

Family engagement and adaptation among home-dwelling colorectal ostomy patient-primary caregiver dyads: A qualitative study

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Abstract

Objective

Guided by the Family Adjustment and Adaptation Response model, this dyadic descriptive qualitative study explored family engagement and adaptation among home-dwelling colorectal ostomy patient-primary caregiver dyads, to inform family-centred ostomy continuing care.

Methods

A descriptive qualitative design was adopted. Fourteen dyads of colorectal ostomy patients and their co-residing primary caregivers were recruited via purposive sampling from a tertiary hospital in Central China. Semi-structured interviews were conducted using a FAAR-derived interview guide. Transcripts were analysed using the Braun-Clarke six-phase thematic analysis combined with directed content analysis in NVivo 14.0. This study adhered to COREQ criteria; dual-researcher coding and member checking were implemented to ensure methodological rigour.

Results

Four core themes and 16 sub-themes were extracted. Ostomy-related stress generated multi-dimensional cumulative family demands, with divergent stress perceptions within dyads. Families mobilised diverse internal and external coping resources, while informal resources exerted double-edged effects, as resource accessibility does not guarantee effective utilisation. Family-level meaning-making underwent dynamic shifts; context-specific health beliefs and over-protective caregiving acted as barriers to positive adaptation. Heterogeneous adaptive outcomes ranged from passive adjustment to positive adaptation or partial maladaptation, and behavioural skill-based adjustment did not equate to systemic family adaptation. Family engagement is a multidimensional dynamic process that encompasses instrumental, emotional, shared-decision-making and empowerment-oriented participation.

Conclusions

Dyadic perceptual divergence and culturally rooted beliefs substantially influence family adaptation for ostomy patients and caregivers. Continuing care should implement whole-family oriented stratified interventions targeting family-level stress, resource gaps and cognitive bias. Further dyadic longitudinal research and FAAR-based family screening tools are needed to optimise family-centred ostomy care.

1 Background

Colorectal cancer ranks among the most prevalent malignancies of the digestive system^[1]. Permanent or temporary enterostomy constitutes a core surgical intervention for disease control and survival prolongation among affected patients^[2]. Surgical alteration of physiological defecatory pathways not only impairs physical function but also exerts profound long-term impacts on patients' life trajectories^[3]. After hospital discharge and returning home, patients face persistent self-management challenges related to ostomy care, including physical morbidities such as stoma leakage and peristomal irritant dermatitis, identity conflicts derived from disturbed body image, as well as participation barriers and social withdrawal during social reintegration^[4].

The family acts as the central context for home-based rehabilitation of ostomy survivors and represents a dynamic interactive system jointly exposed to illness-related stress^[5]. Illness-related care experiences, coping behaviours and psychological status are bidirectionally interactive between patients and their primary family caregivers. Their adaptive trajectories collectively shape overall family functioning and directly predict patients' long-term rehabilitation outcomes and quality of life^[6]. Existing studies concerning colorectal ostomy populations mostly take individual patients as analytical units, focusing on self-management behaviours, quality-of-life assessment and risk-factor analysis for complications^[6, 7]. Several separate investigations have

addressed caregiver-specific outcomes including care burden, burnout and psychological distress^[7, 8]. Such research designs frequently treat patients and caregivers as independent groups for data collection and analysis, failing to capture real-world intrafamilial interaction processes; dyadic empirical studies grounded in a holistic family-system perspective remain scarce^[8].

The Family Adjustment and Adaptation Response (FAAR) model offers a systematic theoretical framework for understanding family adaptation under severe-illness-related stress^[9]. Rather than evaluating individual family members in isolation, this framework conceptualises family adaptation after crisis not as a static one-dimensional outcome, but as a product of ongoing dynamic interactions among family cumulative demands, mobilisable internal-external resources, and shared family meaning-making regarding illness^[10]. Although the FAAR model has been increasingly applied in family-care research for multiple chronic and oncological conditions^[11, 12, 13], dyadic qualitative studies adopting this theoretical lens for post-surgical colorectal ostomy households are still rare, and relevant empirical evidence remains insufficient^[14].

Beyond practical burdens caused by ostomy-associated complications, ostomy families need to accomplish family-role reconstruction and resolve communication conflicts stemming from divergent care perceptions during long-term home adaptation^[14, 15]. Context-specific indigenous health-related beliefs also continuously shape household care-making decisions and resource mobilisation. While quantitative research can describe population-level distributions and correlates of ostomy-related care burden, it cannot sufficiently unpack micro-level intrafamilial interactive processes, individualised illness meaning-construction, and heterogeneous adaptive trajectories across different households^[15, 16]. Current discharge education and post-discharge follow-up services predominantly target individual patients, failing to fully address diverse system-level family needs. Interventions informed by family-oriented empirical evidence are largely absent, which limits the effectiveness of long-term family support^[16].

Given the above-mentioned clinical context and research gaps, this qualitative study adopted semi-structured in-depth interviews with dyads of colorectal ostomy patients and their primary family caregivers guided by the FAAR model. From a dyadic family-system perspective, this study aimed to systematically explore family cumulative care demands, accessible internal-external support resources, shared illness meaning-making processes, and diverse adaptive experiences across households. We intended to identify protective factors facilitating positive family adaptation and characterise unmet support needs. Findings of this study can provide qualitative evidence for developing family-centred ostomy continuing-care strategies and inform clinical stratified support for families at high risk of maladaptation.

2 Methods

2.1 Study design

This was a descriptive qualitative study. According to the FAAR framework, families facing severe-illness stress experience short-term adjustment and long-term adaptation shaped by dynamic interactions among family cumulative demands, internal-external resources, and family meaning-making, finally reaching new family-function equilibrium or maladaptation. Adopting a patient-primary caregiver dyadic perspective, this study explored family-level demands, resources, meaning-making, and trajectories from adjustment toward adaptation among colorectal ostomy households, aiming to unpack the connotation of family engagement and mechanisms of family adaptation. The study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ)^[17].

2.2 Participants

Participants were recruited between February and August 2026 from the gastrointestinal surgery department of a tertiary-level hospital in Central-China. Purposive sampling with maximum variation strategy was applied to achieve heterogeneity across age, gender, ostomy type, post-operative duration, and caregiver-patient kinship to enrich dataset diversity^[17]. Stoma specialist nurses performed preliminary screening. Researchers fully informed potential dyads; both patient and co-resident primary caregiver needed to satisfy eligibility criteria before enrolment.

Inclusion criteria for patients: histologically-confirmed colorectal cancer; aged ≥ 18 years; ≥ 1 month post-ostomy surgery under home-based disease management; intact communication and cognition; awareness of diagnosis, voluntary participation; co-residing with primary caregiver.

Inclusion criteria for primary caregivers: direct family relative undertaking main home-care tasks and co-residing with patient; aged ≥ 18 years; no severe psychiatric or cognitive impairment; voluntary participation.

Exclusion criteria: either dyad member with life-threatening comorbidities, severe mental disorder or cognitive impairment preventing interview completion.

Data saturation determined sample size. After recruiting 12 dyads, no new codes or sub-themes emerged, and recruitment was terminated. Finally, 14 dyads (28 participants) were included.

2.3 Data collection

The semi-structured interview guide was developed around four FAAR-derived domains: family cumulative demands, internal-external family resources, family meaning-making, and processes of adjustment-adaptation. The initial draft was generated via literature review and multidisciplinary group discussion (four stoma-care experts, one qualitative-methodology expert). Two stoma therapists with over 10 years clinical experience reviewed the guide for content validity and clinical appropriateness. Two dyads took part in pilot interviews to refine wording and question sequence; The final patient-version and caregiver-version guides can be found in *Additional file 1*.

All interviews were conducted by one researcher with formal qualitative-research training and five-year clinical stoma-care experience to guarantee consistent interview performance. After obtaining written informed consent, patients and primary caregivers were interviewed separately in one-to-one face-to-face sessions in a quiet private consultation room. Open-ended opening questions were used: for patients "What major changes has the stoma brought to your daily life and your whole family after returning home from hospital?"; for caregivers "What main difficulties and pressures do you encounter when caring for the patient in daily life?". Probing, clarification and paraphrasing were applied to deepen narratives, whilst leading questions were avoided. Each interview lasted 30–45 min. Audio-recording was performed with participant permission; field-notes including non-verbal behaviours and researcher reflections were simultaneously documented. Within 24 h post-interview, two researchers independently transcribed recordings verbatim, and cross-checked transcripts to ensure accuracy and completeness.

2.4 Data analysis

Braun-Clarke six-phase thematic analysis combined with directed content analysis was performed using NVivo 14.0 software for data management and coding^[18]. Pre-defined FAAR-based categories (family cumulative demands, family resources, meaning-making, adjustment-adaptation) served as an initial coding framework, enabling integration of theory-driven top-down guidance and data-driven bottom-up theme generation. Analysis procedures: (1) Two uniformly-trained researchers read all transcripts repeatedly for immersion in raw data; (2) FAAR categories were set as first-level coding nodes, relevant text segments were assigned and descriptive initial codes were generated. New emergent concepts outside the pre-set framework were coded openly to avoid constraining data richness by theoretical presuppositions; (3) Codes with similar connotations were aggregated to generate sub-themes and core themes within each category; (4) Candidate themes were checked against the full transcript dataset to verify alignment with raw narratives and research aims; overlapping or ill-defined themes were re-integrated; (5) Clear definitions were formulated for each theme and sub-theme followed by final naming; (6) Logical relationships across themes were mapped; perspectives from patients and caregivers were compared; representative verbatim quotes were selected to support results and construct the final thematic output. Disagreements in coding were resolved through discussion between the two coders. Where consensus could not be reached, a senior qualitative-research expert acted as third-party arbiter to safeguard coding consistency.

2.5 Rigour

Four quality criteria for qualitative research were applied: credibility, transferability, dependability, and confirmability^[19].

Credibility: maximum-variation purposive sampling ensured participant diversity; investigator triangulation via dual-researcher independent coding; member-checking was undertaken with five dyads, returning transcripts and preliminary themes for participants to verify interpretations against their lived experience; reflective journals were kept by researchers to bracket pre-existing assumptions.

Transferability: thorough description of study setting, participants' socio- demographic-clinical profiles, sampling, data-collection and analytical workflows, enabling readers to judge contextual generalisability.

Dependability: a complete audit trail documented all decisions and revisions across study design, recruitment, interviews and coding to render the research process traceable.

Confirmability: all findings were strictly grounded in original interview data to prevent over-interpretation by researchers; inter-coder consistency was assessed to improve analytical stability and objectivity.

2.6 Ethics approval and consent to participate

This study followed the ethical principles of the Declaration of Helsinki. The research protocol was approved by the ethics committee of Tongji Hospital, Tongji Medical College, Huazhong University of Science and Technology (ethics number: TJ-IRB202412033). All participants provided written informed consent after full disclosure of study purpose, procedures and potential risks. Participants could withdraw unconditionally at any stage without negative impacts on their clinical care and follow-up. All transcripts were anonymised using numeric identifiers. Audio-files and transcripts were encrypted and stored on dedicated research devices accessible only to authorised investigators. Original raw data will be destroyed per institutional regulations upon study completion to guarantee participant privacy and information security.

3 Results

A total of 14 dyads of home-dwelling colorectal ostomy patients and their primary family caregivers were enrolled in this study. Participant characteristics are shown in *Table 1*. Patients were coded P1-P14 and their corresponding caregivers S1-S14. The total interview duration was 563 minutes, yielding verbatim transcripts of approximately 98000 Chinese characters. Guided by the FAAR model and focusing on family engagement and adaptation experiences of patient-caregiver dyads, four core themes and 16 sub-themes were extracted (see *Figure 1*). Open-coded outputs are presented in *Additional file 2*.

3.1 Theme 1: Multifaceted family cumulative demands triggered by illness related stressors

Ostomy surgery acts as a major family-level stressor, generating multi-layered cumulative family demands spanning care-giving burdens, disrupted daily life, psychological-emotional distress and altered social roles. Within the family system, both patients and caregivers are exposed to stress, yet they exhibit divergent priorities in stress perception. These overlapping stressors jointly constitute the starting-point of family adaptation processes.

1. Persistent ostomy related care burdens

Stoma leakage and peristomal skin injury represented recurrent primary care challenges for ostomy households. Beyond physical discomfort for patients, leakage brought substantial additional care burdens.

P1: "I feared leakage most. I had two leakage episodes shortly after discharge, after which I tried hard to figure out the triggers." S2: "Poor application often causes leakage. Sometimes leakage occurs immediately after bag replacement, stoma contents get all over the bed and clothes, and we have to clean up in the middle of the night."

Some families also coped with complications such as parastomal hernia and high-output stoma, which aggravated physical discomfort and uncertainty about prognosis and amplified family tension and feelings of powerlessness.

S5: "He once suffered intestinal obstruction with high-output stoma, producing one to two litres of watery stools per day; he became severely emaciated."

2. Impacts of reconstruction on family daily life and social roles

Illness and ostomy surgery disrupted pre-existing family homeostasis, forcing changes in sleep-wake rhythms, dietary choices and household division of labour.

P2: "I dare not fall asleep until the stoma bag is emptied; I am afraid turning over will cause pressure-related leakage." S10: "Leakage in the middle of the night forces me to get up and clean; I have never enjoyed a full night's sleep."

Out-of-home mobility was restricted and patients generally narrowed their social circles. Some offspring-caregivers faced conflicts between employment and care obligations, while some older caregivers additionally took on grand-child-rearing responsibilities, resulting in multi-role overload.

S13: "I need to manage his stoma care as well as look after my two-year-old grandson. I am kept extremely busy all day long." S7: "I have to go to work, yet I must ask for leave and rush home whenever calls come from home, and my supervisor has complained about this."

3. Dual psychological-emotional burdens and intrafamilial interaction pressures

Patients were vulnerable to body-image-related shame, inferiority and social withdrawal. Caregivers commonly demonstrated suppressed emotional burden: constrained by the cultural norm of "prioritising the patient's needs", they tended to repress their own negative feelings. Parental caregivers additionally experienced distinctive self-blame and guilt. Conflicts around care arrangements and daily-life decisions emerged within some families.

S2: "When he is in pain and loses his temper, I dare not argue and can only endure silently." S9: "I keep blaming myself for failing to take good care of my child, who developed such a serious disease at a young age; I feel extremely guilty."

4. Sustained worries over disease risks and prognosis

Fears of tumour recurrence and metastasis, together with anxiety regarding long-term stoma complications, constituted persistent family stressors. Such psychological distress was further intensified among families who had previously experienced acute adverse clinical events.

P4: "Vascular invasion means cancer cells have invaded blood vessels, and high Ki-67 suggests rapid cell proliferation; I remain quite worried." S11: "Since the emergency episode of parastomal hernia, I live in constant fear. I get nervous whenever he makes any slight movement."

3.2 Theme 2: Mobilised internal-external coping resources within families

Confronted with multiple stressors, families mobilised internal and external resources. Such resources were gradually constructed through repeated trial-and-error and learning during long-term care-giving practice. Both resource accessibility and actual utilisation efficiency directly shaped subsequent family adjustment outcomes.

1. Intrafamilial resources: role division, emotional support and development of care competence

Faced with home-based ostomy-care challenges, households gradually formed differentiated care-division patterns. Technically-demanding tasks such as stoma base-plate cutting and pouch replacement were mostly undertaken by caregivers, whereas patients mainly performed low-intensity tasks including emptying stoma output and simple stoma observation. Task allocation helped share care-giving load. Beyond instrumental division of labour, empathic listening and mutual consolation among family members formed vital intra-psychosocial protective resources. Care competence was not innate, but gradually built in home-care practice. Many households explored individualised care skills adapted to their physical and practical circumstances through repeated trial-and-error.

P2: "I empty and clean the stoma bag, while she cuts the base-plate and attaches the pouch; we cooperate well." P1: "I made a fixation belt at home, and my wife sewed a small cloth pouch to hold the ostomy bag." S6: "When we feel upset, we talk to each other, comfort one another and try to stay positive."

2. Formal healthcare resources: practical limitations of in-hospital discharge education and ostomy-clinic support

Bedside hands-on teaching by nurses during hospitalisation represented the primary channel for families to acquire care knowledge. Nevertheless, participants reported fragmented discharge education and insufficient mastery of practical skills after hospital discharge. Although ostomy clinics offered professional assessment and guidance, barriers existed including low awareness and substantial time costs for hospital visits.

S10: "Nurses demonstrated the procedure once in hospital. It seemed easy to follow, yet I forgot how to perform it once I got home."

3. Informal social resources: double-edged effects of peer-support groups and online health content

Online peer WeChat groups and short-video-based popular-science content provided supplementary practical experience for some families. However, heterogeneous and unfiltered information created confusion in decision-making, showing obvious double-edged-sword effects.

P2: "Instructors within our peer group shared very practical advice, and I also watched operational videos on Douyin." S7: "Messages in peer groups are highly mixed; sometimes different opinions conflict and I do not know whose advice to trust."

4. Material-based instrumental resources: ostomy consumables and assistive devices

Ostomy-related supplies including pouches, barrier rings, skin-care powder and fixation belts functioned as instrumental resources for managing leakage and protecting peristomal skin. Iterative optimisation of consumable configurations via trial-and-error partly alleviated care-giving burdens.

P6: "Switching to a two-piece ostomy pouch worked far better than the one-piece type and extended wearing time."

3.3 Theme 3: Family-level meaning-making regarding illness

According to the FAAR framework, stress-provoking events do not directly determine family adaptive outcomes. Instead, how families interpret and assign meaning to illness exerts a critical mediating role. Patients and caregivers jointly constructed meaning regarding stoma-related illness and care-giving roles; meaning-making could either facilitate positive family adaptation or act as an adaptive barrier.

1. Evolving illness perceptions: from shock-rejection towards chronic-disease acceptance

Most families experienced a cognitive shift from initial shock and rejection toward perceiving the stoma as a life-saving intervention, adopting a chronic-disease-management mindset for home-care. Still, some households persistently failed to accept altered bodily appearance and remained trapped in psychological distress.

P13: "When I first learned I would receive a stoma, I felt my world had collapsed and thought I could no longer live a normal life." S12: "With the passage of time I have come to terms with reality; survival comes first, and I treat it as managing a chronic disease."

2. Meaning-construction of care-giving roles: internalised obligation, autonomy aspirations and conflicts stemming from over-protection

Caregivers generally internalised care-giving as a familial obligation. Meanwhile patients held intrinsic aspirations for self-care and preservation of personal dignity. Some caregivers developed over-protective tendencies and took over all stoma-care tasks, inhibiting patients' self-care practice and generating intrafamilial conflicts.

S1: "We are family. It is my obligation to take good care of him now that he is ill, and I will do my utmost." S9: "I cannot bear to let him do anything. I take charge of everything so he can focus on recovering."

3. Impacts of culturally-rooted beliefs on household care-giving decisions

Indigenous cultural beliefs such as "certain foods act as 'triggering-illness foods' (fa-wu)" and "prolonged bed-rest is required for recovery" profoundly shaped household dietary arrangements and activity-related decisions and created practical care dilemmas.

S6: "Elders claim beef, mutton and shrimp are 'fa-wu' and forbid consumption, yet we also fear insufficient nutritional intake, leaving us in a dilemma."

4. Divergent expectations for disease outcomes and rehabilitation beliefs

For households with temporary stomas, anticipation of stoma reversal constituted an important psychological anchor. Beliefs regarding long-term stoma-carrying life varied across families: some adopted stable chronic-disease-management mindsets, while others remained pessimistic and anxious.

P5: "I am eagerly waiting for reversal surgery; living with a stoma brings great inconvenience."

3.4 Theme 4: Differentiated family adaptive outcomes ranging from passive adjustment to genuine adaptation

Families first entered the adjustment phase. Dynamic interplay among family cumulative demands, mobilised resources and family meaning-making subsequently drove divergence toward positive adaptation or partial maladaptation.

1. The adjustment phase: pervasive chaotic exploratory status in the early post-discharge period

Early post-discharge phase represented a typical adjustment period. Pre-existing household routines broke down; care-skill reserves were insufficient. Families could only respond passively via trial-and-error when confronted with unexpected events such as leakage and skin injury. Intrafamilial conflicts frequently emerged; confusion and helplessness characterised this transitional phase. Anxiety and friction during this phase represented normal components of family adaptation.

S10: "Everything was chaotic right after discharge. Changing a pouch would take more than 30 minutes, and I had nobody to consult. I felt extremely helpless."

2. Positive family adaptation: establishing stable care routines and rebuilding household homeostasis

With accumulated care-giving experience, some families achieved standardised care workflows and reasonable intra-household division-of-labour. Patients gradually resumed social participation, household atmosphere stabilised, and positive family adaptation was realised.

S12: "Now everything is proficient; pouch-changing takes only three to five minutes. We keep regular schedules for meals and walks; daily life largely resembles pre-illness conditions."

3. Partial maladaptation: maintained functional performance yet persistent psychological and care-giving burdens

Some households mastered basic pouch-changing skills and achieved behavioural-level adjustment, yet genuine psychological family adaptation remained absent. Three main forms of partial maladaptation were observed: persistent psychological barriers and social withdrawal among patients; sustained heavy burden among caregivers; trauma-related anxiety and secondary over-protection triggered by prior complication episodes.

S13: "I just endure day-by-day. I cannot call this real adaptation; I am merely getting through each day."

4. Diverse unmet real-world support needs of families

Families demonstrated multi-layered support demands, including practical hands-on discharge education, accessible online or home-visit nursing services, psychological and peer-patient support, as well as individualised dietary-rehabilitation guidance.

P7: "I hope healthcare providers fully educate both patients and family members before discharge, instead of leaving us to explore solutions independently and suffer avoidable setbacks."

4 Discussion

The FAAR model proposes that family adaptation to severe illness-related stress emerges from dynamic interactions among family cumulative demands, internal-external resources, and family meaning-making, rather than a simple linear sequential process^[9]. Drawing on dyadic interview data from 14 Chinese colorectal ostomy patient-primary caregiver pairs, this study unpacked real-world adaptive trajectories of home-dwelling ostomy families. As an acute family stressor, ostomy surgery generated multi-layered cumulative demands, including persistent ostomy-related care burdens, disrupted daily routines, role reconstruction, and dual psychological distress. Consistent with prior FAAR-informed research on cancer-affected families^[11,12], patients and caregivers within the same household exhibited divergent stress perceptions. Patients prioritized body-image concerns and subjective psychosocial suffering, whereas caregivers confronted practical care tasks and frequently suppressed negative emotions under culturally rooted "patient-first" social norms; some parental caregivers even reported self-blame. Such perceptual divergence could amplify intrafamilial strain, and well-intended over-protection might further trigger family conflicts^[20,21].

Internal and external resources served as protective buffers against stress. Nevertheless, resource availability did not equate to effective resource utilisation^[22]. Intrafamilial resources encompassed differentiated care division, mutual emotional support, and practical care skills accumulated through repeated trial-and-error. External resources consisted of formal healthcare support (in-hospital bedside education, ostomy outpatient clinics), informal social resources (peer groups, online health content, kin support), and ostomy-related consumables^[23]. Informal resources exerted obvious double-edged effects: peer-shared and online experiences could supplement care-related knowledge, yet unfiltered information also confused family decision-making^[24].

Meaning-making functions as a core mediating construct within the FAAR model^[12]. Most participants evolved from initial shock and rejection toward viewing ostomy as a life-saving therapeutic measure. However, culturally embedded health beliefs such as food taboos ("favour-yang foods") and the perception that "illness requires prolonged rest", combined with over-protective caregiving and patients' self-blame, distorted care-related decision-making, consumed existing family resources and impeded positive adaptation^[12]. These cultural determinants of these specific situations can enrich the original FAAR model.

Crucially, behavioural adjustment was not equivalent to systemic family adaptation^[24]. Families in the early post-discharge phase commonly remained in the adjustment phase marked by chaos and passive coping. Many households mastered ostomy-changing skills and achieved behavioural adjustment but stayed in partial maladaptation with unresolved psychological distress and intrafamilial tensions. Only buffered cumulative demands, properly utilised resources, and positive meaning-making jointly enabled systemic family re-equilibrium and genuine adaptation. Family participation represented a continuously evolving dyadic process requiring both intrafamilial communication and external healthcare support^[25].

Consistent with global ostomy focused qualitative studies, peristomal leakage and skin injury constituted the most prominent practical stressors and frequently triggered negative emotions and family conflicts^[12]. Caregiver burden, patients' social withdrawal, and insufficient post-discharge continuing-care represented pervasive challenges for ostomy-affected families^[25]. Prior ostom-related qualitative studies mostly recruited either patients or caregivers separately, treating family adaptation as a simple summation of individual-level outcomes and neglecting intrafamilial interactive dynamics^[26]. By adopting dyadic paired interviews, the present study identified perceptual divergence between patients and caregivers, which constituted latent sources of family conflict and complemented evidence generated from single-perspective investigations. Moreover, this study distinguished behavioural adjustment from systemic family adaptation, suggesting that proficiency in ostomy manipulation alone cannot serve as the sole indicator of favourable family outcomes; multi-dimensional evaluation covering practical competence, mental wellbeing and family interaction is therefore required^[27]. Previous FAAR-oriented cancer-family research mainly focused

on family demands and resources, with limited exploration of meaning-making and the distinction between adjustment-adaptation trajectories^[10]. Several publications citing the FAAR framework treated it merely as background theory without empirically testing its interactive components^[13]. This study embedded the complete FAAR framework throughout interview-guide development, open-coding and thematic analysis, incorporated local cultural cognitive factors, and supplemented empirical evidence for FAAR application among colorectal ostomy households.

This study demonstrated that family participation in ostomy home-management comprised four interrelated dimensions: instrumental participation, emotional participation, shared-decision-making participation, and empowerment-oriented participation. Maladaptive over-protective total substitution undermined patients' self-care agency; balanced support-autonomy within the patient-caregiver dyad underpinned constructive family adaptation. Guided by FAAR dimensions, continuing-care should target the whole-family unit rather than individual patients^[28,29]. (1) Cumulative demands: Synchronously assess both patients and primary caregivers across admission, discharge and follow-up. Screen for caregiver emotional overload, multiple-role burden and intrafamilial perceptual divergence to identify high-risk families for early psychosocial intervention^[30,31]; (2) Internal-external resources: Optimise pre-discharge hands-on bedside education to ensure dyads master practical skills. Guide rational intrafamilial labour division and mitigate over-protection. Improve accessibility of formal ostomy services; meanwhile deliver guidance for families to discriminate misleading informal online/peer information, and strengthen rational use of ostomy supplies^[32,33]; (3) Meaning-making: Deliver dual-targeted cognitive intervention for patients and caregivers alongside skill training. Correct local health-related misconceptions, help families reconstruct rational understanding of ostomy as life-saving therapy, and identify irrational role perceptions including over-protection and self-blame^[34,35]; (4) Adjustment-adaptation trajectories: Acknowledge that confusion and intrafamilial conflicts are normal manifestations of the early post-discharge adjustment phase. Follow-up assessments should extend beyond ostomy physical indicators to track family adaptive trajectories. Establish multi-dimensional evaluation criteria and early-warning indicators for maladaptive families to implement stratified support^[36]. Future work could develop brief FAAR-based family-screening instruments for ostomy outpatient and post-discharge follow-up scenarios to operationalise family-centred care^[37].

5 Limitations

Recruitment was conducted within a single tertiary hospital with relatively limited representation of rural households. As a cross-sectional qualitative study relying on retrospective narratives, it cannot capture longitudinal temporal shifts of family demands-resources-meaning-making, despite FAAR being an intrinsically process-driven model. Caregiver participants were dominated by spouses; sample sizes for child- and parent-caregiver subgroups were too small for robust subgroup comparisons. Data were only collected from patient-primary-caregiver dyads without perspectives from other extended-family members. Future dyadic longitudinal qualitative work is required to trace how family cumulative demands, resources and meaning-making evolve across different post-ostomy phases. Moreover, larger-sample studies are needed to compare adaptive patterns across different caregiver subgroups. Based on the present thematic findings, further research could develop and validate brief family-oriented assessment tools for ostomy populations to facilitate clinical family-centred care delivery.

6 Conclusions

This dyadic qualitative study applied the FAAR model to explore family-level experiences among Chinese home-dwelling colorectal ostomy patient primary caregiver. Ostomy-induced cumulative demands, mobilisable internal-external resources, and family meaning-making interacted dynamically to determine whether families achieved benign adaptation or remained in maladjustment. Divergent stress perceptions existed within identical households. Context-specific cultural health beliefs and over-protective caregiving acted as important barriers to positive adaptation. Critically, behavioural adjustment in ostomy-care skills did not guarantee systemic family adaptation.

Family-centred continuing-care should perform synchronous assessment for patients and primary caregivers, implement multi-dimensional interventions targeting family demands, resources and meaning-making, and identify families at maladaptation-risk. Further longitudinal qualitative research is required to trace temporal family-adaptive trajectories. Subsequent studies may

develop family-oriented assessment tools and test the effectiveness of family-centred continuing-care interventions for ostomy populations.

Declarations

Author Contributions

Zhihui Lu: Conceptualization, Methodology, Investigation, Writing-Original draft preparation. **Wenxin Sun:** Data collection, Formal analysis, Validation. **Zijing Huang:** Data analysis, Data interpretation. **Yaxin Gao:** Data analysis, Data interpretation. **Li Zhu :** Supervision, Writing-Reviewing and Editing.

Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Ethics approval statement

This study followed the ethical principles of the Declaration of Helsinki. The research protocol was approved by the ethics committee of Tongji Hospital, Tongji Medical College, Huazhong University of Science and Technology (ethics number: TJ-IRB202412033). All participants provided written informed consent after full disclosure of study purpose, procedures and potential risks. Participants could withdraw unconditionally at any stage without negative impacts on their clinical care and follow-up. All transcripts were anonymised using numeric identifiers. Audio-files and transcripts were encrypted and stored on dedicated research devices accessible only to authorised investigators. Original raw data will be destroyed per institutional regulations upon study completion to guarantee participant privacy and information security.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

AI Use Declaration

The authors acknowledge that generative AI tools were used for reference formatting during manuscript preparation. The final content has been fully reviewed, revised, and approved by all authors, and all authors take full responsibility for the integrity, accuracy, and originality of the work.

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Table 1

Table 1 Participant characteristics of patients and primary family caregivers (n = 28)

Patient ID	Stoma Type	Postoperative Duration (months)	Education Level	Occupation	Caregiver ID	Relationship	Education Level	Occupation
P1	Temporary ileostomy	3	High school	Retired	S1	Spouse	Junior high school	Retired
P2	Temporary ileostomy	3	High school	Employed	S2	Spouse	Primary school	Unemployed
P3	Temporary ileostomy	2	Junior high school	Employed	S3	Daughter	Junior college	Employed
P4	Temporary ileostomy	8	High school	Retired	S4	Son	Junior college	Employed
P5	Permanent descending colostomy	7	University	Student	S5	Mother	Junior high school	Retired
P6	Temporary ileostomy	2	Junior college	Retired	S6	Spouse	Primary school	Unemployed
P7	Permanent sigmoid colostomy	6	Junior high school	Retired	S7	Spouse	Junior high school	Retired
P8	Permanent sigmoid colostomy	12	High school	Retired	S8	Spouse	High school	Retired
P9	Temporary transverse colostomy	5	Junior high school	Employed	S9	Spouse	Junior high school	Unemployed
P10	Permanent sigmoid colostomy	4	Junior high school	Employed	S10	Spouse	High school	Unemployed
P11	Temporary ileostomy	3	Junior high school	Retired	S11	Spouse	Junior high school	Retired
P12	Permanent sigmoid colostomy	7	Primary school	Retired	S12	Spouse	Primary school	Unemployed
P13	Temporary ileostomy	4	High school	Employed	S13	Spouse	High school	Employed
P14	Permanent sigmoid colostomy	10	Junior high school	Retired	S14	Spouse	Junior high school	Retired

Figures

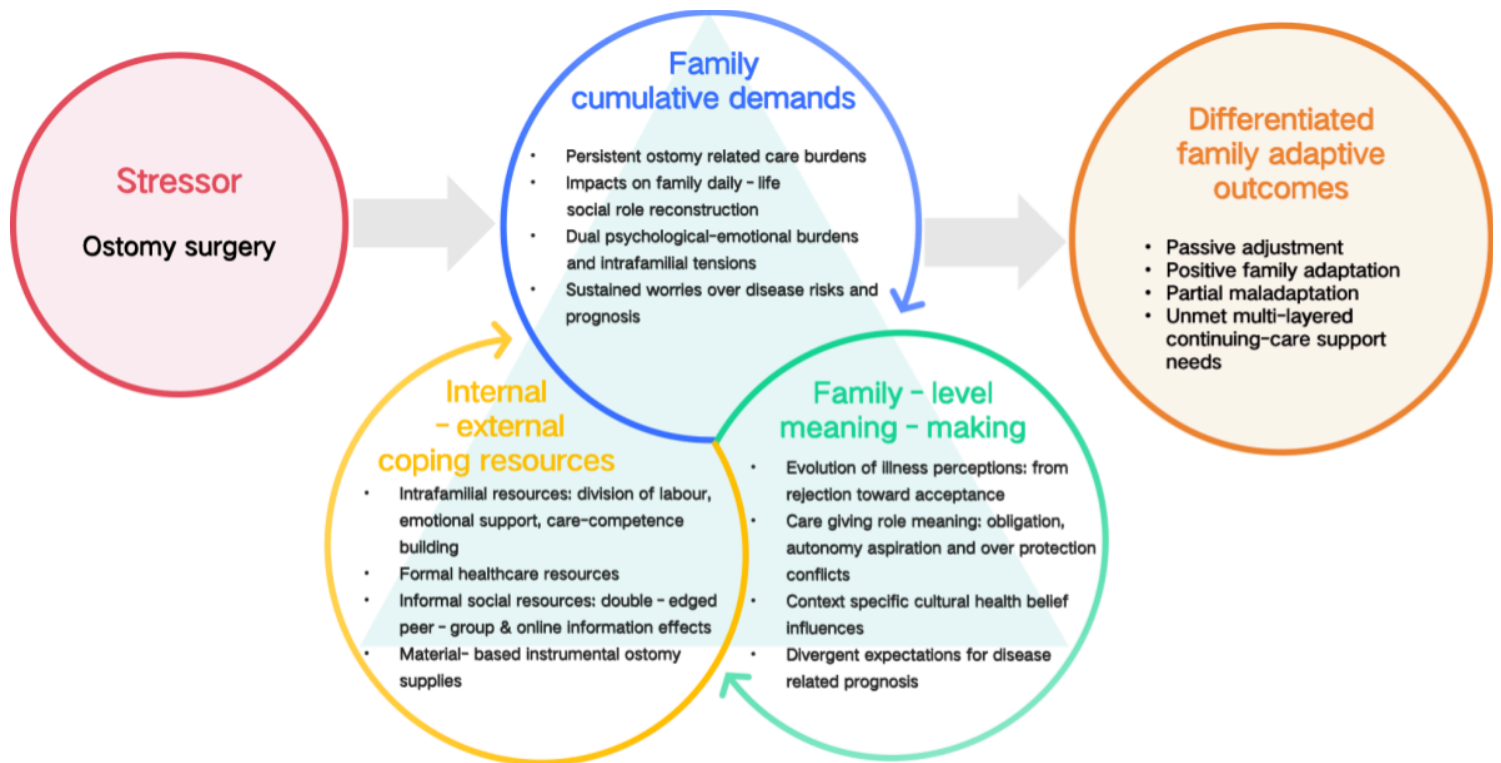


Figure 1

The thematic framework of family engagement and adaptation experiences among colorectal ostomy patients and their primary caregivers

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