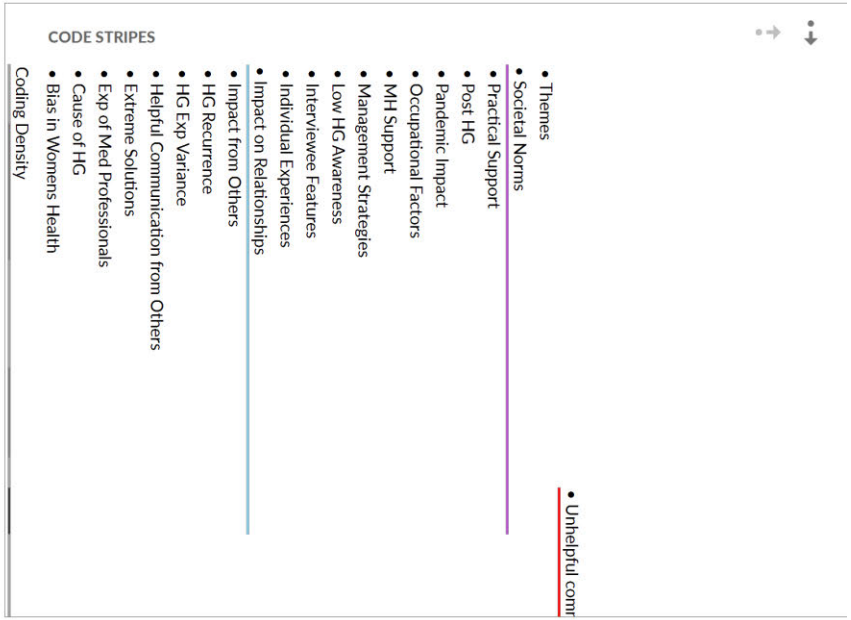
1:19:11.330 --> 1:19:12.50
Brenda
Myself.

1:19:14.50 --> 1:19:20.70
Brenda
There's such a strong narrative around pregnancy being this glowing happy period that if you deviate from that.

1:19:28.610 --> 1:19:29.80
Navin Mistry
Yeah.

1:19:21.450 --> 1:19:35.650
Brenda
Yeah, it kind of feels uncomfortable. And I think just accepting that it isn't because if you're constantly trying to accept that and battling against that, that's that's the hardest bit alongside. Y know, all the kind of physical things. But yeah, emotionally mentally that's.

1:19:37.50 --> 1:19:42.10



Annotations

Item	Content
6	Seems like she felt the societal pressure for her pregnancy to be more in line with the norm, and so found herself holding back from others because what she had to say didn't fit. In order to move forward more healthily/productively, she had to accept that her experience did not line up with the established narrative and become OK with that, after which came the invitation for others to become OK with that. Her becomming OK with it allowed her to stop battling with herself. Unfortunately it sounds like this process consumed a lot of the 1st pregnancy

Appendix O: Draft Group Experiential Themes and Subthemes Summary Excerpt

"It was extraordinarily isolating..."

Explores various factors that contribute to HG often being experienced as very isolating, including not wanting to announce within 1st 12 weeks, not wanting to share the misery of the experience with others ("better alone"), looking at screens on phones etc worsening nausea, how hard and exhausting it can be trying to communicate such an internal experience to others who struggle to understand, and for some choosing to shield their partners from the emotional reality of it because they didn't want to burden them more than they already felt they were

What Others Bring to the HG Experience

What the descriptions of interactions our interviewees described revealed is that others have the potential to add to or reduce the burden of HG. Examples are given of others communicating in the language of morning sickness and why this is frustrating. Also a progression of initially feeling disappointed or frustrated by a lack of understanding from others which could eventually become greater levels of anger or completely losing faith after repeated efforts to inform.

Being Believed and Understood

Looking at how interviewees often described feeling dismissed, invalidated, not taken seriously. As if everyone starts from the assumption that accounts are being exaggerated. The impact of this type of communication with someone actively trying to understand what's happening to them is discussed, often tipping people towards the view they're struggling to cope with routine morning sickness rather than something more severe. This is contrasted with the impact an HG diagnosis can make on how someone sees their experience and themselves. It is also highlighted that actions (such as treatment offered) can communicate understanding or a lack thereof, and the impact this can have on a struggling family.

Tip of the Iceberg

Unfortunately for most, it was reported that even if there was an HG diagnosis, only quite a narrow part of the overall experience of the condition was ever acknowledged and attended to within healthcare settings (usually vomiting and dehydration) with aspects such as nausea, compromised functional capacity, mental health and social/occupational impact neglected and unmentioned. Participants also spoke about how they weren't in a position to attend to their own mental health needs because of how difficult daily survival was. Finally, the fact that all of the clues were there for professionals and others to see that emotional wellbeing was likely strained, and yet most found no enquiries into made beyond routine checklists.

"They wanna get you out of there ASAP"

Focuses on the impact of resource scarcity on treatment experiences as well as how the perception of resource scarcity or lack of treatment options affects people's perceptions of whether there are more treatment options available (e.g. other medications, rehydration, hospital care, etc.) and whether they saw any point in disclosing their difficulties (as they believed nothing would be done about it). Also speaks about the possibility that medics being unaware of the range of treatment/management options for HG, and instead offering sympathy, could be another reason they seem to want patients to leave. Ends on an example of how much of a positive difference it makes when someone is given the time, but this didn't take place in an NHS context.

(How) Can we get through this?

This next superordinate theme covers a point a little further along in the HG experience. The initial impact of HG has been established as well as a sense of what support options might be available externally from others, as discussed in the prior two superordinate themes. Adding these factors