Exploring the Psychological Experiences of Individuals Affected by Pancreatitis

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Thesis Portfolio Abstract

Background: Acute pancreatitis (AP) is a serious inflammatory condition whose incidence in the UK has more than doubled over approximately two decades. Beyond its physical impact, AP is associated with significant psychological burden, including elevated rates of anxiety, depression and impaired quality of life. Despite this, the psychological experience of adults hospitalised with AP remains poorly understood, with no UK-based qualitative study existing prior to this portfolio.

Aim: This portfolio aimed to develop an understanding of the lived and psychological experiences of adults hospitalised with AP and recurrent acute pancreatitis (RAP), and to identify the implications for clinical practice and future research.

Methods: Semi-structured interviews were conducted with fourteen adults who had experienced AP and analysed using reflexive thematic analysis within a critical realist framework. A systematic review of the existing qualitative literature using thematic synthesis was subsequently conducted to synthesise findings on the lived experience of adults hospitalised with AP or RAP.

Results: The qualitative study produced six themes: dual misrecognition and delayed diagnosis; pain, powerlessness and loss of dignity; communication failures and stigma; post-discharge care gaps; adjusting to a new normal; and trauma, fear of recurrence and resilience. The systematic review identified four analytical themes: living under the shadow of uncertainty; the weight of responsibility but never feeling in control; navigating transitions in recovery whilst feeling unprepared and unsupported; and adaptation, resilience and reappraisal in the midst of suffering.

Conclusions: This portfolio highlights the profound and enduring psychological impact of AP, extending well beyond physical recovery. Uncertainty and perceived control were identified as central processes across both studies. The findings promote the importance of integrating psychological care into AP care from diagnosis through to recovery and highlight the need for targeted psychological interventions for this population.

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Chapter One: Thesis Portfolio Introduction

Acute pancreatitis

Acute pancreatitis (AP) is a sudden inflammation of the pancreas - a digestive organ situated behind the stomach - characterised by severe upper abdominal pain, nausea and vomiting (NHS, 2026). Typically triggered by gallstones or alcohol, it requires urgent medical care and whilst most people recover fully, AP can be life-threatening in severe cases (Iannuzzi et al., 2022). AP represents the initial presentation of a continuum of pancreatic inflammatory disease, with recurrent acute pancreatitis (RAP) describing repeated episodes and chronic pancreatitis (CP) characterising long-term progressive pancreatic damage (Sankaran et al., 2015). The global incidence of pancreatitis is rising, with the condition associated with considerable morbidity and mortality and an increasing demand on healthcare resources worldwide (Iannuzzi et al., 2022; Fehér et al., 2026). Among pancreatic diseases, AP occurs most frequently, affecting approximately 34 people per 100,000 annually (Xiao et al., 2016; Iannuzzi et al., 2022). Within the UK, data from the UK Biobank demonstrate a more than doubling of AP cases over approximately two decades, rising from 21.4 to 48.2 per 100,000 people per year (Spagnolo et al., 2022).

AP is classified into mild, moderately severe and severe disease according to the Revised Atlanta Classification, with severity determined primarily by the presence and duration of organ failure (Banks et al., 2013). In the UK, biliary disease represents the most frequently identified cause of AP, accounting for approximately 62% of cases, with alcohol use and smoking among other established risk factors, alongside metabolic conditions, genetic mutations and idiopathic presentations (Spagnolo et al., 2022; Adeniran et al., 2025; Forsmark et al., 2016). Around four in five patients hospitalised with AP experience mild disease, whilst a minority develop severe disease associated with significantly elevated mortality of approximately 15-20% in severe cases (Forsmark et al., 2016; Banks et al., 2013). Following an initial AP episode, approximately one in five patients experiences recurrence, with over a third of those going on to develop CP (Sankaran et al., 2015). Hospitalisation for AP ranges from brief admissions for mild disease to prolonged intensive care for severe and necrotising cases, the latter associated with significant risk of psychological sequelae (Forsmark et al., 2016; McGuire et al., 2022).

Psychological Impact of AP

Beyond the physical burden of hospitalisation, AP can have a considerable psychological impact on patients. A single AP episode has been shown to independently raise the risk of new mental health disorders, with nearly one in ten patients receiving a new diagnosis in the year that followed, particularly in the period immediately following discharge (Khoja et al., 2023). A meta-

analysis by Fehér et al. (2026) found that anxiety affected approximately 23% of AP patients and depressive symptoms were present in approximately 29%, rates exceeding those observed in the general population and in other gastrointestinal conditions. The psychological burden of AP extends beyond anxiety and depression, with pancreatic disease found to be independently associated with elevated suicide risk even after accounting for comorbid mental health conditions, highlighting that the psychological impact of AP can be serious and in some cases life-threatening (Chen et al., 2018).

The impact of AP extends beyond mental health to affect broader quality of life. A recent systematic review and meta-analysis by Xu et al. (2025), drawing on data from over 2,500 patients, found that people with a history of AP showed persistently lower scores than healthy individuals across several quality of life domains, including bodily pain, general health, vitality, emotional functioning and mental health, with impairments documented at follow-up periods of up to almost ten years. Whilst some domains including physical functioning showed less marked deterioration, these findings suggest that recovery from AP involves considerably more than physical healing alone, with impairments particularly pronounced among those with more severe disease requiring intensive care (Xu et al., 2025).

For patients who develop severe or necrotising AP, a form of the disease in which pancreatic tissue dies (Banks et al., 2013), the psychological impact can be particularly significant. These patients often face prolonged hospitalisation and intensive care admission, increasing their vulnerability to anxiety, depression and post-traumatic stress disorder (McGuire et al., 2022). Chang et al. (2025) found that people who require intensive care face a significantly elevated risk of depression and anxiety following discharge, with the duration of hospitalisation linked to greater psychological difficulty. Despite this, the psychological experiences of patients with necrotising pancreatitis have received little research attention, and no tailored interventions specifically targeting their mental health have been developed (McGuire et al., 2022).

Despite the documented psychological burden of AP, qualitative research exploring patients' subjective experiences remains limited. Boije et al. (2019) conducted a phenomenographic study with 16 AP patients in Sweden, finding that recovery from AP involved both physical and emotional dimensions, with fear of recurrence persistently undermining hope and post-discharge support perceived as inadequate. Ma et al. (2022) explored the psychological experiences of 28 AP inpatients in China. The authors found that half did not initially recognise their symptoms as AP, nearly half reported fear of progression or recurrence and many experienced significant stress, guilt and uncertainty, with some describing suicidal ideation in the context of prolonged illness. Liu and Zhang (2020) similarly found that patients hospitalised with recurrent AP in China experienced anxiety,

fear, guilt, shame and helplessness alongside hope and perseverance. Su et al. (2024) explored health literacy needs across the AP journey in China, finding that fear of recurrence was prominent at discharge and that patients felt unsupported following discharge from hospital. Gunic et al. (2026) explored patients' transitions from hospital to home in Denmark, finding that patients experienced significant insecurity and insufficient information following discharge. Whilst the qualitative evidence base remains limited, existing studies highlight the significant psychological burden of AP and the need for psychological support as part of routine care. Whilst these studies offer valuable insight into the psychological experiences of AP patients, all were conducted outside the UK, and none specifically explored experiences of stigma, alcohol-related assumptions or peer support in this population, which could all present differently in a Western culture and healthcare system that might have different perceptions around illness and alcohol use.

The Common Sense Model of Illness Self-Regulation

The Common Sense Model of Illness Self-Regulation (CSM), originally proposed by Leventhal et al. (1980) and subsequently extended by Hagger and Orbell (2022), provides a theoretical framework for understanding how individuals perceive and respond to health threats. The model proposes that when faced with illness, individuals form cognitive and emotional representations which guide their coping responses and behavioural decisions (Leventhal et al., 1980; Hagger & Orbell, 2022). These representations are organised across five dimensions: identity, referring to how patients recognise and name their condition through its symptoms; cause, reflecting beliefs about what brought the illness about; timeline, describing expectations about how long the condition will last; consequences, encompassing the broader effects of illness on everyday life and wellbeing; and personal control, reflecting the degree to which individuals believe they can influence the course of their illness (Leventhal et al., 1980; Hagger & Orbell, 2022). Alongside these cognitive dimensions, the model recognises emotional representations, the fear, anxiety and distress associated with the illness which run alongside cognitive representations to influence how individuals cope with their illness (Hagger & Orbell, 2022). Given the sudden and often uncertain nature of AP, its complex aetiology, and its physical and psychological impact, the CSM offers a helpful lens through which to interpret patients' illness experiences. Whilst the CSM was not adopted as a predetermined framework, it is applied post-hoc to contextualise and interpret the findings of the empirical study in relation to illnesses beliefs, coping and emotional responses.

Uncertainty in Illness

Mishel (1988) proposed that uncertainty in illness arises when individuals are unable to make sense of illness-related events, leaving them without a framework for understanding what is

happening to them or what to expect. The theory identifies several key antecedents of uncertainty including unclear aetiology, unpredictable prognosis, limited information and fragmented care. Mishel (1990) later extended the theory to account for chronic illness, suggesting that when uncertainty persists over time, learning to accept rather than resolve it may be a more adaptive response, though this is a gradual and difficult process. Hansen et al. (2012), in a systematic review of qualitative research on uncertainty across illness contexts, found that uncertainty was consistently associated with significant emotional burden, hypervigilance and loss of control. These patterns are consistent with the experiences described by AP patients in the existing qualitative literature, suggesting that Mishel's framework offers a relevant lens through which to interpret the psychological impact of this condition.

Post-Traumatic Growth

Post-traumatic growth (PTG) was first described by Tedeschi and Calhoun (1996) as positive psychological change that emerges from the struggle with highly challenging life experiences. PTG includes changes across five domains: personal strength, new possibilities, relating to others, appreciation of life and spiritual change. Importantly, PTG does not imply the absence of distress, but that growth and suffering can coexist, often within the same individual at the same time (Tedeschi & Calhoun, 1996). Given the sudden and life-threatening nature of AP, its prolonged recovery and in many cases confrontation with mortality, PTG offers a relevant framework for understanding how some patients may respond to their illness experience. However, PTG is not universal and appears to be shaped by access to support and resources, suggesting it may reflect contextual as much as individual factors (Tedeschi & Calhoun, 1996). Hefferon et al. (2009), in a systematic review of PTG across life-threatening physical illnesses, found that reappraising life priorities, existential reflection and developing new health behaviours were consistent responses to serious illness, supporting the relevance of this framework for understanding the psychological experience of AP.

Stigma and AP

Goffman (1963) was among the first to conceptualise stigma as a social process through which certain characteristics lead to an individual being devalued and marginalised by others. Building on this, Link and Phelan (2001, p. 367) defined stigma as existing "when elements of labelling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them". In the context of health, stigma tends to be higher for conditions perceived as personally controllable (Zell et al., 2026). In the general population, alcohol-related health conditions are among the most highly stigmatised, with individuals perceived as more

responsible for their condition and facing greater social distance than those with substance-unrelated mental health conditions (Kilian et al., 2021). In healthcare contexts specifically, these stigmatising processes may be enacted by providers who hold negative attitudes toward patients with substance use disorders. Van Boekel et al. (2013) found that health professionals commonly held negative attitudes toward patients with substance use disorders, which affected the quality of care provided, with professionals demonstrating reduced empathy, less personal involvement and a focus on completing clinical tasks rather than engaging meaningfully with patients.

Importantly, such stigmatising attitudes are not limited to conditions directly caused by substance use. Carol et al. (2022) found that 69% of patients with non-alcoholic fatty liver disease experienced stigmatisation despite their condition not being alcohol-related, suggesting that conditions merely associated with alcohol use may carry similar stigmatising assumptions regardless of actual cause. When patients are subjected to such assumptions, they may begin to internalise them. Corrigan et al. (2012) describe a four-stage process through which individuals first become aware of negative stereotypes about their condition, come to agree with these stereotypes, apply them to themselves, and ultimately experience harm including shame, reduced self-worth, and loss of confidence in their abilities.

This has particular relevance for AP, a condition that, while associated with alcohol consumption in some cases, has multiple other causes. When healthcare providers automatically assume alcohol causation regardless of actual aetiology, patients whose condition was not alcohol-related may nonetheless experience stigmatising assumptions and internalise blame and shame for a cause that did not apply to them. This concern is recognised at a policy level within UK NHS guidelines, which explicitly caution against assuming that AP is alcohol-related on the basis of alcohol consumption alone (NICE, 2020), underscoring the importance of addressing stigmatising assumptions in this population.

Peer support and AP

In the absence of adequate professional support, individuals with health conditions turn to online peer communities to compensate for unmet needs. These communities can provide emotional support and validation of illness experiences that help individuals make sense of their condition and reduce feelings of isolation (Allen et al., 2016; Day, 2022). Both online and face-to-face peer support groups have demonstrated benefit for people with health conditions, though physical presence in face-to-face settings appears to facilitate deeper engagement and stronger feelings of involvement among members (Huber et al., 2018).

However, peer support carries inherent risks alongside these benefits. Day (2022) found that UK adults in long COVID peer support groups experienced anxiety when exposed to others with more severe or prolonged illness trajectories, with some participants feeling harmed by joining groups too early in their recovery. Similarly, Rueger et al. (2025) found that anxiety can spread between members of online health communities through repeated exposure to peers' emotional experiences, potentially increasing rather than reducing distress. These findings highlight the double-edged nature of peer support, suggesting that whilst online communities can provide valuable emotional support, exposure to others' experiences may not always be beneficial and requires careful consideration.

Given that post-discharge support following AP is frequently limited, leaving patients feeling unsupported during recovery (Boije et al., 2019; Su et al., 2024), patients may turn to peer communities to compensate for these gaps. However, the implications of such support in this population remain poorly understood, particularly in relation to how recovery and understanding is made of this experience.

Aims and Structure of the Thesis Portfolio

The overarching aim of this thesis is to explore the psychological impact of AP from the perspective of patients who have been hospitalised for this condition. A systematic review is presented in Chapter Two. This synthesised qualitative evidence on the lived experience of adults hospitalised with AP or RAP. An empirical study is presented in Chapter Four. This used a qualitative methodology to explore how patients experience and make sense of the psychological impact of AP, from hospitalisation through to recovery, examining how healthcare interactions, social support and unmet needs shape these experiences. The portfolio includes a bridging chapter to outline how the systematic review informed the research question of the empirical study and an extended methodology chapter to provide further detail on the methodological decisions underpinning the empirical study. Finally, a critical appraisal and discussion chapter integrates findings across the thesis, considers their implications for clinical practice and future research and draws overall conclusions.

Chapter Two: Systematic Review

Prepared for Submission to Journal of Health Psychology

(Author guidelines available in Appendix A)

The lived experience of adults with acute or recurrent acute pancreatitis: a systematic review and thematic synthesis of qualitative studies

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Abstract

Acute pancreatitis (AP) is associated with significant psychological burden, yet the lived experience of adults hospitalised with AP or recurrent acute pancreatitis (RAP) remains poorly understood. This systematic review synthesised qualitative evidence on these experiences. Five electronic databases and Google Scholar were searched (April-May 2026), alongside citation searching. Seven studies were included and appraised using the Critical Appraisal Skills Programme tool. Thematic synthesis generated four analytical themes: living under the shadow of uncertainty; the weight of responsibility but never feeling in control; navigating transitions in recovery whilst feeling unprepared and unsupported; and adaptation, resilience and reappraisal in the midst of suffering. Findings indicate substantial psychological distress beyond physical recovery, driven by uncertainty, diminished control and gaps in care. The review concluded that psychological support needs to be integrated into AP care from diagnosis through recovery.

Keywords: acute pancreatitis, recurrent acute pancreatitis, qualitative, systematic review, lived experience, psychological experience, thematic synthesis

Introduction

Acute pancreatitis (AP) is a sudden inflammation of the pancreas characterised by severe abdominal pain, nausea and vomiting, most commonly triggered by gallstones or alcohol and requiring urgent medical care (NHS, 2026; Banks et al., 2013). The global incidence of AP is rising, with incidence in the UK more than doubling over approximately two decades (Spagnolo et al., 2022). Approximately one in five patients experience recurrence following an initial episode, with over a third of those progressing to chronic pancreatitis (CP) (Sankaran et al., 2015). Recurrent acute pancreatitis (RAP) is defined by repeated bouts of AP, typically involving two or more separate attacks, with symptoms substantially resolving between episodes (Sankaran et al., 2015). Whilst gallstones and alcohol represent the most common causes, hypertriglyceridaemia (HTG) is an increasingly recognised aetiology associated with higher rates of recurrence and greater disease severity (Forsmark et al., 2016).

Beyond its physical impact, AP carries a considerable psychological burden. Anxiety affects approximately 23% of patients, depressive symptoms are present in approximately 29% (Fehér et al., 2026). A single episode has been linked to risk of new mental health disorders (Khoja et al., 2023), and pancreatic disease has been linked to elevated suicide risk (Chen et al., 2018). Patients also report persistently poorer quality of life scores in physical, emotional and mental health domains for up to ten years following an episode (Xu et al., 2025). From a health psychology perspective, these impacts may be understood through the Common Sense Model of Illness Self-Regulation (CSM; Leventhal et al., 1980; Hagger and Orbell, 2022), which proposes that individuals form beliefs about their illness that guide their emotional and behavioural responses. The unpredictability and recurrence of AP make this framework particularly relevant for understanding how patients make sense of their condition.

Whilst the quantitative burden of AP is well established, a small number of qualitative studies have begun to explore patients' subjective experiences. Patients have described the sudden transition from health to life-threatening illness as shocking and overwhelming, with recovery involving significant physical and emotional demands and a clear need for healthcare and social support (Boije et al., 2019; Gunic et al., 2026). Studies conducted predominantly in Chinese healthcare contexts have documented negative emotions during hospitalisation including anxiety, fear, helplessness, guilt and shame, alongside fear of recurrence and concerns about the financial burden of illness (Liu and Zhang, 2020; Ma et al., 2022; Chen et al., 2022). Fear of recurrence was particularly prominent at discharge, with patients feeling unsupported and insufficiently informed

following hospitalisation (Su et al., 2024). Stigmatising assumptions about alcohol use from healthcare professionals have also been reported across three countries, suggesting stigma may be a cross-cultural feature of AP care (Kessler et al., 2025).

Despite this evidence, the subjective psychological experience of AP and RAP remains conceptually underdeveloped. Existing systematic reviews have focused predominantly on quantitative outcomes such as health-related quality of life, anxiety and depression (Xu et al., 2025; Fehér et al., 2026), offering valuable epidemiological data but limited insight into how patients actually experience and make sense of their illness. Whilst individual qualitative studies have begun to address this gap, their findings remain fragmented and have not been systematically synthesised, limiting the development of psychologically informed, patient-centred care. Consequently, a systematic review of the qualitative literature was conducted to address the following question:

What is the lived experience of adults with AP or RAP as reported in qualitative studies?

Methods

This systematic review adopted a qualitative thematic synthesis approach following the method developed by Thomas and Harden (2008). The primary researcher adopted a critical realist epistemological stance, acknowledging that whilst the psychological experiences of patients hospitalised with AP represent real phenomena, access to these experiences is necessarily mediated through participants' accounts and researchers' interpretations. The primary researcher is a trainee clinical psychologist with an interest in health psychology but no personal experience of AP. This background leads to sensitivity to the emotional and psychosocial dimensions of illness, but equally invites over-privileging psychological interpretations requiring ongoing reflexive considerations.

The review was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021) and adhered to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement (Tong et al., 2012).

Study Registration

This systematic review was prospectively registered on the International Prospective Register of Systematic Reviews (PROSPERO) prior to data collection (Registration number: CRD420261376308).

Inclusion and Exclusion Criteria

The SPIDER framework (Cooke et al., 2012), comprising five components- Sample, Phenomenon of Interest, Design, Evaluation and Research type - was used to define the inclusion and exclusion criteria, as presented in Table 1.

Table 1

Inclusion and Exclusion Criteria

Component	Inclusion	Exclusion
Sample	Adults aged 18 years or over diagnosed with AP or RAP of any severity and any aetiology;	Children and adolescents under 18 years; studies focusing only on CP
Phenomenon of Interest	Psychological or lived experiences of AP or RAP reported in sufficient detail to enable meaningful coding, including direct participant quotations where available; qualitative component of mixed methods studies	Studies focusing solely on clinical or physical outcomes or intervention outcomes without reporting patient experiences
Design	Qualitative studies of any design including phenomenology, grounded theory, thematic analysis, qualitative descriptive, narrative research and ethnography	Quantitative studies; systematic reviews; case reports (*N* = 1); conference abstracts; opinion pieces and editorials
Evaluation	Studies conducted in any country and any healthcare setting with no geographical restrictions	No exclusions based on setting or geography
Research type	Peer reviewed journal articles published in English with no date restriction	Non-English language studies; grey literature; book chapters

Note. Pregnant women were excluded as AP in pregnancy presents with distinct physiological, psychological and care pathway characteristics that may limit transferability to the broader AP population.

Search Strategy

Searches were conducted by the primary researcher between 30 April and 2 May 2026 across five electronic databases: MEDLINE, PsycINFO, CINAHL, Embase, and Scopus. In MEDLINE, free-text terms were combined with Medical Subject Headings (MeSH) terms to maximise sensitivity.

Equivalent subject headings were used in other databases where available. The full search strategies for all databases are provided in Table 2.

Table 2

Search Strategy

Search block	Terms
Block A -Acute pancreatitis	"acute pancreatitis" OR "recurrent acute pancreatitis" OR "acute recurrent pancreatitis" OR "recurrent pancreatitis" OR "severe acute pancreatitis" OR "necrotising pancreatitis" OR "necrotizing pancreatitis"
Block B - Qualitative methodology and patient experience	qualitative OR "lived experience" OR "thematic analysis" OR "grounded theory" OR "content analysis" OR ethnograph* OR phenomenolog* OR interview* OR "focus group*" OR "patient perspective*" OR "patient experience*"
Full search string	Block A AND Block B

In addition to database searching, complementary searches were conducted including Google Scholar (first 100 results screened), backward citation searching of all included studies and forward citation searching of key included studies. Hand searching of reference lists of relevant systematic reviews was also undertaken.

Study Selection

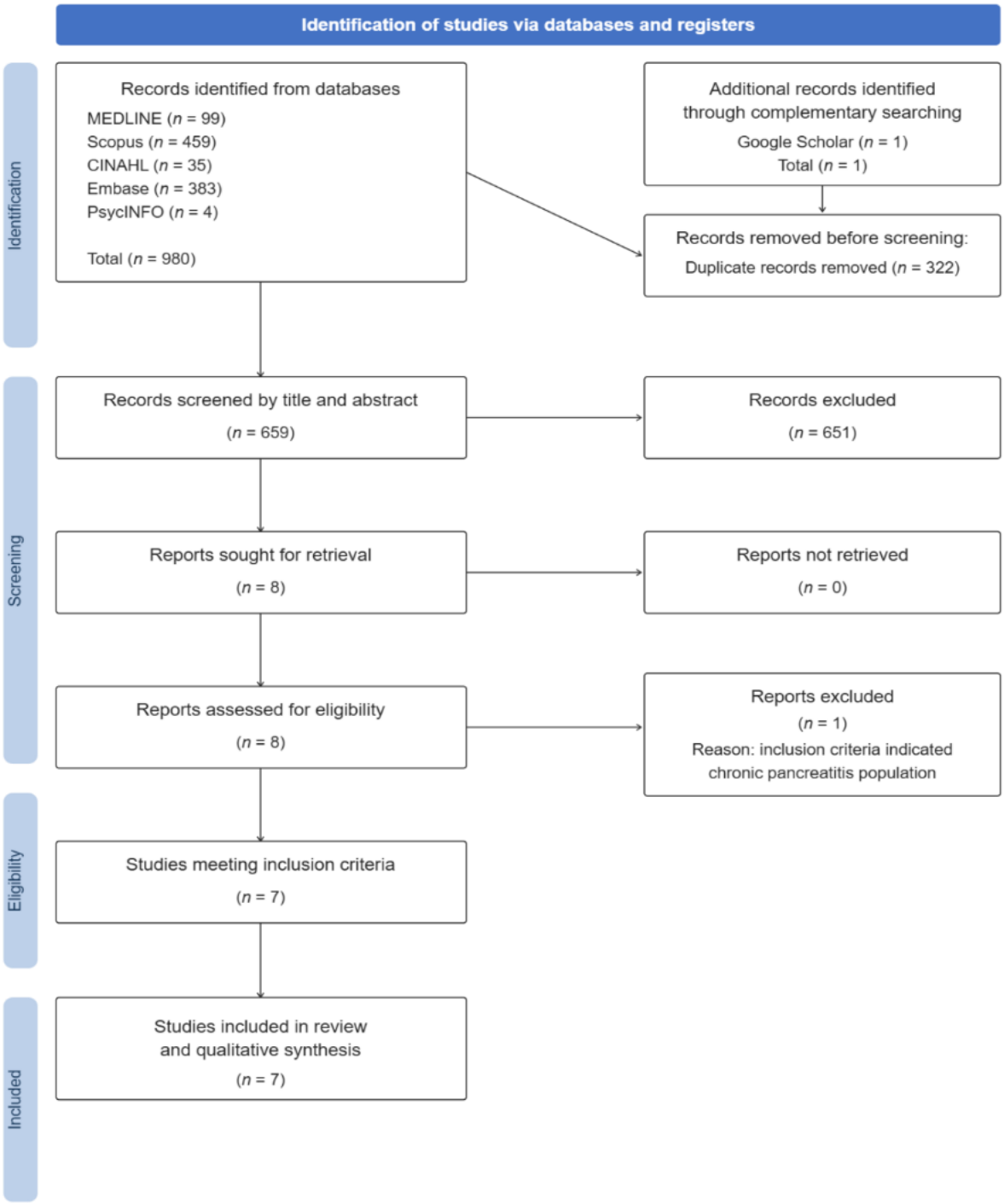
All records identified through database searches were exported to EndNote 2025 for deduplication and subsequently imported into Rayyan (Ouzzani et al., 2016) for further duplicate removal.

A second reviewer independently screened 35% (*n* = 230) of records at title and abstract stage. Inter-rater reliability was assessed using Cohen's Kappa, which yielded a coefficient of 0.763 (95% CI 0.504–1.000), indicating substantial agreement between reviewers (Landis & Koch, 1977). Three disagreements were resolved through discussion, with eight studies taken forward to full text screening.

At full text screening stage, the second reviewer independently screened 50% (*n* = 4) of studies, with 100% agreement reached. One study was excluded at full text stage as the inclusion criteria indicated participants with CP rather than AP. A total of seven studies were included in the review. The screening and selection process is summarised in Figure 1.

Figure 1

PRISMA 2020 Flow Diagram of Study Selection Process



Quality Appraisal

The methodological quality of all seven included studies was assessed using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (2022). As recommended in qualitative systematic reviews, no studies were excluded based on quality appraisal alone (Dixon-Woods et al., 2005). A second reviewer independently appraised 50% (*n* = 4) of studies, with any discrepancies discussed until consensus was reached. Studies were additionally classified as core, central, or peripheral according to their relevance to the review question and methodological quality, following Whiffin et al. (2021). Core studies had the highest relevance to the review question and strongest methodological quality; central studies were methodologically sound but less directly relevant; peripheral studies had weaker methodological quality or more limited relevance to the review question. For example, Su et al. (2024) met all CASP criteria but was classified as central because it was less directly relevant, Gunic et al. (2026) was classified as central because of a weaker CASP profile, and Chen et al. (2022) and Kessler et al. (2025) were classified as peripheral because their focus on HTG-related AP limited their relevance. Classification was a judgement made by the primary researcher following CASP appraisal and was not independently checked.

Data Extraction

Data were extracted by the primary researcher using a data extraction form. Extracted information included study characteristics presented in Table 3, alongside recruitment method, setting, data collection method, analytical approach and key findings. The form was reviewed by the supervisory team to ensure accuracy. The full results and findings sections of all included studies were subsequently imported into NVivo 15 to support the thematic synthesis process.

Data Synthesis

Data were synthesised using the thematic synthesis method developed by Thomas and Harden (2008), comprising three stages. In Stage 1, the full results and findings sections of all included studies were coded line by line in NVivo 15. A reflective diary was maintained throughout to document analytical decisions and support reflexivity. Core studies were coded first, followed by central and then peripheral studies. In Stage 2, codes were grouped across studies into descriptive themes that remained close to the meaning of the original data. In Stage 3, analytical themes were developed through an inductive process, moving beyond description to address the review question.

Trustworthiness

The trustworthiness of this review was considered using Lincoln and Guba's (1985) framework of credibility, dependability, transferability and confirmability. Credibility was supported through second reviewer involvement at screening and quality appraisal stages, ongoing discussion with the supervisory team and close engagement with participant data through line-by-line coding. Dependability was supported through prospective PROSPERO registration, adherence to PRISMA and ENTREQ reporting guidelines and transparent documentation of methodological decisions. Transferability is supported through rich contextual information about included studies, enabling readers to assess applicability of findings to other contexts. Confirmability was supported through maintenance of a reflective diary throughout coding and synthesis, documenting analytical decisions and reducing potential researcher bias.

Results

Study Characteristics

Seven studies published between 2019 and 2026 met the inclusion criteria, comprising a total sample of 134 participants. One study (Chen et al., 2022) included two relatives in focus group discussions. Most studies were conducted in China (n = 4), with others from Sweden, Denmark and a multinational study across the UK, US, and Germany. Sample sizes ranged from nine (Gunic et al., 2026) to 31 (Su et al., 2024). Most studies recruited predominantly male participants, with the exception of Gunic et al. (2026) and Kessler et al. (2025). Ethnicity was rarely reported across studies. Purposive sampling was most used, except for Boije et al. (2019) who used consecutive sampling and Kessler et al. (2025) who recruited via a specialist agency. All studies were conducted in hospital settings, apart from Chen et al. (2022), which was conducted at an outpatient clinic and Kessler et al. (2025), which was conducted via videoconference. Phenomenological approaches were most frequently adopted (n = 4), with studies also using phenomenographic design (n = 1), qualitative descriptive (n = 1), and inductive thematic analysis (n = 1). Full study characteristics are presented in Table 3.

Table 3

Characteristics of Included Studies

Author, year, country	Sample size	Age range	Gender	Disease severity	Aetiology	Study design and analysis	Classification
Boije et al. (2019), Sweden	*n* = 16	Mean 63, range 26–81	75% male, 25% female	Not reported	Gallstones (43.8%), alcohol (31.3%), idiopathic (25%)	Phenomenographic design and analysis (Sjöström and Dahlgren, 2002)	Core
Ma et al. (2022), China	*n* = 28	75% under 60, 25% over 60	71.4% male, 28.6% female	MAP 10.7%, MSAP 64.3%, SAP 25%	Biliary (42.9%), hyperlipidaemia (46.4%), alcohol (7.1%), other (3.6%)	Qualitative descriptive; adapted Colaizzi procedure	Core
Liu and Zhang (2020), China	*n* = 13	Mean 46.92, range 29–64	76.9% male, 23.1% female	Not formally classified; SAP reported in one participant	Alcohol and dietary excess	Phenomenological hermeneutical; Colaizzi's method	Core
Su et al. (2024), China	*n* = 31	Range 18–72	58.1% male, 41.9% female	MAP, MSAP, SAP all included	Hypertriglyceridemic, gallstone, alcoholic	Phenomenological; Colaizzi's method; TIR theoretical framework	Central
Gunic et al. (2026), Denmark	*n* = 9	Range 35–70	33.3% male, 66.7% female	MAP, MSAP, SAP all included	Gallstones (44.4%), medication (33.3%), alcohol (22.2%)	Phenomenological hermeneutical; Malterud systematic text condensation	Central
Chen et al. (2022), China	*n* = 25	Mean 44.9 (SD 8.2)	88% male, 12% female	3/25 admitted to ICU; not formally classified	HTG-RAP; hypertriglyceridaemia specifically	Qualitative; inductive thematic analysis	Peripheral
Kessler et al. (2025), UK, US, Germany	*n* = 12	Mean 43.8, range 32–66	33.3% male, 66.7% female	All hospitalised; mean 9 episodes (range 1–30)	HTG-AP; hypertriglyceridaemia; 3/12 FCS confirmed	Cross-sectional qualitative; thematic and content analysis; MAXQDA	Peripheral

Quality Assessment

The CASP appraisal results are summarised in Table 4. Overall methodological quality was adequate across studies, though several limitations were noted. The relationship between researcher and participant was adequately addressed in only one study (Su et al., 2024), who maintained a reflexive journal throughout data collection and analysis. For the remaining six studies this was rated as "Can't Tell" or "No", with limited or no discussion of researcher background, potential bias, or reflexivity. Rigour of analysis was unclear in three studies -Liu and Zhang (2020), Chen et al. (2022), and Gunic et al. (2026) - due to absence of independent coding, member checking, or insufficient methodological detail. Member checking was reported in Ma et al. (2022), Liu and Zhang (2020), and Su et al. (2024). One study warrants particular consideration regarding potential bias. Kessler et al. (2025) was funded by Ionis Pharmaceuticals, with the first author employed by the funding organisation. Whilst competing interests were declared and the study followed established qualitative methods, findings should be interpreted with this potential conflict of interest in mind.

Table 4

CASP Quality Appraisal Results

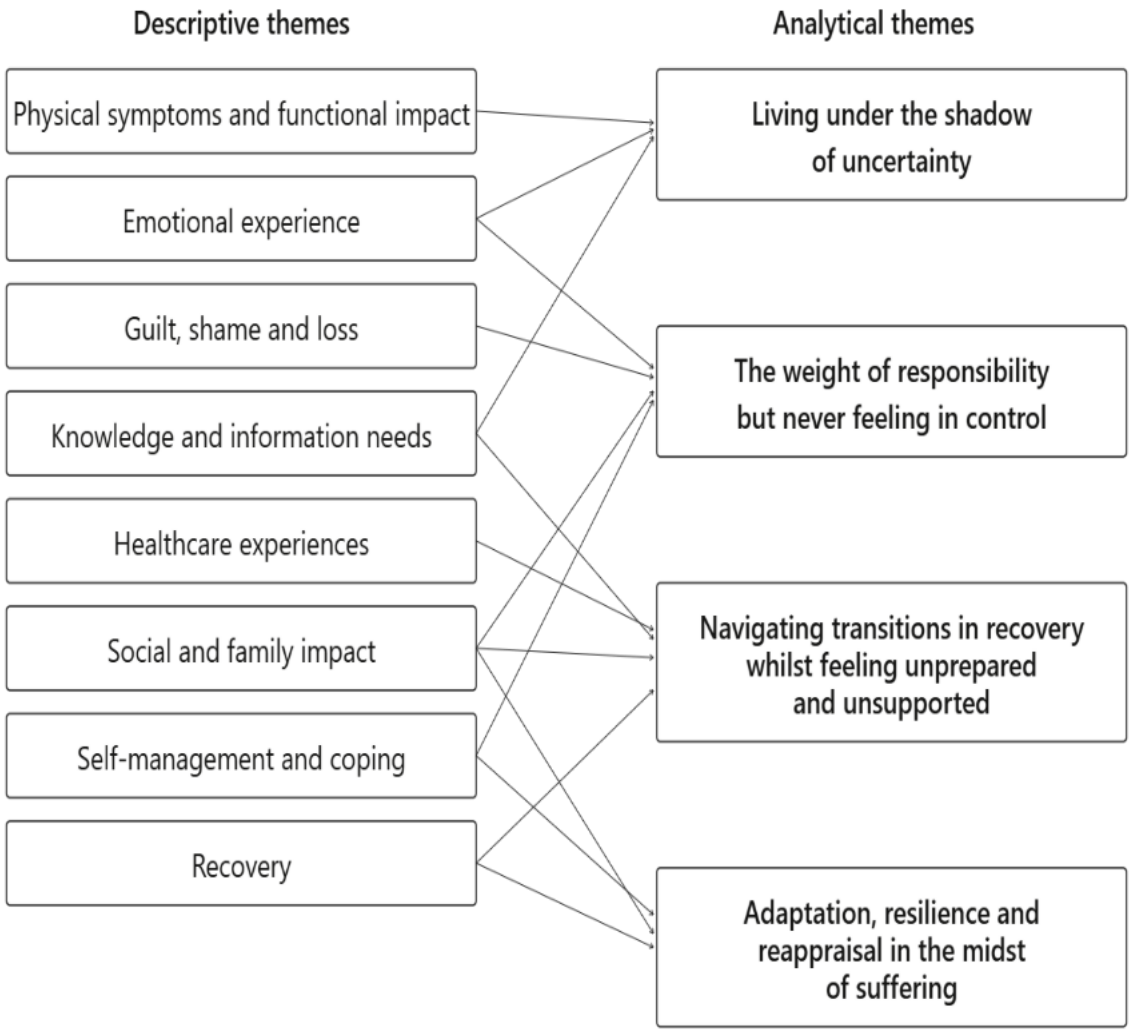
Study	Aims stated	Appropriate methodology	Appropriate design	Appropriate recruitment	Data collection appropriate	Researcher-participant relationship	Ethical issues	Rigorous analysis	Clear findings	Value of research
Boije et al. (2019)	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	Yes	Yes	Can't Tell
Ma et al. (2022)	Yes	Yes	Yes	Yes	Yes	Can't Tell	Can't Tell	Yes	Yes	Yes
Liu and Zhang (2020)	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	Can't Tell	Yes	Yes
Su et al. (2024)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Chen et al. (2022)	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	Can't Tell	Can't Tell	Yes
Gunic et al. (2026)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't Tell	Can't Tell	Yes
Kessler et al. (2025)	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	Yes	Yes	Yes

Thematic Synthesis

Line-by-line coding generated 208 codes, refined to 193 following review and merging. These were organised into eight descriptive themes and subsequently four analytical themes, developed through an iterative process attending to both convergence and divergence across studies. Figure 2 illustrates the relationships between descriptive and analytical themes.

Figure 2

Thematic synthesis: Descriptive and Analytical Themes



Theme 1: Living under the shadow of uncertainty

Uncertainty shaped patients' experiences of AP across all seven studies, from diagnosis through to recovery. For many patients, the sudden and unexplained nature of AP left them unable to make sense of what had happened or trust their bodies.

Most patients had no prior knowledge of AP before their admission. Faced with a sudden and severe illness, many turned to family, friends and the internet for answers, often questioning what they found:

> “I've never heard of pancreatitis before. Can high blood lipids cause pancreatitis? How can my blood lipids be high when I'm so young?” (Su et al., 2024)

Where no clear cause could be identified, questions persisted long after discharge. In idiopathic cases particularly, not knowing why AP had happened made recovery harder. Patients could not identify what to change or how to protect themselves:

> “After all, no one knows why I got this pancreatitis. It is lingering a bit, I feel like that, what went wrong, why did that hit me? I feel like there is a lot undefined about my illness.” (Gunic et al., 2026)

AP could recur without warning and this unpredictability meant uncertainty did not end at discharge. Patients described interpreting everyday physical sensations as potential signs of recurrence, whilst living in a state of constant fear and vigilance. For those with recurrent AP, this fear grew with each episode (Liu and Zhang, 2020):

> “Whenever my belly hurts, the worries about recurrence come to hit me. Then, I will eat nothing. It seems that the process is of waiting for recurrence...It is bothering and besets me anytime and anywhere. It will stay with me lifelong. I desire to get rid of it!” (Chen et al., 2022)

Concerns about progression to CP and cancer were also reported across multiple studies:

> “Will it evolve into chronic (pancreatitis)? Will it become cancer? What will happen if I do nothing?” (Chen et al., 2022)

For some, uncertainty extended to the impact of future episodes on work, relationships and the ability to be present for important moments in their lives (Kessler et al., 2025). In Ma et al. (2022), the psychological burden of living with this level of uncertainty was so severe that one participant described suicidal ideation, highlighting how uncertainty can affect mental health in AP.

Recovery itself brought further uncertainty, with patients describing not knowing how long it would take or whether they would fully recover (Boije et al., 2019; Gunic et al., 2026). AP did not end

at discharge but continued to shape how patients experienced their bodies and thought about their future.

This theme suggests that uncertainty in AP is not confined to diagnosis but becomes an enduring psychological state that shapes illness representations, future expectations and patients' ongoing relationship with their bodies.

Theme 2: The Weight of Responsibility but Never Feeling in Control

Patients across multiple studies described a sense of responsibility for causing AP, preventing it from recurring and burdening their families. Yet despite this, many felt unable to change their behaviour or control the course of AP. This sense of responsibility alongside powerlessness caused significant distress.

AP was not only unpredictable but pervasive. It shaped every decision about food, work, social activities and relationships. Patients described trying hard to prevent recurrence through diet and lifestyle change, driven by an overwhelming desire to regain control:

> "The disease seems to be out of control. Before my last recurrence, I did not eat greasy food, and gratuitously, it attacked me again. I am afraid someday, it will 'blow up.' Will pancreas removal help reduce the recurrence rate? I would rather pay for expensive treatments, only if it gets controlled." (Chen et al., 2022)

Yet despite these efforts, AP could recur anyway. Controlling diet was an exhausting struggle against natural appetite and instinct, whilst physical symptoms, such as pain, fatigue and exhaustion, could not be managed through willpower alone. Loss of independence during recovery added to this, with patients unable to work, care for their families or carry out basic daily tasks (Boije et al., 2019; Gunic et al., 2026). This loss of freedom to eat and live as before brought grief and a sense of lost control and autonomy (Chen et al., 2022; Kessler et al., 2025). Without clear information or guidance from healthcare staff, patients had no way of understanding what had happened or knowing what to do differently, which left them feeling unable to take control of their own health (Su et al., 2024; Gunic et al., 2026; Liu and Zhang, 2020).

Alongside this sense of lost control, guilt was particularly prominent. Many patients felt ashamed of the financial and caregiving burden AP placed on family members. Patients described family members taking leave from work, elderly parents travelling to provide care and children being displaced:

> “I had to call my mother to care for me because my husband could not take leave for work. My mother was 72 years old, and I felt guilty.” (Liu and Zhang, 2020)

For patients with recurrent AP, guilt was compounded by self-blame. Having been through previous episodes, many felt they should have known better and that recurrence was a consequence of their own failure to manage their lifestyle. This self-blame was strongest where alcohol or dietary excess had triggered the episode, leaving patients caught between remorse and an inability to change:

> “I had a very important work project last year, so it was my duty to accomplish it. I had no reason to refuse the requests of the clients, such as drinking, cup after cup. It is a custom for people to reunite at the Spring Festival.” (Liu and Zhang, 2020)

For some patients, social obligations, cultural norms and work pressures made behaviour change feel impossible. In two studies conducted in China (Liu and Zhang, 2020; Chen et al., 2022), patients' ability to control their behaviour was shaped by cultural expectations. Chinese wine and food culture, Spring Festival traditions and workplace drinking obligations were described as forces patients felt unable to resist, despite understanding the consequences. This suggests that perceived control over behaviour is shaped not only by individual factors but also by wider cultural and social norms, which may constrain the extent to which patients can enact recommended changes.

Some patients resigned themselves to recurrence. One participant laughed about returning to the same behaviour that had caused previous episodes. This reflected a deeper sense of helplessness that change was simply not possible:

> “One of my best friends came back...Didn't I go to dinner with him (laughing)? If he invited me next time, I would go for it too. (laughing with naughty expression)” (Liu and Zhang, 2020)

Across studies, patients felt simultaneously responsible for their illness and powerless to change it, trapped between the expectation that they should do better and the reality that social and cultural circumstances made behaviour change very difficult.

In summary, this theme reflects a tension between perceived personal responsibility and actual control, suggesting that expectations for behaviour change may intensify distress when patients feel structurally or socially constrained.

Theme 3: Navigating Transitions in Recovery Whilst Feeling Unprepared and Unsupported

Recovery from AP was rarely straightforward. Rather than a progressive return to health, patients described a demanding, unpredictable and non-linear process marked by setbacks, plateaus and prolonged physical vulnerability that many had not anticipated:

> "Normally, I bounce back quite quickly after a pancreatitis attack but this just seems to have...stopped me doing a lot of things...I can't go back to work today because I can't even walk two feet in front of me." (Kessler et al., 2025)

The physical burden of recovery was significant. Patients described ongoing pain requiring medication weeks after discharge, severe weight loss, persistent fatigue and an inability to carry out basic daily tasks (Boije et al., 2019; Gunic et al., 2026). For some, the severity of physical symptoms after discharge came as a shock:

> "It is like, in the first week after discharge, I was vomiting all the time, I could not have food in me, and I lost 7 kilos during this first week when I came home." (Gunic et al., 2026)

What made this harder was that many patients left hospital feeling unprepared for what recovery would involve. Uncoordinated discharge, inconsistent information from doctors and nurses and absent follow-up left patients confused and unsupported. This contributed to reduced confidence and self-efficacy in managing recovery at home.

> "When I was discharged, I think the doctor said that I can just call and… I called because I did not get prescriptions, and the nurses said that they would send a prescription to the pharmacy today...They didn't do it, so I was absolutely disappointed." (Gunic et al., 2026)

> "When I left the hospital, I felt like I was left alone." (Su et al., 2024)

Without clear guidance or explanation, patients had no framework for managing their condition at home, leaving them feeling vulnerable and uncertain.

Where professional support was absent, family support was essential, providing practical help, emotional reassurance and supervision of lifestyle changes, though it was not always available or consistent (Boije et al., 2019; Ma et al., 2022; Su et al., 2024). Some patients had no family locally, whilst others described family engagement declining over time as AP improved (Boije et al., 2019; Su et al., 2024; Gunic et al., 2026). This variation highlights that inequalities in available support exist

which suggests that recovery experiences may differ significantly depending on social and relational resources.

Feeling unsupported was not only about the absence of information. Some patients described feeling unheard and misunderstood by staff during admission, their pain dismissed, their experiences not acknowledged, their involvement in care planning minimal (Boije et al., 2019; Gunic et al., 2026). For some, this extended to stigma. Patients described being assumed to be alcoholic by healthcare workers regardless of their actual diagnosis.

> “So many medical people still believe alcohol is the main cause of pancreatitis, as soon as you say pancreatitis, they automatically assume you're an alcoholic and you get mistreated from that point onwards.” (Kessler et al., 2025)

Stigma was reported across all three countries included in Kessler et al. (2025) - the UK, US and Germany - suggesting it is not culturally specific. This indicates that illness stigma may persist independently of aetiology and can shape patient and professional interactions across contexts.

Despite feeling unsupported, patients expressed a strong and consistent desire for knowledge, specific, individualised guidance on diet, exercise and disease management to prevent recurrence. Where knowledge was provided, it made a difference. Patients recognised that understanding their condition reduced anxiety and helped them cope. The gap between this desire for knowledge and the inadequacy of what was provided was a consistent finding across the review.

When healthcare was experienced as supportive and responsive, it made a meaningful difference to patients' recovery and psychological wellbeing (Boije et al., 2019; Su et al., 2024).

In summary this theme suggests that recovery is experienced not only as a physical process but also as a disruption to expectations of care. This then leaves patients needing to reconstruct understanding and self-management in the absence of consistent support.

Theme 4: Adaptation, Resilience and Reappraisal in the Midst of Suffering

Despite the significant psychological burden described above, hope, resilience and, for some, a positive reappraisal of life were consistent findings across studies. Trust in the medical team provided an important source of psychological support and confidence in recovery for some patients:

> "Although I have suffered acute pancreatitis four times, I think as long as I follow what the doctor and nurse told me, I will stay healthy. If I suffered it again, I would not give up but would remain positive and seek treatment." (Liu and Zhang, 2020)

Patients demonstrated perseverance, actively seeking information and committing to dietary change despite repeated setbacks, with some finding that awareness of physical vulnerability became a motivating force for change.

Over time, some patients described a genuine shift in how they related to food and lifestyle. Rather than experiencing dietary restriction as deprivation, they developed a physical and psychological aversion to unhealthy food:

> "Now I feel sick of the oleaginous if only one glance at it. To live longer, we adjust eating habits, transform dislikes into likes, and chase the sense of hunger. Once, I was quick-tempered and did my best in work and so emulous, but now, I have changed." (Chen et al., 2022)

For others, AP prompted a broader reappraisal of life values and priorities. Patients described shifting away from an emphasis on work and wealth towards a greater appreciation of health, relationships and the present moment. Some reached a point of peaceful acceptance acknowledging the unpredictability of their illness and the reality of mortality, whilst choosing to make the most of the time they had:

> "At such an age, we will come to the end of life and face death someday. The end is unknown but close, I can do nothing but prolong the end by proper lifestyle." (Chen et al., 2022)

Unexpected benefits were also reported. Some patients discovered previously undetected health conditions during hospitalisation, successfully lost weight, or found that their illness had prompted family members to adopt healthier lifestyles (Chen et al., 2022). For some, AP filtered relationships revealing who their true friends were and providing an opportunity to reflect on what mattered most.

These positive responses did not emerge for all patients or at all stages of the illness; within the same illness, the same person could hold fear and hope, loss and growth. For some, suffering remained dominant throughout, and individualised support that recognises this complexity is therefore needed

In summary, the findings from this theme suggest that adaptation is dynamic and non-linear, where resilience and distress co-exist rather than there being a straightforward trajectory of recovery.

Discussion

This systematic review synthesised qualitative evidence from seven studies exploring the lived experience of adults hospitalised with AP or RAP. It extends existing work by identifying uncertainty and disrupted meaning making, rather than symptom burden alone, as central mechanisms underpinning psychological distress in AP. Across studies, patients described significant psychological distress driven by persistent uncertainty, a sense of responsibility for an illness beyond their control and significant gaps in post-discharge care. Yet despite this, many patients demonstrated resilience, found hope and reappraised what mattered most in life.

Uncertainty was a consistent finding across all seven studies. The sudden and unpredictable nature of AP was combined with no prior knowledge of the condition and, particularly in idiopathic cases, no clear explanation for why it had occurred. This combination left patients feeling unable to make sense of their experience or feel certain about their future. Patients experienced fear of recurrence, concerns about disease progression and psychological distress that persisted long after discharge. This suggests that distress in AP may be driven more by uncertainty and lack of explanatory coherence than by physical severity alone. This challenges the assumption that psychological burden is simply secondary to illness intensity.

Previous research has documented high rates of anxiety and depression following AP, with a single episode raising the risk of new mental health disorders (Fehér et al., 2026; Khoja et al., 2023). This review extends those findings by providing a qualitative understanding of how psychological distress develops in AP, with uncertainty about cause, recurrence and prognosis playing a central role. These findings closely align with Mishel's (1988) theory suggesting uncertainty arises from unclear aetiology, unpredictable prognosis, limited information and fragmented care. Hansen et al. (2012) found similar patterns across multiple conditions, with uncertainty consistently associated with hypervigilance, emotional burden and loss of control. Clear communication and organised care pathways were identified as key strategies for reducing uncertainty, both of which were consistently absent in this review. Together, these findings highlight uncertainty as a central organising process linking cognitive, emotional and behavioural responses to AP.

Patients consistently described feeling responsible for causing AP and preventing recurrence whilst feeling unable to control the course of their illness. This was compounded by self-blame when

recurrence occurred despite patients' efforts, guilt about the burden placed on families and social and cultural pressures that made behaviour change feel impossible. These findings can be understood through the CSM (Leventhal et al., 1980; Hagger and Orbell, 2022), whereby patients developed beliefs about cause, consequences and controllability, alongside strong emotional responses including fear, guilt and shame.

Self-blame when recurrence occurred despite patients' efforts has been associated with depressive symptoms and a sense of personal failure in physical illness (Bennett et al., 2013; Beverly et al., 2012). In AP, this was evident in patients who felt they had failed despite facing social obligations, cultural pressure and an inherently unpredictable disease. Findings around social and cultural pressures, including workplace drinking obligations and food culture, came mainly from studies conducted in China (Liu and Zhang, 2020; Chen et al., 2022) and may not directly translate to Western contexts. This highlights how perceived control is shaped not only by individual behaviour but by broader social and cultural constraints.

The loss of freedom to eat and live as before was a further source of distress. Patients mourned a previous way of life and struggled to integrate a new illness identity alongside their existing sense of self. This connects to the identity dimension of the CSM, which describes how patients come to recognise and understand their condition through its symptoms and limitations. In AP, this process was complicated by the unpredictable nature of the illness, which made it difficult for patients to develop a stable illness identity or adjust to living with a condition that could return without warning. These findings suggest that AP is experienced as a disruption to identity continuity, requiring patients to renegotiate their sense of self in relation to an unpredictable body. This suggests that psychological support addressing self-blame, guilt and identity adjustment may be beneficial for patients with AP, particularly those who experience recurrence.

Across studies, patients described feeling unprepared for recovery and unsupported during the transition from hospital to home. Recovery was experienced as demanding and non-linear, with many patients struggling to manage their condition independently without clear guidance on diet, medication or what to expect. These findings indicate that distress is shaped not only by illness experience but also by systemic gaps in care, including fragmented discharge processes and lack of coordinated follow-up.

Many patients left hospital without clear information or a coordinated discharge plan, leaving them without a framework for managing their condition at home. An international survey found that 87.5% of hospitals and hospital departments managing AP have no discharge protocol in

place (Nagy et al., 2023). The consequences may be significant, given that AP patients are at greatest risk of developing new mental health disorders in the months immediately following their episode (Khoja et al., 2023). In this context, patients expressed a clear desire for individualised guidance on diet, lifestyle and disease management to reduce anxiety and support coping. This is supported by Hansen et al. (2012), who found that clear and accurate information was a key strategy for reducing uncertainty across illness contexts. NICE (2020) guidelines emphasise the importance of comprehensive information and psychological support for AP patients, yet the findings of this review suggest this is rarely achieved in practice.

Family support was identified as essential during recovery, providing practical help and emotional reassurance. However, it was not always available or consistent. Some patients lacked family nearby, whilst others described family engagement declining over time as symptoms improved. Where family support was absent or inconsistent, patients were left to navigate recovery alone, reinforcing the importance of professional follow-up beyond discharge.

Feeling unsupported extended beyond the absence of information. Some patients described feeling unheard and misunderstood by staff, with their pain dismissed and their involvement in care planning minimal. For some, this extended to stigma. Patients were assumed to be alcoholic by healthcare workers regardless of their actual diagnosis, a pattern reported across all three countries in Kessler et al. (2025). Van Boekel et al. (2013) found that healthcare professionals commonly held negative attitudes toward patients with substance use disorders, which affected the quality of care they received. Carol et al. (2022) found that most patients with non-alcoholic fatty liver disease experienced stigmatisation despite no alcohol involvement, suggesting that conditions associated with alcohol carry stigmatising assumptions regardless of actual cause. Corrigan et al. (2012) describe how exposure to stigmatising assumptions can lead individuals to internalise blame and shame. Staff education about the multiple causes of AP and training in non-stigmatising communication are therefore important priorities, consistent with NICE (2020) guidance cautioning against assuming AP is alcohol related. These findings indicate that stigma is not only a social issue but is embedded within healthcare interactions, shaping how patients with AP experience care and contributing to internalised blame.

Despite the significant physical and psychological burden described above, many patients demonstrated resilience, adapting to their illness and finding hope even in the midst of suffering. Patients described reappraising life values and priorities, developing new relationships with food and lifestyle and reaching a degree of acceptance, including in some cases a peaceful acknowledgement of mortality. These findings are consistent with post-traumatic growth (PTG; Tedeschi and Calhoun,

1996), which describes positive psychological change emerging from highly challenging life experiences. However, these positive responses were not universal and appeared to be shaped by contextual factors such as access to support and resources, suggesting that PTG may not reflect individual resilience alone. Hefferon et al. (2009), in a systematic review of PTG across life-threatening physical illnesses, found that reappraising life priorities, existential reflection and developing new health behaviours were consistent responses to serious illness.

These positive responses did not emerge for all patients or at all stages of the illness, and for some the burden described above remained dominant throughout. This reflects the complexity of the psychological experience of AP. Resilience and suffering coexisted, often within the same person at the same time. Individualised psychological support that recognises both the burden and the potential for growth is therefore needed.

Together these findings highlight the need for integrated psychological support alongside physical care in AP, including clear communication from diagnosis, structured discharge planning, non-stigmatising healthcare interactions and follow-up support that extends beyond the acute episode. Integrated psychological support does not require an AP specific psychology pathway, given the lack of dedicated psychology provision for people with AP. It could instead be built into existing care. Nurses and other staff could be supported to screen for distress and signpost to relevant services, which would help address the lack of psychological support patients described. Psychologists already working in other departments or services could offer training, consultation and supervision to staff caring for people with AP, for example in non-stigmatising communication and clear information-giving, which would address the stigma and information gaps patients described. Upskilling existing staff in this way would likely have low financial implications, making it more feasible to implement. People with more significant difficulties would still need direct psychological input.

Strengths and Limitations

This review has a number of strengths. It is the first thematic synthesis of qualitative evidence on the psychological experiences of adults hospitalised with AP or RAP. Methods were rigorous, including prospective PROSPERO registration, adherence to PRISMA and ENTREQ guidelines and second reviewer involvement throughout. Thematic synthesis allowed findings to move beyond description toward analytical interpretation relevant to clinical practice.

Several limitations should be noted. Four of the seven included studies were conducted in China, which may limit the transferability of some findings to Western and UK NHS contexts. No UK

qualitative studies on the psychological experiences of AP were identified, a notable gap given the distinct characteristics of NHS care pathways. Whilst men are slightly more frequently affected by AP in some populations, the underrepresentation of women in qualitative samples nonetheless limits understanding of potential gender differences in psychological experience. Most studies focused on recovery rather than the acute inpatient experience with only two specifically recruiting inpatients. Only two studies focused specifically on RAP, meaning the evidence base for recurrent disease remains limited. Finally, Kessler et al. (2025) was funded by a pharmaceutical company with the first author employed by the funding organisation; whilst competing interests were declared, this should be considered when interpreting those findings. Variation in methodological approaches across studies may have influenced the depth of psychological insight captured, particularly where analyses remained more descriptive.

Future Research

This review highlights several important gaps. Most included studies were conducted in Chinese healthcare contexts and no UK qualitative studies were identified, limiting transferability to NHS and other Western settings. Future research should ensure adequate representation of women to better understand potential gender differences. The acute inpatient experience remains largely underexplored, with most studies focusing on recovery, therefore research examining psychological experiences during hospitalisation is needed. Finally, whilst this review identifies significant psychological burden, no psychological interventions specifically designed for AP patients were identified. Development and evaluation of targeted psychological support for this population represents an important priority.

Conclusion

This systematic review provides the first synthesis of qualitative evidence on the lived experience of adults hospitalised with AP or RAP, revealing significant psychological distress that extends well beyond physical recovery. Uncertainty, loss of control, feeling unprepared and unsupported and the absence of adequate psychological care were identified as consistent themes across diverse cultural contexts and healthcare settings. These findings indicate that psychological support needs to be integrated into AP care from diagnosis through to recovery and highlight the need for further qualitative research, particularly within underrepresented healthcare contexts including the UK, to inform targeted psychological support for this population. Through identifying uncertainty and perceived control as central processes, this review offers a theoretically grounded

framework for understanding psychological distress in AP that moves beyond symptom burden alone.

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Chapter Three: Bridging Chapter

The systematic review presented in Chapter Two synthesised qualitative evidence from seven studies exploring the lived experience of adults hospitalised with acute pancreatitis (AP) or recurrent acute pancreatitis (RAP), identifying four analytical themes. Together these revealed significant psychological distress from onset through to recovery, driven by persistent uncertainty, a tension between feeling responsible for the illness whilst feeling unable to control it and significant gaps in care during the transition from hospital to home. Alongside this burden, many patients demonstrated resilience and reappraised life priorities in the midst of significant suffering.

The systematic review also revealed important gaps in the existing literature. Whilst one study included UK participants alongside those from the US and Germany (Kessler et al., 2025), that study focused specifically on hypertriglyceridaemia (HTG) related AP and was not designed to explore the UK healthcare experience. No UK-based qualitative study explicitly exploring the psychological experiences of AP from onset to recovery existed at the time of this review. The role of peer support had not been examined in any of the included studies, despite the SR findings demonstrating that post-discharge support is frequently absent, leaving patients to navigate recovery without professional guidance. Most studies also focused on specific phases of the illness journey rather than the full experience from symptom onset through to recovery. The empirical study presented in Chapter Four sought to address these gaps. It is the first UK-based qualitative study to explore the psychological experience of AP across the full illness trajectory, with participants recruited through peer support groups.

Chapter Four: Empirical Paper

Prepared for submission to Psychology, Health and Medicine

(Author guidelines available in Appendix B)

Stories from the Forgotten Patients: A Qualitative Study Exploring the Psychological Experiences of Patients Diagnosed with Acute Pancreatitis

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Abstract

The global incidence of acute pancreatitis (AP) is increasing with the rates in the UK more than doubling over the past two decades. Despite growing evidence of psychological burden, no UK-based qualitative study has explicitly examined psychological experiences of AP from onset to recovery. This study explored the psychological experiences of individuals diagnosed with AP and hospitalised for it. A qualitative design was employed using reflexive thematic analysis (Braun and Clarke, 2022) within a critical realist framework. Fourteen semi-structured interviews were conducted with adults who had experienced AP, recruited through peer support groups. Six themes were identified: dual misrecognition and delayed diagnosis; pain, powerlessness and loss of dignity during hospitalisation; communication failures and stigma; post-discharge care gaps; adjusting to a new normal; and trauma, fear of recurrence and resilience. Findings reveal enduring psychological distress shaped by delayed diagnosis, inadequate pain management, stigmatising assumptions about alcohol, absence of discharge planning and persistent fear of recurrence. Despite these challenges, many participants demonstrated resilience and post-traumatic growth. These findings emphasise the need for integrated psychological care in AP care, including clear communication, structured discharge planning, non-stigmatising healthcare interactions and ongoing support beyond the acute episode.

Keywords: acute pancreatitis, qualitative, psychological experience, reflexive thematic analysis, stigma, fear of recurrence, peer support

Introduction

Acute pancreatitis (AP) is a sudden inflammation of the pancreas characterised by severe abdominal pain, nausea and vomiting, most commonly triggered by gallstones or alcohol and requiring urgent medical care (NHS, 2026; Banks et al., 2013). Within the UK, incidence has more than doubled over approximately two decades, rising from 21.4 to 48.2 per 100,000 people per year (Spagnolo et al., 2022). Around four in five patients experience mild disease and recover without major complications, whilst a minority develop severe AP with mortality affecting approximately 15-20% in severe cases (Forsmark et al., 2016; Banks et al., 2013). Severe or necrotising AP often requires intensive care admission and prolonged hospitalisation (Forsmark et al., 2016). Following an initial AP episode, approximately one in five patients experiences recurrence, with over a third of those going on to develop chronic pancreatitis (CP) (Sankaran et al., 2015).

The challenges of AP extend beyond its physical impact. Khoja et al. (2023) found that a single episode of AP can independently raise the likelihood of developing mental health disorders, including major depressive and anxiety disorders. A meta-analysis by Fehér et al. (2026) found that anxiety affected approximately 23% of AP patients and depressive symptoms were present in approximately 29%, rates exceeding those observed in the general population and in other gastrointestinal conditions. Individuals with severe or necrotising AP, who often require intensive care admission, face heightened vulnerability to mental health difficulties (McGuire et al., 2022). Additionally, AP has been linked to an increased risk of suicide (Chen et al., 2018).

A recent systematic review and meta-analysis by Xu et al. (2025), drawing on data from over 2,500 patients, found that people with a history of AP showed persistently lower quality of life scores than healthy individuals across physical, emotional and mental health domains, with impairments documented for up to almost ten years.

Although QoL instruments provide an insight into the impact of a disease, they often fall short in capturing the subjective experience of a disease (Hamming & De Vries, 2007), suggesting qualitative approaches are needed. Yet the psychological experiences of patients with AP have been scarcely explored using qualitative methods (Boije et al., 2019).

Existing qualitative studies have begun to explore the psychological burden of AP, documenting a range of negative emotions including anxiety, fear, helplessness, guilt and shame during hospitalisation (Liu and Zhang, 2020; Ma et al., 2022). Recovery has been found to involve significant physical and emotional demands, with patients feeling unsupported and insufficiently informed following discharge (Boije et al., 2019; Gunic et al., 2026; Su et al., 2024). Fear of

recurrence was particularly prominent at discharge, with patients expressing a clear need for better disease-related knowledge and support (Su et al., 2024; Ma et al., 2022). Together, these findings highlight the psychological burden of AP and the importance of patient-centred approaches and targeted support.

These findings can be understood through Leventhal's Common-Sense Model of illness self-regulation (CSM; Leventhal et al., 1980; Hagger & Orbell, 2022). This emphasises that individuals form illness beliefs that guide their emotional and behavioural responses. Applying this framework helps contextualise how patients with AP make sense of the sudden onset of symptoms, uncertainty and the wider psychological, social and existential impact of the condition.

The psychological impact of AP is recognised in NICE guidelines (NICE, 2020), which highlight the importance of providing patients with pancreatitis, as well as their family members and caregivers, with comprehensive information on various aspects of care, including psychological support where required. The need for psychological support is further emphasised by Szatmary et al. (2022), who highlight that physical and psychological issues are interconnected and frequently exacerbated by anxiety, underscoring the importance of building therapeutic relationships with patients to alleviate psychological distress.

While the importance of psychological support for individuals with AP is emphasised in the NICE Guidelines and the above literature, there remains a notable gap, as no UK based qualitative study explicitly exploring the psychological experiences of AP from onset to recovery exists.

Research aim

The aim of this study was to explore and understand the psychological experiences of individuals who have been diagnosed with AP and hospitalised for it.

Research Questions

Primary Question:

- How do patients who have been diagnosed with AP and hospitalised for it experience and make sense of the psychological impact of the illness?

Secondary Questions:

- How do psychological experiences change across different stages of AP, from hospitalisation through treatment and recovery?
- How do patients describe coping, adaptation, and survival in response to the psychological impact of AP?
- How are patients' psychological experiences shaped by healthcare interactions and social support?
- What unmet psychological and service needs do patients with AP identify?

Materials and Methods

Design

This study employed a qualitative design using the Reflexive Thematic Analysis (RTA) framework proposed by Braun and Clarke (2022). The research adopted a critical realist perspective, which posits that an objective reality exists independently of human interactions and practices, even though our ability to fully access it may be limited (Flick, 2014). Critical realism acknowledges the influence of broader historical, cultural and social contexts on our understanding of reality (Willig, 2001; Harper, 2011). This perspective was deemed the most appropriate as psychological distress in AP can be understood as arising from the real physiological severity of the condition, but also the social context in which uncertainty is interpreted. This study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong et al., 2007).

Participants

Fourteen participants were recruited from a local peer support group and a Facebook group. Sample size was guided by information power (Malterud et al., 2016), where a sample holding more relevant information needs fewer participants. I judged the sample sufficient once the interviews were rich enough to address the research aims. The participants were adults living in the United Kingdom. Eligibility criteria are provided in Table 1.

Table 1

Inclusion and Exclusion Criteria

Inclusion	Exclusion
• Adults aged 18 years or older	• Diagnosis or suspicion of CP, RAP, or pancreatic cancer

- Had experienced at least one episode of AP
- Currently residing in the UK
- Able to communicate in English

- Cognitive impairment (e.g., dementia, stroke) that would affect ability to provide informed consent or participate in interview
- Unable to communicate in English

Ethical Approval

The study received ethical approval from the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee (ETH2425-0438).

Procedure

Participants were recruited through two channels. Initial recruitment took place through a local peer support group for individuals who had experienced AP. The lead researcher attended a peer support group meeting in early February 2025 to introduce the study. Potential participants were provided with a study information poster, a Participant Information Sheet (PIS) and Consent Form via email one week prior to the meeting and given time to review materials before deciding whether to participate.

As initial recruitment yielded only five participants, whose accounts were not rich enough to address the research aims, additional recruitment took place through an online peer support group. With permission from group administrators, the research poster was shared in a Facebook group for people affected by pancreatitis including AP, RAP and CP. Interested individuals contacted the lead researcher via email and were provided with the Participant Information Sheet and Consent Form. Following review, to ensure participants met inclusion and exclusion criteria, an interview was arranged.

Data Collection

Data collection took place between April and July 2025. All participants provided written informed consent prior to interview.

Semi-Structured Interview Guide

The semi-structured interview guide, developed based on previous research on patient experiences of critical illness and recovery and reviewed with PPI contributors, explored participants'

experiences across multiple domains. These included life and health prior to illness onset, experiences of symptom recognition and help-seeking, hospitalisation (including communication with healthcare staff and psychological support received), discharge and recovery, long-term psychological effects, impact on quality of life, relationships and daily functioning, coping strategies and resources utilised, and unmet needs with suggestions for service improvement.

Two interviews were conducted face-to-face (one audio-recorded, one video-recorded), with the remaining twelve conducted via Microsoft Teams video conferencing. All interviews were audio or video recorded with participant permission. Interview duration ranged from 30 to 80 minutes.

Patient and Public Involvement (PPI)

Prior to commencing data collection, PPI activities were conducted in February 2025. Two PPI meetings were held. The first meeting involved two people who had experienced AP and the spouse of one participant. The second meeting involved consultation with an Accident and Emergency (A&E) physician from a local hospital. These meetings reviewed all study materials including the Participant Information Sheet, Poster, Consent Forms, and Interview Guide. Feedback was incorporated into the final study design.

Data Analysis

Interview recordings were transcribed verbatim using Microsoft Teams automated transcription tool, with transcripts subsequently checked for accuracy by the lead researcher. Data were analysed using inductive RTA following the approach outlined by Braun and Clarke (2022). An inductive approach was chosen because it allowed me to construct themes from participants' accounts rather than from a pre-existing framework (Braun & Clarke, 2022), which suited the limited existing research on the lived experience of AP.

Analysis was supported by NVivo qualitative data analysis software (version 15). The six-phase process of RTA was followed (Braun & Clarke, 2022) involving familiarisation with the data, generating initial codes, constructing themes, reviewing themes, defining and naming themes and producing the final write-up. The coding process was iterative and recursive, reviewed throughout in consultation with the research supervisor, resulting in 891 codes organised into 26 clusters and subsequently six themes.

Reflexivity

As a trainee clinical psychologist with an interest in health psychology but no personal experience of AP, the lead researcher approached the study with curiosity about participants' experiences while maintaining awareness of potential assumptions about illness experiences drawn from clinical training and the broader healthcare context.

The lead researcher engaged in reflexive practice through maintaining a journal during data collection and analysis (Braun & Clarke, 2022). In line with Braun and Clarke's (2022) recommendations, the primary researcher undertook initial coding, with thematic development reviewed collaboratively through regular supervision. Rigour was established using Lincoln and Guba's (1985) quality criteria, which evaluate credibility, transferability, dependability and confirmability to demonstrate trustworthiness within a critical realist framework.

Results

A total of fourteen individuals (6 male, 8 female) who had experienced at least one episode of AP participated in the study. Participants ranged in age from 44 to 72 years (M = 59.6, SD = 8.9). Participant demographics are presented in Table 2.

Most participants (n = 11) had experienced a single AP episode, whilst three had experienced multiple episodes. Gallstones were the most commonly reported aetiology (n = 10), with the remaining participants reporting idiopathic causes (n = 3) or multiple contributing factors including alcohol and stress (n = 1). Over half of participants (n = 8) required ICU admission.

Table 2

Patient Demographics

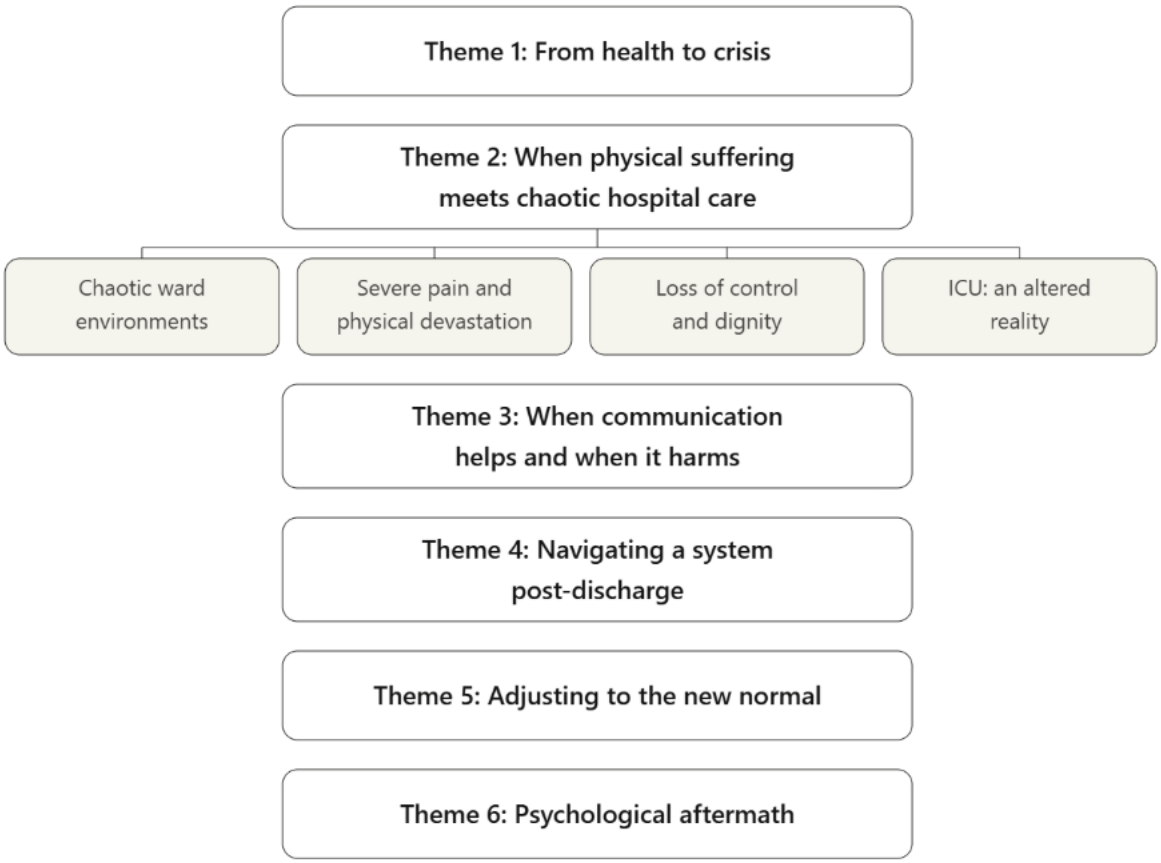
Characteristic	n	%
Gender		
Male	6	42.9
Female	8	57.1
Age		
Range	44-72 years	
Mean (SD)	M = 59.6, SD = 8.9	
Ethnicity		
White British (English)	7	50.0
White British (Scottish)	1	7.1

White Irish	1	7.1
White European	1	7.1
White American	1	7.1
White Australian	1	7.1
Any other White background	1	7.1
Black Caribbean	1	7.1
Employment Status		
Employed full-time	7	50.0
Employed part-time	2	14.3
Retired	5	35.7
Marital Status		
Married	12	85.7
Widowed	1	7.1
Domestic partnership/Civil union	1	7.1
Highest Education		
Secondary education	2	14.3
Some college/university	3	21.4
Bachelor's degree	5	35.7
Master's degree	3	21.4
PhD	1	7.1
Number of AP Episodes		
1 episode	11	78.6
2 episodes	2	14.3
3 episodes	1	7.1
Reported Cause of AP		
Gallstones	10	71.4
Unknown/Idiopathic	3	21.4
Multiple factors (alcohol, stress)	1	7.1
ICU Admission		
Yes	8	57.1
No	6	42.9
Recruitment Source		
Local peer support group	5	35.7
Facebook support groups	9	64.3
Interview Mode		
Face-to-face	2	14.3
Video call (MS Teams)	12	85.7

Analysis identified six themes illustrated in Figure 1.

Figure 1

Themes and Subthemes



Theme 1: From health to crisis: A perfect storm of symptom misrecognition and delayed diagnosis

The first theme describes how participants transitioned from active, healthy lives to medical crisis, shaped by symptom misrecognition by both patients and healthcare providers. Most participants described no prior knowledge of AP and did not perceive early symptoms as serious. Some later reflected on cumulative strain before their episode. One described "*a long period of quite a lot of physical and mental strain"* (P07). This retrospective search for explanation suggests

participants were trying to make sense of why AP happened, looking for triggers in lives that had felt manageable at the time.

The progression to crisis typically followed a pattern of initial dismissal followed by sudden deterioration. Many dismissed early symptoms as indigestion or a stomach bug, delaying help-seeking. One recalled: "*I felt quite ill and was being sick and had pain and I waited for it to go off. I thought perhaps it was a bug, but eventually, after five days, I went to the hospital"* (P13). When symptoms escalated, the deterioration was rapid and overwhelming: "*It all happened within two hours. Literally, from being like you and I are now, to on the floor, not being able to communicate in any way really with the pain"* (P08). For some participants, nothing signalled that something serious was happening until it had become a crisis. After the crisis, feeling well no longer felt safe, which may help explain the distrust of their bodies described in Theme 6.

Even when participants sought help, providers often misdiagnosed the condition. One explained: "*They thought it was food poisoning... they said 'give it 24-48 hours, it should be fine'. So I said 'OK', because obviously I trusted them"* (P12). For participants who already thought their symptoms were minor, the reassurance confirmed that. This dual misrecognition by both patients and providers created delays while AP worsened. P07 sensed the illness was different from gallbladder attacks but, without information about what to look for, was left to judge its severity herself: "why didn't I push harder? I knew this was different." This regret shows how responsibility for recognising illness fell to patients who had little control over their care.

The severity of the crisis, excruciating pain, uncontrollable vomiting and complete loss of functioning created intense fear. Fear of death arose at different points for different participants: some during the acute crisis, others later in hospital when they realised how critically ill they were. One described: "*I said to him I am not gonna come out from here, I am just gonna die... I honestly thought I was"* (P02). Yet alongside fear came determination: "*I just thought I've got to get better. I can't give up here, I have to fight"* (P12). The determination did not replace the fear but may have offered a way to act when little else was in participants' control.

This represented a "perfect storm" where early symptoms were dismissed by patients and providers as minor conditions, followed by sudden deterioration that transformed normal lives into medical emergencies within hours, leaving participants facing intense fear with little time to prepare.

Theme 2: When physical suffering meets chaotic hospital care: Pain, powerlessness and loss of dignity

Hospitalisation for AP meant enduring not only life-threatening illness but also chaotic ward conditions, severe uncontrolled pain, loss of autonomy and sometimes hallucinations and memory loss. Participants faced these challenges when they were at their most vulnerable.

Chaotic Ward Environments

Hospital wards were often chaotic and prevented rest when participants needed to recover. One described: "*I stayed in the surgical emergency unit for three days, but I could not sleep. It was like a war zone in there... it was really busy. It was Christmas ... I had no sleep" (*P07). Participants were exposed to others' suffering and death: "*I was on one ward where someone died. That was difficult... because it's not private, is it?"* (P01). Frequent bed moves disrupted care and prevented any sense of stability: "*I moved bed eighteen times"* (P01). The ward, expected to be a place of safety and recovery, offered little continuity or rest, leaving participants little control over the basic conditions of their recovery.

Severe Pain and Physical Devastation

Participants experienced excruciating pain that often could not be controlled despite maximum medication. Some described pain worse than childbirth: "*I had 27 hours of labour with my daughter, I'd had various gallbladder attacks... nothing came anywhere near this"* (P07).

Despite maximum medication, pain remained uncontrolled: "*They had thrown every drug they could possibly think at me you know and my pain was still not under control."* (P14). Pain relief was often delayed: "*I didn't get no pain relief and I would be screaming for pain and I had to wait hours for it... this used to happen mostly at night time ... when the shifts were changing"* (P02). Pain that medication could not control was distressing enough, but delays in relief suggest that some of the suffering came from how care was organised and not from the illness alone.

Alongside pain, participants experienced severe physical deterioration. Prolonged inability to eat caused dramatic weight loss: "*I lost about 35 kilos"* (P01). Muscle wasting following ICU stay left participants unable to walk: "*I hadn't stood up for three months, four months, five months. I literally couldn't move myself* and what was challenging*, I thought that this may be it for me physically. Maybe I'm not going to walk properly again"* (P04). This combination of uncontrolled pain and body deterioration left participants feeling helpless and overwhelmed.

Loss of Control and Dignity

Hospitalisation took away participants' autonomy when they were most vulnerable. One described: "*I felt powerless. And I felt like my strength had been taken away and my voice had been taken away"* (P06). Participants lost control of their bodies: "*I had no control over my bowel, I had no control over my bladder, I'd lost the capacity to walk"* (P14). Another described the impact: "*I was quite an independent person who, you know, had a full time job... I was reduced to having to have my bottom wiped, and being turned in the bed, it's quite tough"* (P12). For some participants the gap between their independent pre-illness self and their dependent hospital self created distress and threatened their sense of who they were.

Physical weakness prevented participants from advocating for their needs: "*I couldn't actually even muster, 'this is not right, you know, can you please see me?'... I was just so weak"* (P11). The embarrassment of personal care was sometimes compounded by being cared for by young nurses: "*They are used to it but some of them are younger than my daughters and I didn't like that"* (P02). Seeing their changed bodies shocked participants: "*No one warned me... I looked down and I had staples all across me and I just freaked out"* (P02).

ICU: An Altered Reality

For participants who went to ICU, the experience was both life-saving and disorienting. One described it as "a *safe place, but a very surreal* place" (P14). This combination of safety and strangeness reflected the duality of ICU where participants were being kept alive but in an environment unlike anything they had experienced.

Many experienced hallucinations and fragmented consciousness that created lasting uncertainty about what was real. Hallucinations were often frightening and involved being trapped or kidnapped: *"I couldn't speak and I just felt like I was being held somewhere you know against my will and my family didn't know and it's just horrible"* (P12). These hallucinations mirrored the reality of physical powerlessness. Others could not tell afterwards what had really happened**:** *"I thought someone had stabbed me... I remember going to get a knife to kill someone to protect my son... I woke up thinking I'd actually done these things"* (P04). The hallucinated events were not real, but the fear they produced was, and participants were left carrying it.

Memory loss left participants unable to understand their own experience: "*I don't remember January. I don't remember February... I didn't have a concept of time"* (P04). These memory gaps meant participants could not make sense of what happened to them, leaving them with fragmented

experiences they could not fully process. Without a continuous memory of what happened, participants had no way to check the frightening fragments against events, so the experience stayed unresolved.

Hospitalisation for AP meant surviving not just the illness itself, but chaotic conditions that prevented rest, uncontrolled pain, loss of dignity and autonomy, physical decline, and sometimes a frightening loss of reality.

Theme 3: When communication helps and when it harms: Compassion, stigma and failures

Beyond the physical challenges of hospitalisation, participants' experiences were shaped by how healthcare staff communicated with them. Communication during hospitalisation ranged from compassionate and supportive to dismissive and stigmatising. At its worst, poor communication left participants confused about their diagnosis and treatment, dismissed when seeking help, and actively stigmatised through assumptions about alcohol use. At its best, compassionate communication provided emotional support that helped participants endure crisis.

Participants frequently described how staff failed to provide clear explanations about what was happening to them medically. This lack of information was compounded by inconsistencies between healthcare providers, leaving patients confused about their diagnosis and treatment, and uncertain about what was happening to their own bodies, and what would happen next. One participant described: *"No one was making any sense because they weren't telling me why. I didn't know I had had operations" (P04)*. Another explained: "*I said, 'what is going on with me? Can you tell me what's going on?' You have necrosis, you have this and that. But it was only ever given to me in wee snippets. So I had to sort of like piece it together like a jigsaw'* (P11). This metaphor illustrates how participants had to actively make sense of fragmented information while acutely unwell. Relying on the clinicians responsible for providing that information left participants feeling helpless when answers were not forthcoming. Left to make sense of their own condition themselves, participants appear to have learned a self-reliance under threat, not an individual trait - one that resurfaces later, in Theme 6, as hypervigilance.

Beyond information failures, participants experienced active dismissal and stigma. This took two main forms: assumptions that AP was alcohol-caused and disbelief that patients' symptoms or pain were real. Both left participants feeling judged and unable to advocate for themselves. Some faced persistent assumptions about alcohol use. "*I felt I had to justify myself... I said I have the occasional glass of wine with friends, and he said 'alcohol friends are not good friends, they will persuade you to have more alcohol.' My friend was with me and I said, 'well, I have a glass of wine*

with this friend and she's brought me to hospital.' …But he was definitely being very judgmental, he clearly didn't believe me" (P13). Alcohol-related assumptions were not only imposed by others but also internalised. P11, whose AP was later attributed to gallstones, initially blamed herself: *"I was immediately questioning myself because I thought I've had cocktails and I've had champagne for my birthday... and I've maybe just gone overboard."* She later reflected: *"I felt I've done this to myself... when actually it wasn't that, it was my gallbladder and there was nothing I could do about it."* This suggests that repeated cultural and clinical associations between AP and alcohol shaped participants' own causal beliefs, prompting self-blame even where the medical facts did not support it.

Others experienced disbelief of their symptoms. One participant described: "*I was very gaslighted by consultants... They'd wake me up and say 'you weren't in pain when I first walked in but now you're rolling around in agony'... The amount of eye rolls I'd have from people because they didn't know what was wrong"* (P09). This dismissal left participants feeling powerless, unable to secure pain relief or care when their own account of their body was not believed. This may explain why peer support later felt validating: participants needed confirmation from others that their pain and experience were real, having had this denied by clinicians.

However, when communication was effective and compassionate, the impact was powerfully positive. One explained: "*I didn't feel judged... I felt loved and supported. I wrote copious letters to the hospital afterwards... telling them what a difference their compassionate care made"* (P14). One participant described how thoughtful explanation empowered them: "*The consultant said 'I just want you to draw on your strength so that when we ask you, you understand the reason why you have to do it' and that really stayed with me, it was really quite powerful"* (P12). This stands in contrast to the powerlessness and fragmented sense-making described earlier: participants who received compassionate communication made sense of their illness with staff, rather than alone, and felt more in control as a result.

This highlights communication's dual potential: staff could either compound patients' loss of control and self-doubt through dismissal and stigma, or support their sense of control through honest explanation and compassion.

Theme 4: Navigating a system post-discharge where pathways are unclear or often don't exist

Most participants faced an abrupt and poorly coordinated transition from intensive hospital support to minimal or nonexistent post-discharge care. The contrast was sharp, from continuous

monitoring in hospital to little guidance, follow-up or access to support at home. Without a clear care pathway, participants were left to navigate recovery without professional help.

The lack of follow-up was pervasive. One described: "*I didn't have any aftercare, I found it a bit weird. I didn't have a follow up appointment... kind of exploded out of hospital that day... 'right, you're going home'... having no safety net felt very hard because there was no follow up*" (P07). The 'safety net' metaphor captures a sudden, complete withdrawal of hospital monitoring before participants' own capacity to manage recovery had caught up. This left them uncertain whether problems would be caught before becoming serious, extending the uncertainty described in Theme 3 into the post-discharge period. Beyond physical monitoring, psychological support was equally absent: "*There was nobody there to talk to me about that...no, it wasn't even hinted that it would be necessary"* (P14). For those who did access trauma therapy, it was typically self-initiated rather than routinely provided. This likely meant support depended on whether a patient recognised their own distress as significant enough to warrant help, leaving those less able to name or advocate for it without support.

Information and guidance were equally absent. One participant captured the void: "*An absolute empty black hole of information, support, psychological support,* cognitive in terms of informative, you know, giving you information" (P14). Dietary guidance was particularly inadequate. One recalled: "*We begged, we actually begged to see a dietician... we could not get no one and sort of explain what sort of diet I can have. Little things but it meant a lot to us"* (P02). Another was told simply: "*Keep eating low fat food. That was all I was told"*(P10).

Participants also had to navigate this system with little support. One explained: "*I had to think to myself, I need to be really assertive here... I actually need to stick up for myself"* (P11). Some paid privately to access the care they needed: "*I paid to consult with a pancreatic dietitian"* (P13). The same participant described being discharged without adequate pain management: *"They were just going to send me home with liquid food... I said I need to be able to manage the pain at home... then they sent me home with some [painkillers] that I've not tried in hospital"* (P13). Being seriously unwell usually carries an expectation of being cared for; here, that expectation was reversed. Participants had to become assertive advocates for their own care, sometimes at direct financial cost, while still recovering. This is a forced return to responsibility before they had the physical or emotional resources to carry it.

This reveals a fragmented system where pathways existed in hospital but disappeared post-discharge. Whereas dismissal in hospital left some participants unable to advocate for themselves,

the absence of post-discharge pathways forced them to self-advocate when they were least equipped to do so.

Theme 5: Adjusting to the new normal: learning what can be helpful and unhelpful

Participants had to learn to navigate life after AP largely on their own, making proactive changes to prevent recurrence while managing the impact on identity, relationships and work. Without adequate professional guidance, they learned through trial and error what helped and what did not.

Many adopted healthier habits to prevent recurrence, extending to vigilant self-monitoring and self-experimentation with diet. Without adequate professional support, participants became researchers of their own bodies: "I mean from trial and error... I worked out that I could have 5 to 8 grammes of fat... but I could tolerate that without having the Creon"(P13). This experimentation might look like taking charge of their own care, but it was forced, not chosen. Getting the dosage or diet wrong meant real physical consequences, and without knowing which changes were helping, uncertainty became part of every ordinary decision.

In the absence of professional support, participants independently found peer communities through local peer support groups or Facebook groups and information through sites such as Guts UK. Whilst peer support provided validation: "*Reading other people's experiences did help me because I thought I was going mad... because they're telling me, you know, just have this experiment... So I'd experiment... and then I'd be ill. But I do know that most people can't have normal fats in their diet just from reading about it"* (P13), it also exposed participants to frightening possibilities: "*I need to step out of that community because I'm seeing too many stories of people having more than one episode of AP or developing chronic pancreatitis... and I think that's probably fuelling my anxiety about if this thing going to come back"* (P07). This shows the risk of peer support having to fill a gap that should have been clinical guidance; it gave people validation, but also advice, like 'just experiment,' that did not work for everyone.

AP created a paradox in family relationships. Participants needed support but felt guilty for burdening loved ones: "*I'm just nothing but trouble for my wife. She can't enjoy life now"* (P03). Another could not share their experience: "*I felt like I couldn't talk to them about what it had felt like to go through that because it was so obviously, I had put them through it as well. I disappeared from their lives"* (P07). Protecting family through silence came at a cost. It left participants without the one thing that might have helped: someone who truly understood what they were going through.

AP fundamentally changed participants' sense of self. This was not simply about physical limitations but a fundamental identity rupture: "*I felt there was the pre pancreatic [name] and the post pancreatic [name]"* (P14). P14 did not describe feeling different. She described a pre and post version of herself, as if a boundary had been drawn between them, capturing how sudden and total the change initially felt. Participants grieved the loss of spontaneity: "*It's a permanent denial of freedom... just the simple freedoms of life to go out and choose anything from the menu and have a glass of wine"* (P07).

Work was disrupted, affecting income, professional identity and daily structure. Some returned to work prematurely: "*I went back to work... I thought well, I need to work, I need to earn money"* (P12). This risked compromising recovery itself, and potentially reinforced the sense, seen elsewhere in this theme, of a body that could not be trusted or fully relied on. Others lost career opportunities: "*Nobody would employ me now... I could have probably got consultancy work... earning about three times more...it's affected my quality of life"* (P03). Unlike P12's delayed return, P03's loss was permanent. This echoes P14's sense of AP creating a genuinely different person, not a temporarily limited one.

Adjusting to life after AP meant learning what helped, peer validation, family support, and what did not, isolation, anxiety-provoking comparisons, premature return to work. What distinguishes adaptation to AP is that participants had to take on roles normally held by professionals, acting as their own dietitian, clinician and risk manager, without being able to tell whether it was working.

Theme 6: Psychological aftermath: Processing trauma, living with fear of recurrence and finding resilience

Participants faced ongoing psychological consequences during and after their physical recovery from AP.

The fear of AP returning was persistent and pervasive. One participant described: "*It sits on my shoulder all the time. It's such a scary, traumatic, horrendous, painful, disrupting time in my life. And I'm always waiting for it to come back. It doesn't organise me completely. And I try to organise it, but it's there"* (P14). Because AP had come without a clear cause, and with early signs that were easy to miss, participants could not be sure when they were safe. Precautions such as avoiding alcohol or cutting down on fat offered no guarantee, so the fear stayed constant. Physical sensations triggered worry with small pains becoming potential warnings: *"I still have pains, you know, and I still feel, oh, gosh, I better not do anything, I better not have, you know... And it just terrifies me that I*

don't want to push anything. I don't want to find myself in that situation again" (P11). This hypervigilance extended to worries about developing CP or pancreatic cancer. Watching for warning signs offered some sense of control, but it also kept attention on the body, so ordinary sensations kept feeding the fear.

Participants felt their bodies betrayed them, leaving them feeling fragile and unsafe. One described: *"The physical sensation, I felt very unsafe. I didn't trust my own body and very, very weak as well"* (P09). Without expert guidance, participants did not receive the reassurance that would normally tell them a sensation was harmless, so they had no way of checking their own judgement of their bodies.

Many experienced trauma symptoms including flashbacks, nightmares, and intrusive memories. One described: *"I started to feel really traumatised by things. I'd have flashbacks, I'd have nightmares. I couldn't get my head around everything that had happened because it was so frightening... because, you know, I nearly died, I could have died... I just find it really, really difficult"* (P12). Another believed she experienced PTSD: *"My sleep was disturbed... it was like I was outside my body. Sometimes I felt I was not an integrated whole person"* (P14). These symptoms reflect the ongoing psychological impact of life-threatening illness.

Participants also described periods of low mood and loss of hope after leaving hospital. One recalled: *"I couldn't see where things were going... I'd probably had thoughts of this just isn't worth going on"* (P01). With no one explaining what recovery would involve or how long it would take, he had no picture of a way forward, and hope faded. Retrospectively, many participants often described the psychological impact as becoming more apparent once physical recovery had progressed.

Despite ongoing challenges, many participants developed acceptance and positive reappraisal. One explained: "*A wake up call can be really good in some ways... do I need to go to work for 70 hours a week? Probably not at the moment. That's not going to be the best thing for me, for my health"* (P07). Another described deep gratitude: *"The Pancreatitis has enriched what was already good... the Pancreatitis has enriched my awareness of how lucky I am, I am lucky to be alive"* (P14). Acceptance did not replace distress: P14's gratitude came alongside the constant fear and trauma symptoms she described above. For some participants, the life-threatening experience itself prompted them to rethink how they lived and what mattered.

Discussion

This study explored the psychological experiences of people hospitalised with AP, from symptom onset through recovery. These findings suggest that AP creates profound psychological suffering that extends well beyond physical recovery, with systemic gaps in recognition, communication, pain management and continuity of care compounding this suffering.

Previous research has documented patient delays in recognising AP severity. Ma et al. (2022) found that patients often failed to recognise disease severity, leading to delays in seeking care. Boije et al. (2019) found that the sudden transition from being healthy to facing a life-threatening condition was a significant source of stress for patients, who described the experience as shocking and surreal. Su et al. (2024) reported that lack of disease knowledge contributed to fear and anxiety during acute episodes. However, this study shows how provider misdiagnosis compounds the problem, revealing a pattern of dual misrecognition where both patients and providers failed to recognise AP, creating delays whilst the condition rapidly deteriorated. Unlike conditions such as heart attack where symptoms are widely recognised by both public and clinicians, AP presents with non-specific symptoms that can be easily dismissed or misattributed. The rapid progression from dismissible symptoms to life-threatening crisis within hours meant participants had no time to mentally adjust or understand what was happening, intensifying the psychological impact.

Whilst psychological distress during AP hospitalisation has been documented broadly (Ma et al., 2022; Su et al., 2024), the specific psychological impact of uncontrolled pain alongside environmental chaos and loss of dignity has not previously been examined in the qualitative literature. This study reveals that pain management failures did not occur in isolation but alongside chaotic ward conditions and loss of dignity through physical dependence on staff for intimate care and physical weakness that prevented advocacy. This highlights the need for public health education about AP warning signs and clinical education ensuring that A&E staff recognise AP as a differential diagnosis for acute abdominal pain. Improving care requires addressing pain management, ward environments and maintaining dignity through sensitive personal care as simultaneous rather than isolated priorities.

Beyond pain and environmental challenges, some participants described assumptions from healthcare staff that AP was alcohol-caused, despite actual aetiology being unknown or non-alcohol-related, creating feelings of blame and self-doubt. Stigma from healthcare workers has been

reported previously by Kessler et al. (2025) across three countries and the current study confirms these findings within a UK context, adding further evidence that alcohol-related stigma from clinicians may be present across different healthcare systems.

The persistence of alcohol assumptions despite unknown aetiology may reflect implicit biases among healthcare professionals. FitzGerald and Hurst (2017) found that healthcare professionals commonly hold unconscious biases about substance use that adversely affect their interactions with patients, which may explain the automatic alcohol associations and stigmatising encounters observed in this study. Corrigan et al. (2012) describe how exposure to stigmatising assumptions can lead individuals to internalise blame and shame, a pattern reflected in participants' accounts. This suggests staff education about the multiple causes of AP and training in non-stigmatising communication are important priorities.

Su et al. (2024) found that AP patients used unofficial sources including internet resources, family, and friends to obtain disease information, expressing a desire for professional medical guidance during their diagnosis and treatment. This study supports these findings whilst adding an important dimension, where some patients faced not just information gaps but active dismissal, with staff expressing disbelief about symptom severity through dismissive comments. In contrast, when communication was compassionate and informative, participants described it as empowering rather than frightening. Research demonstrates that effective clinical communication affects health outcomes beyond information provision, providing emotional support that can reduce distress and improve patient experience (McCabe, 2004; Street et al., 2009). This suggests that communication training for AP care should emphasise emotional support and validation alongside clear information.

Previous research has documented the absence of adequate post-discharge support in AP, with patients reporting feeling alone and unsupported following discharge (Boije et al., 2019), experiencing insecurity due to insufficient information (Gunic et al., 2026) and expressing a clear need for ongoing clinical support to reduce recurrence risk (Su et al., 2024).. The current study supports these findings and reveals their severity in the UK context. Despite experiencing life-threatening illness, uncontrolled pain, loss of dignity, stigmatisation and in some cases ICU delirium, no participants were routinely offered psychological support. Those who eventually accessed trauma therapy did so through self-referral, often long after discharge. These gaps likely reflect systemic resource limitations and underdeveloped post-discharge pathways for AP rather than individual staff failures. Structured discharge pathways could include timely specialist follow-up, dietitian access, clear written information and routine psychological screening (McGuire et al., 2022). Given the lack of dedicated psychology provision for people with AP, existing staff such as nurses could be

supported to screen for distress and signpost patients to relevant services, with psychologists from other departments or services offering training and consultation. People with more significant difficulties, such as the trauma symptoms described above, would still need direct psychological input.

Without adequate professional support, participants sought peer communities primarily through online Facebook groups. This study is the first qualitative study of AP to examine the role of peer support, revealing its dual nature. Whilst peer communities provided crucial validation that participants' experiences were real and common, exposure to stories of disease progression sometimes increased rather than reduced anxiety. This suggests that AP-specific peer support groups may better serve patients' needs by preventing anxiety-provoking comparisons whilst maintaining validation benefits. Healthcare providers could facilitate access to appropriately matched peer support rather than leaving patients to navigate this alone.

The experience of AP extended beyond hospitalisation to fundamentally reshape participants' sense of self and daily life. Participants described a profound identity rupture, grieving the loss of spontaneity and freedom whilst navigating the demands of a new illness identity alongside previous roles at work and within their families. These findings can be understood through CSM of illness self-regulation (Leventhal et al., 1980; Hagger and Orbell, 2022), whereby patients develop beliefs about cause, consequences and controllability that shape their emotional and behavioural responses. In AP, the unpredictable nature of the illness made it difficult to develop a stable illness identity or feel in control, contributing to guilt and self-blame when self-management efforts failed.

Persistent fear of recurrence was the most pervasive ongoing challenge following discharge. Fear of recurrence has been documented across previous AP qualitative studies (Ma et al., 2022; Boije et al., 2019; Su et al., 2024). Ma et al. (2022) reported that 46% of patients feared relapse, whilst patients with idiopathic AP experienced particular anxiety related to not knowing the cause of their illness (Boije et al., 2019). This study confirms these patterns and extends them by showing how uncertainty about aetiology intensifies fear beyond what has previously been described. Even participants with identified causes such as gallstones worried about unknown additional factors that might trigger future episodes, suggesting that uncertainty fuels ongoing anxiety regardless of whether a cause has been identified.

These findings align closely with Mishel's (1988) uncertainty in illness theory, which identifies unclear aetiology, unpredictable prognosis, limited information and fragmented care as

key drivers of uncertainty. In AP, the absence of a clear explanatory framework left participants unable to make sense of their experience or feel confident about their future, sustaining hypervigilance long after physical recovery. Addressing uncertainty directly through clear information about recurrence risk and prevention strategies may therefore be as important as addressing physical symptoms.

Over half of participants required ICU care, experiencing hallucinations, memory fragmentation and altered consciousness. McGuire et al. (2022) documented high PTSD risk in necrotising pancreatitis requiring critical care and the current study supports these findings, with many participants describing flashbacks, nightmares and intrusive memories consistent with trauma symptoms. One participant described experiences suggestive of suicidal ideation, highlighting the importance of routine psychological screening following discharge.

However, alongside trauma and fear, participants also demonstrated resilience and post-traumatic growth (PTG), describing fundamental shifts in priorities and life enrichment through awareness of mortality. These findings are consistent with PTG theory (Tedeschi and Calhoun, 1996), which describes positive psychological change emerging from highly challenging life experiences. Ma et al. (2022) noted similar patterns of resilience in AP though research in this area remains limited. Psychological support should therefore assess individual experiences rather than assume uniform negative outcomes, supporting both trauma processing and the integration of growth and meaning.

Strengths and Limitations

To the best of the author's knowledge, this is the first UK-based qualitative study exploring the psychological experiences of people hospitalised with AP. Whilst existing qualitative studies have examined aspects of the AP experience, such as recovery (Boije et al., 2019), psychological experiences during hospitalisation (Ma et al., 2022), transitions from hospital to home (Gunic et al., 2026) and health literacy needs (Su et al., 2024), most were conducted outside the UK and focused on specific phases of the illness journey rather than the experience as a whole. The present study is distinctive in capturing participants' experiences across the full trajectory from onset through hospitalisation to recovery within a UK context, offering a more complete picture of the psychological impact of AP over time.

Participants were recruited through two peer support groups rather than through clinical settings as in previous studies. Whilst this meant findings may not fully represent the broader AP population, it captured the experiences of those whose support needs had not been fully met through healthcare, which is itself an important finding. The role of peer support in AP has not

previously been examined qualitatively, and the experiences of stigma and alcohol-related assumptions, whilst noted by Kessler et al. (2025), have not been examined within a UK context prior to this study.

Several limitations should be noted. The study was conducted within a UK context and findings may not be fully transferable to healthcare systems with different structures or cultural approaches to AP care. RTA necessarily involves researcher interpretation and different analysts might identify different themes. To enhance rigour, this study followed established Braun and Clarke (2022) guidelines throughout and the researcher maintained a reflexive journal to support ongoing critical self-reflection. Participants were recruited after recovery rather than during acute illness and the time elapsed between hospitalisation and participation varied across individuals, introducing the possibility of recall bias, though the vivid detail with which participants described their experiences suggests memories remained strong. The sample was predominantly White British, with limited ethnic diversity, which may limit the transferability of findings to more diverse populations. Illness severity was not formally verified using the Revised Atlanta Classification or medical records and no distinction was made between mild, moderate and severe or necrotising AP, limiting the ability to draw conclusions about whether psychological experiences differed according to disease severity. Finally, member checking and returning transcripts to participants were not undertaken, which is acknowledged as a limitation of the study.

Future Research

Several important areas warrant further investigation. Future research should seek to recruit more ethnically diverse samples to better understand how cultural context shapes the psychological experience of AP. The perspectives of family members and carers, identified as important sources of support in this study, were outside the scope of the current research and should be explored in future qualitative work. Examining psychological experiences across different levels of disease severity, including severe and necrotising AP separately, would provide a more nuanced understanding of how illness trajectory shapes psychological outcomes. Whilst this study identifies significant psychological burden, no psychological interventions specifically designed for AP patients were identified in the literature. Development and evaluation of targeted psychological support for this population represents an important priority.

Conclusion

AP creates profound psychological impact extending well beyond physical recovery. Key findings include dual misrecognition by both patients and providers, stigma from healthcare professionals, post-discharge care gaps, the dual nature of peer support and clear links between uncertainty and fear of recurrence. These findings align with Mishel's (1988) uncertainty in illness theory and the CSM (Leventhal et al., 1980; Hagger and Orbell, 2022), providing a theoretically grounded framework for understanding psychological distress in AP beyond symptom burden alone. Addressing these findings requires systemic changes including staff education to reduce stigma and improve communication, structured discharge pathways with psychological screening and support, and facilitated access to appropriate peer support. Without dedicated psychology provision for people with AP, existing staff could be supported to screen for distress and signpost to services, with psychologists from other departments offering training and consultation. Recognising the full scope of psychological suffering is essential for improving care for people experiencing this serious and underrecognised condition.

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Chapter Five: Empirical Paper Extended Methodology

This chapter expands on the Method section of the empirical paper, providing detailed discussion of the study's philosophical foundations, methodological decisions and reflexivity.

Ontology and Epistemology

Research is guided by philosophical assumptions about reality and knowledge. Ontology concerns what is considered real and what exists. Epistemology concerns how we can know about reality and what counts as valid evidence. It is often argued that ontology precedes epistemology, given that assumptions about reality inform how knowledge is generated (Boswell & Babchuk, 2023).

This research adopted a critical realist position. Critical realism combines a realist ontology with a relativistic epistemology (Stutchbury, 2021). Ontologically, critical realism views reality as existing at three interconnected levels (Tikly, 2015). The first level comprises what individuals directly observe and experience. The second level consists of events and phenomena that occur regardless of whether they are observed. The third level encompasses the underlying mechanisms and structures that cause observable events. In this study, acute pancreatitis (AP) operates at all three levels: as a real biological condition with causal mechanisms (inflammation, organ damage) that produce observable events (hospitalisation, pain) experienced by participants.

Epistemologically, critical realism recognises that our understanding of reality is mediated by subjective interpretation and social construction (Stutchbury, 2021). Whilst AP exists as an objective phenomenon, how people experience and make sense of it is shaped by their social contexts, cultural backgrounds and available frameworks for understanding illness. Therefore, participants' accounts reveal their subjective experiences of a real phenomenon.

Critical realism is compatible with RTA, which does not prescribe a specific epistemological position (Braun & Clarke, 2006, 2019). These ontological and epistemological assumptions shaped methodological decisions throughout the research. Consistent with critical realism's recognition that knowledge is shaped by interpretation and context, data were coded by the primary researcher with supervisor review of developing themes, rather than seeking inter-rater reliability which would be inappropriate given the epistemological stance (Braun & Clarke, 2022). A reflexive diary was maintained throughout data collection and analysis to examine how the researcher's own assumptions and emotional responses influenced interpretation.

Rationale for Methodology

Rationale for Reflexive Thematic Analysis (RTA)

RTA as outlined by Braun and Clarke (2022) was selected over other qualitative approaches for several reasons. RTA is explicitly compatible with critical realism (Braun & Clarke, 2022), allowing analysis of both semantic content and latent meanings. This aligned with the study's aim to understand both participants' experiences and the broader healthcare and social contexts shaping these experiences. RTA is a flexible method not tied to specific theoretical frameworks (Braun & Clarke, 2022). Given the limited existing research on psychological experiences of AP, this flexibility was essential, allowing me to construct themes inductively from participants' accounts rather than testing predetermined theoretical frameworks.

Alternative approaches were considered. Interpretative Phenomenological Analysis (IPA) was not selected because its idiographic commitment to in-depth analysis of small samples (typically 3-6 participants) was less suited to this study's aims. The research sought to identify patterns across a larger sample (n = 14) and to consider social and systemic factors shaping experiences, rather than focusing exclusively on individual phenomenology. Grounded Theory's goal of developing explanatory theory through theoretical sampling and constant comparison was not the primary aim; the study sought to explore and describe psychological experiences rather than generate formal theory. Framework Analysis typically begins with predetermined theoretical frameworks or policy questions. Given the exploratory nature of this research and the absence of existing frameworks specific to AP, a more inductive approach was required.

Rationale for Semi-Structured Interviews

Semi-structured interviews were important given that participants' experiences varied. Some had experienced intensive care admissions with fragmented memories, whilst others had shorter hospital stays with clearer recollection. The flexibility allowed the researcher to adapt questioning to individual circumstances whilst ensuring key topics were covered across all interviews. The semi-structured interview guide is provided in Appendix C.

Rationale for Individual Rather Than Joint Interviews

The decision to conduct individual rather than joint interviews came from Public and Patient Involvement (PPI) activities and ethical considerations. During the PPI meeting, which included two people who had experienced AP and one spouse, participants raised the value of including family members' perspectives, citing concerns about memory gaps from intensive care admissions.

Following supervision discussion, the decision was made to focus on individual interviews for several reasons. The study aimed to understand patients' own psychological experiences; joint interviews risked prioritising relational dynamics over individual experiences. Participants might feel unable to discuss certain topics (e.g., relationship strain, feelings of burden, private fears) with partners present, potentially limiting the depth and honesty of their accounts. One participant who initially requested his wife's presence due to memory concerns subsequently recalled significant detail during his individual interview, suggesting the request may have reflected a need for emotional support rather than memory assistance. The importance of family perspectives was acknowledged and identified as an important area for future research.

In practice, flexibility was maintained where appropriate. One participant with reading and writing difficulties had his wife present for support, but she did not participate or answer questions. This was agreed in supervision and clearly explained to both parties beforehand.

Ethical Considerations

Ethical Approval

The study received ethical approval from the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee (ETH2425-0438; see Appendix D). NHS ethics approval was not required because participants were recruited through peer support groups rather than NHS services and the study was not conducted on NHS premises.

Informed Consent

All participants were fully informed about the research prior to participation. Each participant received a Participant Information Sheet and Consent Form detailing the voluntary nature of participation, the right to withdraw at any point until transcription and analysis were complete and procedures for ensuring confidentiality and anonymity. Participants were given at least one week to review these materials before interviews, with contact information provided for questions or concerns. Prior to each interview, participants verbally confirmed their consent, with the researcher explicitly checking understanding of voluntary participation, the right to decline specific questions, and the right to stop the interview at any time. All interviews were audio or video recorded only with explicit participant permission.

Confidentiality and Anonymity

Participant confidentiality was maintained throughout the research process. All recordings and transcripts were securely stored and encrypted, with access limited to the lead researcher and research supervisor. Interviews were transcribed verbatim, with all identifying information removed during transcription. Participants were assigned pseudonyms and any references to specific hospitals, locations, clinicians, or other identifying details were removed or anonymised in transcripts. In accordance with the BPS Code of Human Research Ethics (2021), all data are stored securely and will be retained for 10 years following completion and publication, following University of East Anglia Research Data Management Policy (UEA, 2022). Participants were informed that confidentiality would be maintained except where necessary to manage risk. No such situations arose during the research.

Participant Wellbeing

Given the sensitive nature of the research, several measures were implemented to protect participant wellbeing. Participants were informed in advance that some interview questions might evoke distressing memories. They were reminded at the beginning of each interview that they could decline to answer any question, pause the interview, or terminate it at any time without explanation. All participants were provided with information about mental health support services, including contact details for Samaritans, Mind, and Guts UK Charity, as well as guidance to contact their GP or emergency services if needed. The lead researcher remained alert to signs of distress during interviews. Whilst some participants became emotional when discussing particularly difficult experiences, none requested to stop or pause interviews. Several participants stated they valued the opportunity to share their experiences and appreciated having someone listen to them.

When one participant contacted the researcher whilst still hospitalised following an AP episode, ethical concerns arose about her readiness to participate. The researcher responded by emphasising the importance of physical and emotional recovery before participation, encouraging her to make contact post-discharge if she still felt ready. This was discussed in supervision before an interview was arranged following her discharge and confirmation of readiness. The interview subsequently went ahead with no concerns arising during or after.

Researcher Wellbeing

The interviews involved discussing sensitive and distressing content, including experiences of severe pain, near-death experiences, intensive care hallucinations and feelings of being let down by healthcare services. To protect the lead researcher's emotional wellbeing, several strategies were implemented. A reflexive diary was maintained throughout data collection and analysis, providing

space to document and process emotional responses to participants' accounts. Regular supervision meetings provided opportunities to debrief after emotionally difficult interviews and discuss emerging emotional responses. Supervision also provided space to reflect on how emotional responses might be influencing data collection and analysis. The lead researcher had access to University of East Anglia wellbeing services if additional support were needed, though this was not utilised. Following completion of interviews, the researcher reflected on the cumulative emotional impact and the need for adequate processing time before beginning transcription and analysis.

Peer Support Group Recruitment

Peer support group recruitment was chosen for several reasons. Members had already shown willingness to discuss their experiences with others, suggesting they might be comfortable participating in research interviews. The group provided an existing community context where research could be introduced in a supportive, non-clinical setting. Recruiting through peer support groups rather than NHS services meant NHS ethics approval was not required, simplifying the ethical approval process whilst maintaining ethical rigour through University ethics procedures.

A potential ethical concern was that peer support group members might feel pressured to participate due to group dynamics or social expectations. Several steps were taken to mitigate this risk. The lead researcher introduced the study in person, allowing potential participants to ask questions before deciding whether to participate. Study materials (Poster, Participant Information Sheet, and Consent Form; see Appendices E, F, G) were provided via email one week prior to this meeting, giving members time to review materials privately without immediate group pressure. During the introduction, the voluntary nature of participation was explicitly emphasised, with clear statements that there was no obligation to take part and that declining would not affect their support from the peer group. In practice, there was no evidence of coercion; participants were genuinely eager to share their experiences, with several expressing gratitude for the opportunity to contribute to research. A limitation of recruiting through peer support groups was the potential to attract individuals who were more engaged or motivated to share their experiences, which may have introduced an element of sampling bias.

Facebook Group Recruitment

Response to Facebook recruitment was substantial and rapid. Within days of posting, numerous individuals expressed interest, highlighting the strong desire among AP patients to share their experiences. This aligns with observations during interviews that many participants felt their voices had not been heard by healthcare professionals and valued the opportunity to contribute to

research that might improve future care. Similarly to peer support group recruitment, Facebook recruitment may have captured those more motivated to share their experiences, which should be considered when interpreting findings.

Sample Size

Data saturation was initially considered to guide recruitment, but it fits poorly with RTA, where meaning is produced through the researcher's interpretation, not discovered in the data (Braun & Clarke, 2021). Sample size was instead guided by information power (Malterud et al., 2016). I judged the sample sufficient once the interviews were rich enough to address the research aims, a decision made during data collection.

Data Collection

Prior to each interview, participants completed a demographics questionnaire to provide background information about their AP history, age, gender and ethnicity (see Appendix H). No notable differences emerged in interview quality or depth between face-to-face and online formats. The flexibility of online interviews may have increased accessibility for participants who would have found travel difficult due to ongoing fatigue or other post-pancreatitis limitations.

Reflexivity

Positioning as Researcher

As a trainee clinical psychologist with an interest in health psychology, I approached this research without personal experience of AP and I had not worked with AP patients in clinical practice prior to this research. This positioning had both advantages and limitations. The absence of personal experience with AP meant I approached participants' accounts with curiosity rather than assumptions about what the experience "should" be like. My clinical psychology training provided interviewing skills, comfort discussing emotional content and awareness of psychological concepts that might inform analysis. However, my clinical background also risked inadvertently adopting a therapeutic rather than research stance during interviews, requiring attention to maintaining appropriate boundaries.

My positioning as a researcher was also shaped by personal and cultural factors. As a Greek person living in the UK for eight years, my views about healthcare systems have been shaped by experiences of both Greek and UK healthcare. Whilst I initially perceived the NHS as more organised than Greek public healthcare, over time I became aware of gaps in NHS care, particularly around preventative care, patient-clinician communication and quick access to care. These observations

may have influenced my emotional responses to participants' accounts of inadequate care. These observations, combined with personal values around justice, fairness, and equitable access to quality care, likely influenced my emotional responses to participants' accounts of inadequate care and may have heightened my sensitivity to healthcare system failures.

Emotional Impact and Influence on Analysis

The research had a profound emotional impact that began during the first interviews and intensified throughout data collection and analysis. After completing all interviews, I reflected:

> *"It has been a week since I completed the interviews and reflecting back, I realise that at the end of most of them, I was left with a heavy feeling. That weight lingered. Recently, I had a dream that I had AP, I woke up terrified. I have been trying to understand why that dream shook me so much and I think it's connected to the fear I absorbed from the participants. It's not just their stories, it's how I imagined myself in their place." (Reflexive Diary, 14/07/2025).*

The unpredictable, sudden onset of AP described by participants, often in previously healthy individuals, may have challenged my sense of control over my own health, triggering anxiety about personal vulnerability to similar sudden, life-threatening illness. This fear was compounded by participants' descriptions of inadequate healthcare responses, heightening my sense of vulnerability not only to illness itself but to potential failings in care should I or loved ones require emergency treatment.

During analysis, emotional responses continued. Reading one participant's account, I noted:

> *"When I read this, it honestly makes me feel scared. It sounds like he didn't have good care, and imagining myself in that position feels horrible. I also feel frustrated because he had almost no support, especially after discharge, and that leaves me feeling uneasy about how vulnerable he must have felt. It is hard not to respond emotionally when the experience sounds so overwhelming and isolating." (Reflexive Diary, 22/11/2025).*

Another entry notes:

> *"I feel I get drawn into the horror of people's experiences, and I think part of me is reacting to the fear of poor care if something similar ever happened to me" (Reflexive Diary, 29/11/2025).*

Perhaps the most powerful response was a sense of obligation to participants and desire to bring justice to their experiences.

> *"As soon as I came in contact with people face to face from peer support and people online and they were talking about how difficult their stories were I felt I had an obligation to make their voices heard. I think what stuck with me was that they felt forgotten due to the lack of follow up care and I felt I had to bring justice to that I had to fight for them I wanted to show them that there is someone here that hears them"* (Reflexive Diary, *20/07/2025).*

This sense of obligation was intensified by participants' explicit gratitude:

> *"Several participants told me they were grateful for the opportunity to be part of this research. I get the sense that many feel their voices have not been heard by professionals" (Reflexive Diary, 07/07/2025).*

Whilst advocacy and research are distinct roles, my commitment to my personal values of fairness and equitable access to care shaped both my emotional responses and my determination to ensure participants' voices were heard.

These emotional responses inevitably influenced the analytical process. My frustration with inadequate care may have heightened my attention to themes around healthcare system failures, potentially leading me to emphasise these aspects more strongly in the Discussion. Conversely, my focus on suffering may have risked underemphasising the positive experiences some participants reported, such as excellent specialist care or successful recovery.

I remained conscious of these potential biases throughout analysis. To mitigate their influence, I deliberately coded positive experiences and successful coping strategies alongside accounts of suffering. During theme development, I regularly questioned whether themes accurately reflected the range of participants' experiences or were disproportionately weighted toward distressing content. When uncertainty arose about whether a theme was data-driven or emotion-driven, I returned to transcripts to re-examine what participants actually said, using their words rather than my interpretations as the primary guide. Supervision discussions provided external perspective, challenging me to ensure analytical claims remained grounded in data rather than driven by emotional responses.

Rather than attempting to eliminate emotional responses- which would be neither possible nor desirable- the approach involved acknowledging them, examining their potential influence and using this awareness to inform rather than distort analysis.

Trustworthiness of the Empirical Study

Quality and rigour in this study were assessed using Lincoln and Guba's (1985) framework for trustworthiness in qualitative research. This framework evaluates credibility, transferability, dependability, and confirmability.

Credibility

Credibility concerns whether findings are trustworthy and reflect participants' realities. Several strategies enhanced credibility in this study.

Thematic analysis was initially proposed as the analytical approach. Following engagement with Braun and Clarke's work (2019, 2022), RTA was adopted as it aligned more closely with the study's critical realist epistemology. An inductive approach was used in which codes were developed from the data rather than using a predetermined codebook (Braun & Clarke, 2022). All interviews were transcribed verbatim using NVivo 15 software. Familiarisation involved listening and re-listening to audio recordings and reading and re-reading transcripts multiple times before beginning coding. Interviews lasted 30-80 minutes and the interview guide was flexible, allowing participants to focus on what mattered most to them.

The results section provides detailed descriptions of themes supported by extracts, allowing readers to assess the fit between data and interpretation. A reflexive diary was maintained throughout all stages to document potential biases and emotional responses.

Regular supervision meetings (every other week) provided opportunities to discuss developing themes and test interpretations against data. The supervisor reviewed theme development and data extracts where needed. Whilst this did not constitute independent coding or inter-rater reliability checks which are inconsistent with RTA principles (Braun & Clarke, 2022) it provided peer review that enhanced credibility. Working with one supervisor rather than a supervisory team meant analytical perspectives were more limited; however, this consistency supported coherent development of interpretations. PPI members, including peer support group members and an Accident & Emergency consultant, reviewed study materials and provided feedback on study design decisions.

Transferability

Transferability concerns whether findings are applicable to other settings or populations. Participants were recruited through convenience sampling from a peer support group and a Facebook group, resulting in 14 participants from across the UK. The sample included eight females and six males, achieving better gender balance than previous qualitative studies of AP which have

predominantly recruited male participants. Detailed demographic information was provided. The results section provides detailed accounts of participants' experiences with sufficient context to allow readers to assess whether findings might be relevant to other AP populations, other critical illness contexts or other healthcare systems.

Dependability

Dependability concerns the consistency of findings and whether the research process can be tracked and followed. An audit trail was maintained throughout the study. The reflexive diary documented research decisions and the analytical process at each stage. NVivo files recorded the development of codes, code clusters and themes over time. The initial thematic framework developed prior to supervisory discussion and the finalised thematic framework following supervision are provided in Appendices I and J, supporting transparency of the analytical process. Supervision notes documented discussions about methodological and analytical decisions, including decisions about participant inclusion. Transparent reporting of the methodology in this chapter allows others to follow the research process from data collection through analysis to final themes.

Confirmability

Confirmability concerns the degree to which findings are shaped by participants' experiences rather than researcher bias. The audit trail described above supports confirmability by demonstrating how themes were developed from data. The reflexive diary documented instances where the researcher's assumptions or emotional responses risked influencing interpretation and these were addressed through supervision and returning to the data. The results section includes extensive extracts that allow readers to assess whether interpretations are grounded in what participants said. Regular supervision provided external review of whether analytical claims were supported by data extracts. An analytical challenge arose in distinguishing between experiences specific to acute pancreatitis and those reflecting broader patterns in critical illness. This was resolved by focusing on how participants themselves framed their experiences, ensuring interpretations remained grounded in their accounts rather than imposed assumptions about what was unique to AP.

Chapter Six: General Discussion and Critical Evaluation

This final chapter brings together the findings from the systematic review and empirical paper. It discusses their combined contribution to the existing literature, considers the strengths and limitations of both studies and outlines the implications for clinical practice and future research. The primary researcher's reflections on the research process are also included.

Researcher's Reflexivity

The existing literature on the psychological components of acute pancreatitis (AP) has been predominantly quantitative, focusing on rates of anxiety, depression and quality of life. Whilst this provides valuable epidemiological data, it offers limited insight into how patients actually experience and make sense of their illness. Despite a small number of qualitative studies beginning to explore patients' experiences, their findings remained fragmented and no UK-based qualitative study existed. This thesis portfolio therefore aimed to address this gap by synthesising the existing qualitative evidence through a systematic review and conducting the first UK-based qualitative study exploring the psychological experience of AP.

Engaging with participants' accounts in the empirical paper and with the qualitative literature in the systematic review, reinforced how significantly the psychological impact of AP has been overlooked in both research and clinical practice. Patients described suffering that extended well beyond physical recovery, yet psychological support was rarely offered or available. This highlighted the importance of integrating psychological care into AP care from diagnosis through to recovery.

As a trainee clinical psychologist with an interest in health psychology but no personal experience of AP, I approached both studies with curiosity about patients' experiences whilst remaining aware that my clinical background could lead to over-privileging psychological interpretations. Maintaining a reflexive journal throughout data collection and analysis helped me remain conscious of this and regular supervision provided an important space to reflect on analytical decisions throughout the process.

Reflecting more deeply on my positioning, I am aware that my identity as a researcher shaped not only how I engaged with the data but how I interpreted it. As a Greek woman who has lived in the UK for eight years, I grew up within a culture where food holds important social and relational significance, alcohol is embedded in social and cultural life. Family roles have been traditionally defined, with caregiving often falling to women. These cultural frameworks are not

neutral. When participants described guilt about burdening family members, self-blame around diet and alcohol, or the loss of freedom to eat and socialise as before, I may have been particularly attuned to the weight of these experiences, having grown up in a context where such obligations feel familiar. I cannot be certain whether this sensitivity enriched my interpretation or risked over-emphasising these themes. Being a woman may also have shaped how I interpreted experiences of feeling unheard and dismissed in healthcare. I may have been particularly attuned to accounts of pain being minimised and dignity being compromised, which could have influenced how I weighted these themes in the empirical paper. Whilst I am aware this attunement may have led me to privilege these accounts, I believe it also allowed me to recognise their significance. Beyond my gender and cultural background, having no personal experience of AP was both an advantage and a limitation. It allowed analytical distance and genuine curiosity, but also required ongoing reflexivity to avoid misinterpreting the embodied suffering participants described. Throughout both studies, supervision provided a critical space to examine how my assumptions were shaping interpretation. Many hours were spent turning the data over, questioning whether analytical decisions were driven by the data or by my own emotional responses, and ensuring that the voices of participants remained central rather than filtered through my own lens.

Summary of Findings

The systematic review synthesised qualitative evidence from seven studies exploring the lived experience of adults hospitalised with AP or recurrent acute pancreatitis (RAP). Four analytical themes were identified: living under the shadow of uncertainty, the weight of responsibility but never feeling in control, navigating transitions in recovery whilst feeling unprepared and unsupported, and adaptation, resilience and reappraisal in the midst of suffering. Together these themes revealed significant psychological distress from onset through to recovery, driven by persistent uncertainty, a tension between feeling responsible for the illness whilst feeling unable to control it and significant gaps in care during the transition from hospital to home. Alongside this burden, many patients demonstrated resilience, reappraised life priorities and found hope even in the midst of significant suffering.

The empirical paper explored the psychological experiences of fourteen adults hospitalised with AP in the UK, from symptom onset through to recovery. Six themes were identified: from health to crisis, when physical suffering meets chaotic hospital care, when communication helps and when it harms, navigating a system post-discharge where pathways are unclear or often do not exist, adjusting to the new normal and psychological aftermath. These themes revealed a profound physical and psychological burden extending well beyond the acute episode. These were shaped by

delayed recognition of AP by both patients and healthcare providers, inadequate pain management, communication failures including stigmatising assumptions about alcohol use, significant post-discharge care gaps and persistent fear of recurrence and trauma symptoms. Despite these challenges, many participants demonstrated resilience and post-traumatic growth, with family and peer support playing an important role in recovery.

Combined Discussion

Across the portfolio the findings revealed significant psychological distress in adults hospitalised with AP, extending well beyond physical recovery. Uncertainty, fear of recurrence, poor discharge planning, communication failures and stigma were consistent findings across both studies. Alongside this burden, resilience, positive reappraisal and the importance of family support were also identified consistently across both studies.

The empirical paper added several important findings not captured in the SR literature. The pre-hospital experience of dual misrecognition, where both patients and healthcare providers failed to recognise AP early leading to delays whilst the condition rapidly deteriorated, was not captured in any of the SR studies. The acute inpatient experience was explored in greater depth, including chaotic ward environments, loss of dignity and the disorienting experience of ICU admission, which was particularly prominent given that over half of the participants interviewed required intensive care. Trauma symptoms including flashbacks, nightmares and PTSD-like experiences were more explicitly captured in the empirical paper than in the SR literature. The role of peer support, including its double-edged nature in providing validation whilst simultaneously generating anxiety about disease progression, was entirely absent from the SR literature. Finally, the empirical paper confirmed stigmatising assumptions from clinicians, as reported by Kessler et al. (2025), and extended these findings within a UK context. From a theoretical lens these findings matter. This is because they demonstrate that psychological distress in AP is not a sole consequence of physical severity. The findings show that it is fundamentally shaped by the interaction between uncertainty, perceived responsibility, and lack of control across the duration of the illness. These findings move our understanding of AP from a predominantly medical condition to a biopsychosocial one, where making meaning, stigma, and systemic care experiences should be seen as central to patient outcomes.

Uncertainty was identified as a central finding across both studies, from the sudden onset of an unfamiliar and unexplained illness through to the persistent fear of recurrence and disease progression following discharge. In the systematic review, uncertainty shaped patients' experiences

across all seven studies, whilst in the empirical paper participants described not knowing why AP had happened, not understanding what was occurring during hospitalisation and living with ongoing fear of recurrence after discharge. These findings are consistent with Mishel's (1988) uncertainty in illness theory. This identifies unclear aetiology, unpredictable prognosis, limited information and fragmented care as key sources of uncertainty. Each of these features was strongly reflected across both studies. Importantly, the empirical paper extended this further by showing how uncertainty began before hospitalisation, with participants dismissing early symptoms. It also persisted long after discharge, with participants describing hypervigilance and trauma symptoms, suggesting it remained present across the entire illness journey."

Closely related to uncertainty was the tension between feeling responsible for causing AP and preventing recurrence, whilst feeling unable to control the course of the illness. This was evident across both studies, though the systematic review captured this tension more prominently, particularly in the Chinese studies where cultural obligations around food and alcohol made behaviour change feel impossible despite patients understanding the consequences. Furthermore, variations in cultural healthcare systems, particularly in relation to accessing follow-up care, patient to clinician communication, and expectations of family involvement, may also shape how patients experience control, support, and recovery. These findings can be understood through the Common Sense Model of Illness Self-Regulation (CSM; Leventhal et al., 1980; Hagger & Orbell, 2022), whereby patients developed beliefs about cause, consequences and controllability alongside strong emotional responses including fear, guilt and shame. When recurrence happened despite their efforts, self-blame and guilt were significant, consistent with evidence linking self-blame in physical illness to depressive symptoms and a sense of personal failure (Bennett et al., 2013; Beverly et al., 2012). Whilst cultural obligations were less prominent in the empirical paper, loss of control and autonomy were particularly acute during hospitalisation, compounded by inadequate pain management, loss of dignity and in many cases the disorienting experience of ICU admission.

Stigma was present across both studies, with patients assumed to be alcoholic by healthcare workers regardless of their actual diagnosis. The empirical paper confirmed these findings within a UK context, extending those reported by Kessler et al. (2025). Corrigan et al. (2012) describe how exposure to stigmatising assumptions can lead individuals to internalise blame and shame, a pattern reflected across both studies. Importantly, stigma was not experienced in isolation but interacted with the self-blame and guilt already present, compounding patients' psychological distress.

Gaps in care during the transition from hospital to home were consistently reported across both studies. Patients left hospital without clear information, a coordinated discharge plan or

adequate follow-up, leaving them to navigate a demanding and non-linear recovery alone. This was particularly significant given that AP patients are at greatest risk of developing new mental health disorders in the months immediately following discharge (Khoja et al., 2023). In the empirical paper this was described as an absence of structured information and coordinated support, with participants having to self-advocate, experiment with diet independently and in some cases pay privately for basic support such as dietitian consultations. Communication failures during hospitalisation compounded these difficulties, ranging from inconsistent and fragmented information to active dismissal of symptoms, both of which were captured across both studies.

Despite the significant burden described above, resilience, positive reappraisal and adaptation occurred alongside suffering in both studies. Patients described reappraising life values and priorities, developing new relationships with food and lifestyle and in some cases reaching a peaceful acceptance of mortality. These findings are consistent with post-traumatic growth (PTG; Tedeschi & Calhoun, 1996), which describes positive psychological change emerging from highly challenging life experiences. However, these positive responses were not universal and appeared to be shaped by access to support and resources, suggesting that PTG in this context may reflect structural factors as much as individual resilience. Family support played an important role in recovery across both studies, though it was not always available or consistent, reinforcing the importance of professional follow-up and peer support beyond discharge.

Strengths and Limitations

Both studies were conducted using transparent and well-established methods. The systematic review was prospectively registered on PROSPERO and conducted in accordance with PRISMA and ENTREQ guidelines, with second reviewer involvement at screening and quality appraisal stages. The empirical paper followed Braun and Clarke's (2022) reflexive thematic analysis framework, with rigour established through reflexive journalling, regular supervisory review and close adherence to established guidelines throughout.

The main limitation of the systematic review was the predominance of Chinese studies, which raises questions about the transferability of findings to UK and other Western healthcare contexts. Given cultural differences around alcohol norms, healthcare systems and the role of family, the applicability of findings to these contexts should be treated with caution The empirical paper directly addresses this by providing the first UK-based qualitative data on the psychological experience of AP. It confirmed several SR findings whilst adding important dimensions not captured

in the existing literature, including the acute inpatient experience, peer support and trauma symptoms.

Recruitment source is both a strength and a limitation of the empirical paper. Recruiting through support groups reached participants who had actively sought peer connection following their illness, suggesting their needs had not been fully met through healthcare and may have facilitated more open accounts of their experiences. However, it may not fully represent the broader AP population, as those who do not seek peer support may have had different experiences, or there might have been bias towards those displaying more help seeking behaviours and engaging with the research. This is an important consideration when interpreting the findings.

In terms of gender, the SR literature was predominantly male. This limits understanding of potential gender differences in psychological experience. The empirical paper addressed this more successfully, with slightly more female than male participants. Ethnic diversity was limited across both studies, with the empirical paper sample being predominantly White British and ethnicity was rarely reported across SR studies, limiting the transferability of findings to more diverse populations.

Finally, the empirical paper focused on AP only, whilst the SR included RAP. The psychological experience of recurrent disease therefore remains underexplored in primary qualitative research and warrants further investigation.

Implications for Clinical Practice and Services

The findings of this portfolio highlight the importance of recognising and addressing the psychological impact of AP alongside its physical management, across the entire illness trajectory from onset through to recovery.

Both studies highlighted that AP was poorly recognised, by patients who dismissed early symptoms and by healthcare providers who misdiagnosed the condition. Public health education about the warning signs of AP and clinical education ensuring that emergency department and primary care staff recognise AP as a differential diagnosis for acute abdominal pain are therefore important priorities, particularly given the speed at which the condition can become critical.

Once hospitalised, patients faced multiple simultaneous challenges that compounded their suffering. Pain management, ward environments, dignity and autonomy all require attention. Some patients described pain so severe it felt unbearable despite maximum medication and ward conditions that prevented rest during critical illness. Maintaining dignity through sensitive personal

care and ensuring patients retain a voice in decisions about their care, even when physically weak, are essential components of compassionate AP care.

Communication was identified as a key theme across both studies, ranging from stigmatising assumptions about alcohol use to active dismissal of symptoms and inconsistent information. Staff education about the multiple causes of AP and training in non-stigmatising, compassionate communication are therefore important priorities, consistent with NICE (2020) guidance cautioning against assuming AP is alcohol related. When communication was compassionate and informative, it made a meaningful difference to patients' experiences, suggesting that communication training should emphasise emotional support and validation alongside clear information provision.

Both studies highlighted significant gaps in care following discharge. Patients left hospital without clear information, dietary guidance, coordinated follow-up or psychological support. Structured discharge pathways for AP should include timely specialist follow-up, access to dietitians with AP expertise, clear written information about recurrence risk and prevention strategies and routine psychological screening. NICE (2020) guidelines emphasise the importance of comprehensive information and psychological support for AP patients, yet the findings of this portfolio suggest this is rarely achieved in practice.

Delivering integrated psychological support does not require an AP specific psychology pathway, which would be unrealistic given the lack of dedicated psychology provision for people with AP. Nurses and other clinicians could be supported to screen for distress and signpost patients to relevant services, which would address the lack of psychological support reported in both studies. Psychologists already working in other departments or services could offer training, consultation and supervision to staff, for example in non-stigmatising communication and clear information-giving. This would likely have low financial implications, making it more feasible to implement. People with more significant difficulties, such as persistent fear of recurrence or trauma symptoms, would still need direct psychological input, which the routine screening recommended above could help identify.

Finally, peer support played an important and complex role in recovery in the empirical paper. Whilst peer communities provided validation and practical information, exposure to stories of disease progression sometimes increased rather than reduced anxiety. Healthcare providers could facilitate access to appropriately matched peer support, for example AP-specific groups rather than broader pancreatitis communities, rather than leaving patients to navigate this alone.

Implications for Future Research

This portfolio identifies several important gaps warranting further investigation. The empirical paper represents the first UK-based qualitative study of the psychological experience of AP, but further research in UK settings is needed, including exploration of the role of peer support and alcohol-related stigma in shaping patients' experiences of care. The SR highlighted that most existing qualitative studies were conducted in Chinese healthcare contexts and future research should explore whether findings translate to other Western healthcare settings where cultural norms around alcohol, food, social obligation and healthcare systems may differ.

Both studies lacked ethnic diversity and future research should seek to recruit more ethnically diverse samples to better understand how cultural context shapes the psychological experience of AP. Future research should also ensure adequate representation of women to better understand any potential gender differences in psychological experience.

Whilst some studies captured aspects of the inpatient experience, most existing qualitative research has focused on recovery. Further research examining psychological experiences during hospitalisation, including the impact of ICU admission, would therefore add to the existing literature. The psychological experience of RAP also remains underexplored in primary qualitative research, with only two SR studies focusing specifically on recurrent disease.

Family members and carers were identified as important sources of support across both studies, yet their perspectives were absent from the qualitative literature. Future research should include family member and/or carer perspectives to better understand the relational impact of AP and the support needs of those around the patient.

Finally, whilst both studies identified significant psychological burden, no psychological interventions specifically designed for AP patients were identified in the literature. Development and evaluation of targeted psychological support for this population represents an important priority, informed by the findings of this portfolio.

Conclusion

This portfolio presents the first thematic synthesis of qualitative evidence on the psychological experience of adults hospitalised with AP or RAP and the first UK-based qualitative study in this area. Together, the two studies reveal significant psychological distress extending well beyond physical recovery, shaped by uncertainty, loss of control, stigma, communication failures and gaps in care. Alongside this burden, many patients demonstrated resilience and positive reappraisal.

Uncertainty and perceived control were identified as central processes across both studies, providing a theoretically grounded framework for understanding psychological distress in AP beyond symptom burden alone. The findings suggest that the failure to integrate psychological care into AP care represents a critical gap in current healthcare provision, rather than an optional enhancement to existing services. Further research and the development of targeted psychological interventions for this population represent important next steps.

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Appendices

Appendix A. Journal of Health Psychology: Author Guidelines

Retrieved from https://journals.sagepub.com/author-instructions/HPQ (June 2026)

Your article must be within the scope of the journal and be of sufficient quality. If not, it will not be reviewed. Please read the journal's Aims and Scope to see if your article is appropriate.

Due to the volume of submissions, your submission may be recommended for transfer to other Sage journals rather than be reviewed.

The manuscript must be your original work, you must have the rights to the work, and you must have obtained and be able to supply all necessary permissions for the reproduction of any copyright works not owned by you, including figures, illustrations, tables, lengthy quotations, or other material previously published elsewhere.

Article types

(a) Full-length Reports on empirical studies. The word limit including the reference list and tables/figures for this article type is a maximum of 8,000 words.

(b) Rapid Reports on empirical studies. The word limit including the reference list and tables/figures for this article type is a maximum of 4,000 words.

(c) Review Articles including systematic reviews, narrative reviews, and theoretical contributions. The word limit including the reference list and tables/figures for this article type is a maximum of 8,000 words.

(d) Mini-reviews focusing on emerging topics. The word limit including the reference list and tables/figures for this article type is a maximum of 4,000 words. Mini-reviews can apply any approach to literature reviewing, including a systematic review approach that results in a small body of literature being included.

(e) Commissioned Editorials that have been approved in advance by the Editors (email hpq@sagepub.com with formal enquiries). This article type is typically reserved for introducing special issues or special collections. The word limit including the reference list and tables/figures for this article type is 3,000 words.

The total word limit for each article type also includes the abstract, which itself **must not** exceed 150 words. **Abstracts must be unstructured (i.e., no subheadings are required).** The abstract text must

be included in the main manuscript file. Word limits **do not** cover any supplementary materials included with the article.

Exemptions to the word limit including the reference list and tables/figures are not routinely granted. Any request for exemptions should be given in the cover letter at the time of submission and are only granted in exceptional circumstances. In most cases, supplementary files can be used to communicate additional aspects of relevance such as more detailed protocols, additional tables/figures, or secondary analyses.

Preregistration of Studies and Analysis Plans

Researchers conducting experimental studies are encouraged to pre-register your research design, variables, treatment conditions, and an analysis plan in an independent, institutional registry (e.g., http://clinicaltrials.gov/). Including an analysis plan involves specification of sequence of analyses or the statistical model that will be reported.

For preregistered studies, the following requirements apply:

1. The authors must, in acknowledgments or the first footnote, indicate that research was preregistered in an independent, institutional registry (with name and link to its location) with an analysis plan;

2. The authors must also:

a. Confirm in the text that the study was registered prior to conducting the research with links to the time-stamped preregistration(s) at the institutional registry, and that the preregistration adheres to the disclosure requirements of the institutional registry or those required for the preregistered badge with analysis plans maintained by the Center for Open Science.

b. Report all pre-registered analyses in the text, or, if there were changes in the analysis plan following preregistration, those changes must be disclosed with explanation for the changes clearly distinguish in text analyses that were preregistered from those that were not, such as having separate sections in the results for confirmatory and exploratory analyses (these changes are added as a separate document linked to the text of the main paper)

Clinical trial registration

The journal conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first participant enrollment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

Reporting guidelines

Your manuscript **must** follow the relevant EQUATOR Network reporting guidelines, depending on the type of study. The EQUATOR wizard can help identify the appropriate guideline. You will need to upload the appropriate checklist with your submission.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives.

If your research involves animals, you will be asked to confirm that you have carefully read and adhered to the ARRIVE guidelines.

Formatting your manuscript

Accepted file types

The preferred format for your manuscript is Word. You do not need to follow a template, but please ensure your heading levels are clear, and the sections clearly defined.

The LaTeX files are also accepted. A LaTeX template is available on the Sage Journal Author Gateway.

Your article title, keywords, and abstract all contribute to its position in search engine results, directly affecting the number of people who see your work. For details of what you can do to influence this, visit How to help readers find your article online.

Title

Your manuscript's title should be concise, descriptive, unambiguous, accurate, and reflect the precise contents of the manuscript. A descriptive title that includes the topic of the manuscript makes an article more findable in the major indexing services.

Abstract

Please include an unstructured abstract of 150 words between the title and main body of your manuscript that concisely states the purpose of the research, major findings, and conclusions. Submissions that do not meet this requirement will not be considered.

For clinical trials, the trial registry name and URL, and registration number must be included at the end of the abstract.

Keywords

Please include a minimum of 5 keywords, listed after the abstract. Keywords should be as specific as possible to the research topic.

Artwork, figures, and other graphics

For guidance on the preparation of illustrations, pictures, and graphs in electronic format, please read Sage's artwork guidelines.

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To ensure fair and anonymous peer review, your manuscript must be fully anonymized. Please ensure any identifying information is removed from the main manuscript document and included on the Title Page instead. Do not include any author names in the manuscript file name and remove names from headers and footers. This version of the manuscript **will** be sent to the peer reviewers. The Title Page **will not** be sent to peer reviewers. See the Sage Journal Author Gateway for detailed guidance on making an anonymous submission.

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    - **All persons eligible for authorship must be included at the time of submission (please see the authorship section for more information)**.
- Contact information for the corresponding author: name, institutional address, phone, email
- Acknowledgments section
- Declaration of conflicting interest
- Funding statement
- Ethical approval and informed consent statements
- Data availability statement

- Any other identifying information related to the authors and/or their institutions, funders, approval committees, etc, that might compromise anonymity.

Acknowledgments

If you are including an Acknowledgements section, this will be published at the end of your article. The Acknowledgments section should include all contributors who do not meet the criteria for authorship. Per ICMJE recommendations, it is best practice to obtain consent from non-author contributors who you are acknowledging in your manuscript.

Writing assistance and third party submissions: if you have received any writing or editing assistance from a third-party, for example a specialist communications company, this must be clearly stated in the Acknowledgements section and in the covering letter. Please see the Sage Author Gateway for what information to include in your Acknowledgements section. If your submission is being made on your behalf by someone who is not listed as an author, for example the third-party who provided writing/editing assistance, you must state this in the Acknowledgements and also in your covering letter. **Please note that the journal editor reserves the right to not consider submissions made by a third party rather than by the author/s themselves.**

Author contributions

You will be asked to list the contribution of each author as part of the submission process. Please include the Author Contributions heading within your submission after the Acknowledgements section. The information you give on submission will then show under the Author Contributions heading later at the proofing stage.

Statements and declarations

To ensure proper anonymization, please include a section with the heading 'Statements and Declarations' on your title page, after the Acknowledgements section [and Author Contributions section if applicable] including each of the sub-headings listed below. If a declaration is not applicable to your submission, you must still include the heading and state 'Not applicable' underneath. Please note that you may be asked to justify why a declaration was not applicable to your submission by the Editorial Office. This information will be added to the end of your published paper.

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Please include your ethics approval statements under this heading, even if you have already included ethics approval information in your methods section. If ethical approval was not required, you need

to explicitly state this. You can find information on what to say in your ethical statements as well as example statements on our Publication ethics and research integrity policies page.

All papers reporting studies involving human participants, human data or human tissue must state that the relevant Ethics Committee or Institutional Review Board approved the study, or waived the requirement for approval, providing the full name and institution of the review committee in addition to the approval number. If applicable, please also include this information in the Methods section of your manuscript.

Consent to participate

Please include any participant consent information under this heading and state whether informed consent to participate was written or verbal. If the requirement for informed consent to participate has been waived by the relevant Ethics Committee or Institutional Review Board (i.e. where it has been deemed that consent would be impossible or impracticable to obtain), please state this. If this is not applicable to your manuscript, please state 'Not applicable' in this section. More information and example statements can be found on our Publication ethics and research integrity policies page.

Consent for publication

Submissions containing any data from an individual person (including individual details, images or videos) must include a statement confirming that informed consent for publication was provided by the participant(s) or a legally authorized representative. Non-essential identifying details should be omitted. Please do not submit the participant's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent to publish but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file in addition to the statement confirming that consent to publish was obtained within the manuscript text. If this is not applicable to your manuscript, please state 'Not applicable' in this section.

Declaration of conflicting interest

The journal requires a declaration of conflicting interests from all authors so that a statement can be included in your article. For guidance on conflict of interest statements, see our policy on conflicting interest declarations and the ICMJE recommendations.

If no conflict exists, your statement should read: 'The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article'.

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Every in-text citation must have a corresponding citation in the reference list and vice versa. Corresponding citations must have identical spelling and year.

Authors should update any references to preprints when a peer reviewed version is made available, to cite the published research. Citations to preprints are otherwise discouraged.

Appendix B. Psychology, Health & Medicine: Author Guidelines

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Preparing Your Paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

Article Types

Research Article

- Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should be no more than 7000 words.
- Should contain an unstructured abstract of 300 words.
- Should contain between 3 and 8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

Method

- Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; author contributions statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).
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- Author Contributions Statement: Please provide an author contributions statement at the end of your article, before the references, that outlines which author(s) were involved in the conception and design, or analysis and interpretation of the data; the drafting of the paper, revising it critically for intellectual content; and the final approval of the version to be published; and that all authors agree to be accountable for all aspects of the work.
- Further information about this article type: Methods articles are a medium length, peer-reviewed article type that describes an advancement or development of current methods and research procedures. These should include adequate and appropriate validation to be considered. Any datasets associated with the paper must publish all experimental controls and make full datasets available where possible. If there are concerns about identifying factors in datasets, these should be discussed with the Editor-in-Chief prior to submission.
- Please note, that authors submitting protocol and methodology articles have the option to share their methods on protocols.io. Please note, this is not required for submission but is encouraged.

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- Should contain between 3 and 6 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
- Data notes are a short peer-reviewed article type that concisely describe research data (dataset) stored in a repository, prior to submission. Data notes do not include any interpretation or conclusion of the data (see preparing your paper). Data notes should only describe the data. The dataset of Data notes can be either original (not previously published), or be issued from a published research article as long as the datasets have not already been published.
- The recommendations for the **title page** and **abstract** of Data Notes and Research Articles are the same. See above section for details.
- **Key policy highlights** (3 to 5 in total) should have approximately 100 words, which set out the main findings of the paper that are of specific relevance to policy makers. These key policy highlights should be presented as a bulleted list of concise but complete sentences. They form part of the submission and will be published below the academic abstract.

- **Introduction**: This should explain the rationale, the objective and the importance for creating the dataset(s).
- **Materials and Methods** section should provide the full and detailed procedure description, as a separate text document which should be uploaded together with the data to the data repository. The full methods description must be sufficiently detailed to allow others to reproduce the data.
- **Data description**: This section should be purely descriptive and not offer an interpretation of the data. Authors should refer to all data files and datasets that have been deposited in adequate **repositories** .
- **Author Contributions statement**: This outlines which author(s) were involved in the conception and design, or analysis and interpretation of the data; the drafting of the paper, revising it critically for intellectual content; and the final approval of the version to be published; and that all authors agree to be accountable for all aspects of the work.
- **Data availability statement**: This statement tells the reader where the research data associated with a paper is available, and under what conditions the data can be accessed. They also include links (where applicable) to the data set.
- **References**: Acceptable sources that can be cited in the reference section include published or accepted articles and preprint manuscripts with a citable DOI or arXiv URL

Review Article

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- Should contain an unstructured abstract of 300 words.
- Should contain between 3 and 8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

Image Descriptions

This journal now adds image descriptions (alternative text, alt text), to all images conveying information necessary for an understanding of your work. Image descriptions are typically used by systems such as pronouncing screen readers to make images accessible to people that cannot read or see the object due to a visual disability. Image descriptions can also provide better image context/descriptions to search engines, helping them to index an image properly and improve the discoverability of your research.

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Note that, regardless of the file format of the original submission, an editable version of the article must be supplied at the revision stage.

Appendix C. Semi structured Interview Guide

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Topic Guide

When did you experience your first episode of Acute Pancreatitis?

Can you describe your experience of being hospitalized for Acute Pancreatitis?

- What were your thoughts and feelings?
- What was your experience like during your hospital stay?
- Do you recall how long your hospital stay was?
- If you spent time in the Intensive Care Unit (ICU) during your hospital stay, can you describe what that experience was like?
- What did your healthcare providers tell you about the potential causes of your condition? How did you feel about the information they shared? Did you have any regular updates in simple language about your care ?/ Were things explained to you in simple language ?
- Were there any specific moments that were particularly challenging or comforting?
- How did you manage your emotions during this time?
- Did you receive any psychological support?
- Could you tell me if you were taking any medications for other health conditions at the time of your hospital stay?

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- Have you had any treatment for depression or anxiety, such as medication or therapy?

Can you describe your experience after being discharged from the hospital?

- Were there any challenges you faced once you were back home?
- Did you have any follow-up appointments or continued medical care?
- Were you prescribed or recommended any specific medications or therapies to aid in your recovery?

How has your recovery process been since your discharge?

Have you experienced any long-term psychological effects?

How has your episode of Acute Pancreatitis affected your overall quality of life?

- How has this experience impacted your relationships with family and friends?
- Have you noticed any changes in your mental health, such as increased anxiety or depression?

Have you used any strategies to cope with the psychological impact of Acute Pancreatitis?

- If yes, what were they and did you find any of them helpful?
- Have you engaged in any support groups or therapy sessions?
- How has your support network (family, friends, healthcare providers) helped you?

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Based on your experience, are there any specific services or resources you wish had been available to you?

- If yes, what would they be?
- Are there any changes you would recommend for future patients?

Concluding questions

- Is there anything else you would like to share about your experience that we haven't covered?
- Do you have any questions for me about the study or the interview process?

Appendix D. Ethics Approval Letter

University of East Anglia
Norwich Research Park
Norwich. NR4 7TJ

Email: ethicsmonitor@uea.ac.uk
Web: www.uea.ac.uk

Study title: Stories from the Forgotten Patients: A Qualitative Study Exploring the Psychological Experiences of Patients Diagnosed with Acute Pancreatitis.

Application ID: ETH2425-0438

Dear Theoni,

Your application was considered on 30th January 2025 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

The decision is: **approved**.

You are therefore able to start your project subject to any other necessary approvals being given.

If your study involves NHS staff and facilities, you will require Health Research Authority (HRA) governance approval before you can start this project (even though you did not require NHS-REC ethics approval). Please consult the HRA webpage about the application required, which is submitted through the IRAS system.

This approval will expire on **30th September 2026**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.

It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).

Please can you send your report once your project is completed to the FMH S-REC (fmh.ethics@uea.ac.uk).

I would like to wish you every success with your project.

On behalf of the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee)

Yours sincerely,

Dr Paul Linsley

Appendix E. Study Poster

University of East Anglia

PARTICIPANTS NEEDED



Have you had Acute Pancreatitis?

We need your help to understand the psychological experiences of people who have been diagnosed with Acute Pancreatitis and hospitilised for it.

Can I participate?

You can participate if you..

- Have had an episode of Acute Pancreatitis that required hospitalisation.
- Have not been diagnosed with Chronic Pancreatitis, and Pancreatic cancer.
- Are aged 18+.
- Are able to communicate in English.
- Are currently living in the UK.

What does the study involve?

Participants will either:

- Attend an interview (approximately 60 minutes), which can be conducted in person or online,

OR

- Complete an online survey (approximately 10 minutes).

If you would like to get involved in the important study or would like more information about it please contact me:

Theoni Kyriazopoulou

Email: Theoni.Kyriazopoulou@uea.ac.uk

Enter a draw to win one of three £20 prizes!

Appendix F. Participant Information Sheet

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Participant Information Sheet

A Study Exploring Experiences of Acute Pancreatitis Requiring Hospitalisation

I would like to invite you to take part in a research study. Before you decide, I would like to explain why the research is being carried out and what it will involve. Please read the following information and take time to decide whether or not you wish to take part. Ask us if there is anything that is not clear or if you would like more information. Thank you for reading this.

1. What is the purpose of the study?

This study aims to explore the experience of people who have been diagnosed with acute pancreatitis and were hospitalised for it.

2. Why have I been invited?

You have been invited because you may have experienced an episode of acute pancreatitis requiring hospitalization, and the researcher is interested in discussing your experience as part of this study. The study aims to include between 12 and 15 participants.

3. Do I have to take part?
No. Taking part in this study is entirely voluntary. You can choose not to participate or withdraw from the study at any time up to the point of analysis without providing a reason.

4. What will happen if I take part?

If you agree to participate, the researcher will contact you to confirm your availability and arrange either an online or face-to-face interview. The discussion will focus on your hospital experience and recovery from acute pancreatitis and will last up to 60 minutes.

5. What will the meeting be like?

The researcher is interested in hearing about your own experience. You are welcome to discuss as much or as little as you wish, and any topics you prefer not to discuss will be respected.

6. Can I withdraw if I change my mind?

Yes. You can withdraw from the study at any time up to the point of analysis, and your data will be removed. After analysis, withdrawal will no longer be possible, as the data will have been processed and included in the study findings. If you choose to withdraw, this will not affect your future medical care or your ability to participate in other research studies.

7. Will my data be anonymous and kept confidential?

All data will be treated as confidential and pseudonymised. This means your identity will be replaced with a unique code, and the link between your name and this code will be securely stored in a separate file. If you disclose any information that suggests a current risk to yourself or others, the researcher has a duty of care to inform the relevant services. Your

discussion will be recorded, transcribed, and securely stored. You may request a copy of your transcript if desired.

8. How will my data be stored and used?

All research data will be securely stored and retained for 10 years after the study's completion and publication, following University of East Anglia (UEA)'s Research Data Management Policy (2022). Data will only be used for this study and not shared with third parties.

In compliance with the Data Protection Act 2018 and GDPR, data will be stored securely in UEA's OneDrive system, which is protected by multi-factor (security) authentication. Access will be limited to the researcher, Theoni Kyriazopoulou (Trainee Clinical Psychologist, UEA Clinical Psychology Doctorate programme), and her supervisors:

- **Dr Sophie Oakes-Rogers**: Clinical Psychologist, Mental Health Liaison Service, Norfolk and Norwich University Hospital.
- **Dr John Davies**: Clinical Psychologist, Mental Health Liaison Service, Norfolk and Norwich University Hospital.
- **Dr Adrian Leddy**: Clinical Associate Professor, UEA Clinical Psychology Doctorate programme.

9. Are there any risks to taking part?

Discussing your experience of acute pancreatitis may evoke emotional responses. If you feel distressed at any time during the interview, you are free to pause or stop without explanation. I will address any concerns or distress at the end of the session to ensure you feel supported.

If you experience distress, you can access support through:

- **Samaritans**: Call 116 123 (Free, 24/7) or visit www.samaritans.org.
- **Mind**: Call 0300 123 3393 or visit www.mind.org.uk.
- **Guts UK**: Visit www.gutscharity.org.uk.
- **Crisis Text Line**: Text "SHOUT" to 85258 (Free, 24/7).
- **GP or Emergency Services**: Contact your GP, or call 999 in a crisis.

These resources will also be provided in the debrief.

10. What are the possible benefits of taking part?

Participating allows you to share your experience and contribute to better understanding of acute pancreatitis.

As a token of appreciation, you may enter a draw to win one of three £20 prizes. Your contact details for the prize draw will be kept separate from your study data.

11. What will happen to the results of the study?

The information collected will be written up and potentially published in a journal. Your discussion may be quoted in the article, but you will not be identified personally. If you are interested in finding out about the results from the study, you can request a summary to be sent to you.

12. Will participating in the study cost me any money?

You have the option to attend the interview either online or face-to-face. If you opt for a face-to-face interview at UEA, you can claim back any parking costs.

13. Complaints

If you have any further concerns about any aspect of the study, please contact my supervisor Dr Adrian Leddy (Clinical Associate Professor, UEA Clinical Psychology Doctorate programme) on a.leddy@uea.ac.uk. We will try to resolve any complaint or concern raised within the research team. However, if you feel your concern has not been addressed satisfactorily, please contact Dr Peter Beazley (Deputy Programme Director, UEA Clinical Psychology Doctorate programme) on p.beazley@uea.ac.uk.

14. Who is organising and funding the research?

This research is organised by Theoni Kyriazopoulou (Trainee Clinical Psychologist, UEA Clinical Psychology Doctorate programme) and Dr Sophie Oakes-Rogers (Clinical Psychologist, Mental Health Liaison Service, Norfolk and Norwich University Hospital) and Dr John Davies (Clinical Psychologist, Mental Health Liaison Service, Norfolk and Norwich University Hospital). It is funded by the University of East Anglia Doctoral Programme in Clinical Psychology.

15. Who do I contact if I have questions about the study?

If you have any questions you would like to discuss before or after your participation in the study, please speak to the researcher (Theoni Kyriazopoulou) or her supervisors (Dr Sophie Oakes-Rogers, Dr John Davies or Dr Adrian Leddy) who will do their best to support you with any queries:

- Theoni Kyriazopoulou, Trainee Clinical Psychologist (study researcher), UEA Clinical Psychology Doctorate programme, T.Kyriazopoulou@uea.ac.uk
- Dr Sophie Oakes-Rogers, Clinical Psychologist, Mental Health Liaison Service, Norfolk and Norwich University Hospital, s.oakes-rogers@nsft.nhs.uk
- Dr John Davies, Clinical Psychologist, Mental Health Liaison Service, Norfolk and Norwich University Hospital, john.davies@nsft.nhs.uk
- Dr Adrian Leddy, Clinical Associate Professor in Clinical Psychology, UEA Clinical Psychology Doctorate programme, a.leddy@uea.ac.uk

Appendix G. Consent Form

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Participant Consent Form

Title of the project: A Study Exploring Experiences of Acute Pancreatitis Requiring Hospitalization

Researchers and contact details:

Theoni Kyriazopoulou, Trainee Clinical Psychologist, UEA Clinical Psychology Doctorate programme, T.Kyriazopoulou@uea.ac.uk

Dr Sophie Oakes-Rogers, Clinical Psychologist, Mental Health Liaison Service, Norfolk and Norwich University Hospital, s.oakes-rogers@nsft.nhs.uk

Dr John Davies, Clinical Psychologist, Mental Health Liaison Service, Norfolk and Norwich University Hospital, john.davies@nsft.nhs.uk

Dr Adrian Leddy, Clinical Associate Professor in Clinical Psychology, UEA Clinical Psychology Doctorate programme, a.leddy@uea.ac.uk

Statements of Understanding:

Please initial each box and sign/print your name at the bottom if you agree to participate.

1. I confirm that I have read and understood the participant information sheet for the above study. I have had the opportunity to consider the information, ask questions and have received satisfactory answers.

☐

2. I understand that participation in this study is voluntary, and I can withdraw at any time up to the point of analysis, and my data will be removed. After analysis, withdrawal will not be possible as the data would have been processed into study findings. Withdrawal will not affect my future medical care or participation in other research studies.

☐

3. I understand that my interview will be recorded using the audio or video recording function in Microsoft Teams, and I give my consent for this.

☐

4. I understand that my data will be securely stored in UEA's OneDrive system, protected by multi-factor (security) authentication, and retained for 10 years after the

University of East Anglia

study's completion date. Data will only be used for this study, will not be shared with third parties, and will be accessible only to the researcher and her supervisors.

☐

5. I understand that should I disclose any information that raises concerns about my safety or the safety of other people, the researcher has a duty of care to inform the relevant services.

☐

6. I understand and agree that quotes from my interview may be used in research reports and publications, with all data pseudonymised to ensure my confidentiality. Any identifying information will be removed, and my identity will not be disclosed.

☐

7. I agree to take part in the above study.

☐

Name of research participant: _____

Signature: _____

Date: _____

Name of researcher: Theoni Kyriazopoulou

Signature of principal investigator _____

Date_____

Appendix H. Demographics Questionnaire

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Demographic Information

Thank you for volunteering to participate in the above study. Please fill in the demographic information requested below.

Participant pseudonymised code:

1) What is your age?

2) What is your gender?

() Male

() Female

() Prefer not to say

() Other (Please specify):

3) What is your ethnic group?

Asian or Asian British:

() Asian British – English, Scottish, Welsh, or Northern Irish

() Asian Bangladeshi

() Asian Indian

() Asian Pakistani

() Chinese

() Any other Asian background – *Please specify:* _____

Black or Black British:

() Black British – English, Scottish, Welsh, or Northern Irish

() Black African

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() Black Caribbean

() Any other Black background – *Please specify:* _____

Mixed or Multiple Ethnic Groups:

() White & Asian

() White & Black African

() White & Black Caribbean

() Any other Mixed or multiple ethnic background – *Please specify:* _____

White:

() White British – English

() White British – Scottish

() White British – Welsh

() White Northern Irish

() Irish

() Gypsy or Irish Traveler

() Roma

() White European

() Any other White background – *Please specify:* _____

Other Ethnic Group:

() Arab

() Hispanic / North American

() Middle Eastern / North African

() Any other ethnic group – *Please specify:* _____

4) What is your employment status

() Employed full-time

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() Employed part-time

() Unemployed (currently looking for work)

() Unemployed (not currently looking for work)

() Retired

() On sick leave

() Other (Please specify):

5) What is your current living situation?

() Living alone

() Living with souse/partner

() Living with family

() Living with roommates

() Other (please specify):

6) What is your marital status?

() Single

() Married

() In a domestic partnership/civil union

() Separated

() Divorced

() Widowed



() Other (please specify):

7) What is the highest level of education you have completed?

() No formal education

() Primary education

() Secondary education

() Some college/university

() Bachelor's degree

() Master's degree

() Doctorate

()Other (please specify):

8) When did you experience your first episode of Acute Pancreatitis? (Please provide the month and year if possible.)

9) Do you know what caused your Acute Pancreatitis?

() Gallstones

() Alcohol

() Other (please specify):

() Unknown

10) Have you ever been admitted to the Intensive Care Unit (ICU) for Acute Pancreatitis?

() Yes

() No



11) If you were admitted to the ICU, how long was your stay? (Please provide the number of days.)

12) Have you got any other physical or mental health conditions?

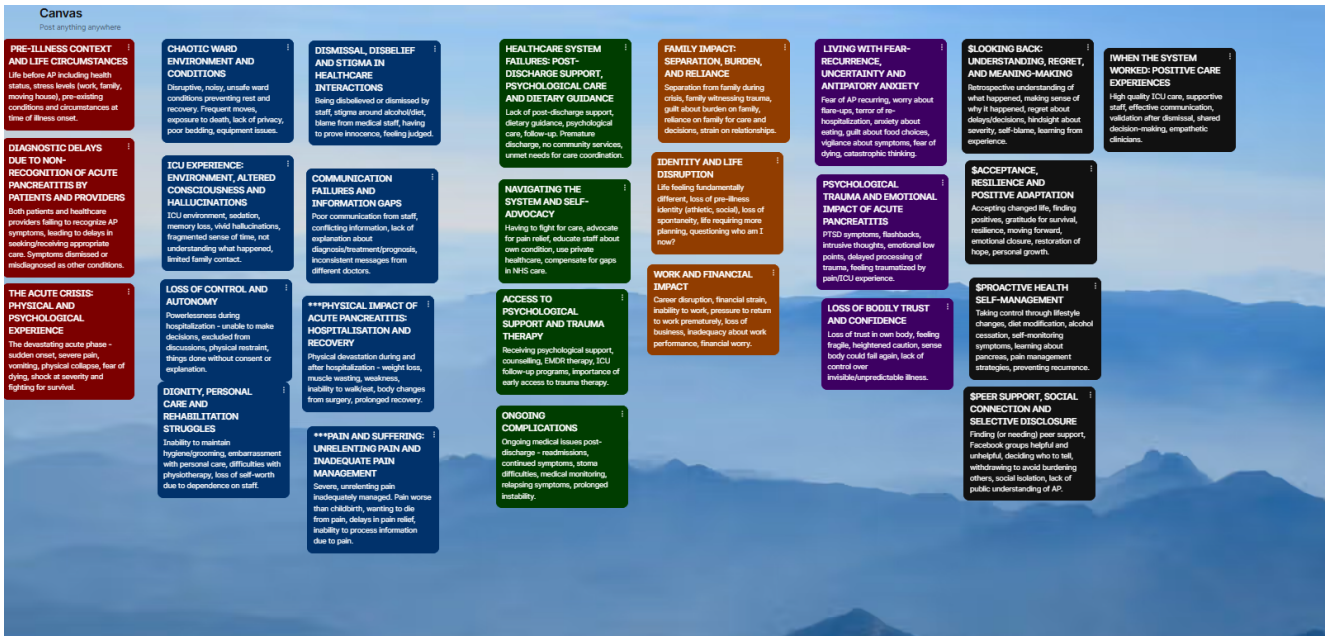
() Heart condition

() Lung condition

() Diabetes

() Other

Appendix I. Initial Thematic Framework



Appendix J. Final Thematic Framework

