

Current Status of Caregiver Burden and Nursing Management for Pediatric Enterostomy Patients Abroad

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Abstract

Pediatric enterostomy is a common surgical procedure for congenital anorectal malformations, intestinal necrosis complicated with shock, extensive intra-abdominal infection and other acute abdominal emergencies, as well as perianal trauma in children. However, due to their lack of self-care abilities, pediatric enterostomy patients must heavily rely on their caregivers for postoperative stoma care and other needs, which creates physical and psychological burdens for the caregivers to a certain extent. Currently, there is limited attention in China regarding the burden on caregivers of pediatric enterostomy patients postoperatively. This article, through reviewing foreign literature, elaborates on the evolution of perspectives on caregiver burden abroad, assessment tools for caregiver burden, analyzes caregivers' understanding of and needs for stoma care, summarizes nursing management measures implemented by foreign medical institutions, and proposes future prospects, with the expectation of further improving family nursing management for pediatric enterostomy and reducing caregiver burden.

Full Text

Caregiver Burden and Nursing Management After Pediatric Colostomy Surgery Abroad: Current Status

Abstract

Pediatric colostomy is a common surgical method for acute abdominal diseases such as congenital anorectal malformations, intestinal necrosis combined with

shock, widespread abdominal infections, and perianal trauma in children. However, due to the lack of self-care ability, children with intestinal stomas have to rely heavily on their caregivers for postoperative stoma care, which to some extent creates physiological and psychological burdens for caregivers. At present, there is relatively little research in China on the burden of postoperative caregivers for children with intestinal stomas. This article elaborates on the evolution of caregiver burden perspectives abroad, assessment tools for caregiver burden, analysis of caregivers' understanding and needs for stoma care, summarizes nursing management measures for caregivers in foreign medical institutions, and proposes prospects for further improving home care management for pediatric colostomy to reduce caregivers' burden.

Keywords: Enterostomy; Child; The burden of caregivers; Family care; Nursing Management

Pediatric colostomy is a common surgical procedure for congenital anorectal malformations, intestinal necrosis with shock, widespread abdominal infections, and other acute abdominal conditions, as well as perianal trauma in children. Due to their lack of self-care ability, children with intestinal stomas must rely entirely on caregivers for post-discharge stoma care at home, creating significant physical and psychological burdens for these caregivers. However, current domestic research on caregiver burden in this population remains limited, and there is a lack of family care guidelines and health education materials tailored to the Chinese context that could alleviate caregiver burden. Studies have shown that nursing management programs based on multimedia applications can enhance the effectiveness of family care while reducing postoperative complication rates and caregiver burden. Given that international research on caregiver burden and nursing management has become increasingly sophisticated in recent years, this article systematically analyzes and reviews key findings from abroad to provide a foundation for research and practice in China.

Factors Influencing Caregiver Burden

1.1 Family and Social Support

In recent years, caregiver burden has gradually gained attention internationally. A qualitative analysis revealed that caregivers consistently reported that stoma care creates financial strain and social relationship difficulties. While most parents gradually accept their child's colostomy, a minority find it unacceptable, primarily due to social isolation stemming from odor, frequent stoma care requirements, and complications. In developing countries, pediatric ostomies can destabilize families, leading to divorce in some cases, with caregivers reporting that they must quit their jobs to provide care. For families with unstable incomes and limited access to medical facilities, seeking treatment for stoma-related complications imposes additional financial burdens. In predominantly Muslim families, caregivers often perceive the condition as a form of punishment within their close social networks. Research indicates that mothers in

such families exhibit significantly higher rates of post-traumatic stress disorder (23%) compared to fathers (5.3%), underscoring the need to assess parental psychological status during home follow-up visits.

1.2 Caregiver Education Level

A Somali survey of 16 pediatric colostomy caregivers found an average age of 32.5 ± 4.2 years, with 75% (n=12) having limited education that negatively impacted their acquisition of stoma care knowledge. Caregivers primarily lacked understanding of stoma appliances and had limited preparation, knowledge, and engagement in home care procedures. Postoperative complications represent a common and serious challenge in pediatric colostomy care, including high-output stomas, stenosis, and prolapse, which can lead to malnutrition, intestinal obstruction, and ischemic necrosis, thereby impeding recovery. Consequently, providing accessible education and hands-on training for caregivers is essential.

1.3 Healthcare System Factors

A Turkish survey of 155 pediatric emergency nurses revealed that colostomy care (37.4%) and discharge education (24.5%) were among the most frequently missed nursing practices. Due to nursing staff shortages, discharge education for colostomy care is often neglected, leaving caregivers ill-equipped to manage stoma care at home. Since family caregivers must assume full responsibility for stoma care after discharge, their need for ongoing education in knowledge and skills has become increasingly apparent. Research shows that caregivers are increasingly concerned about postoperative quality of life, gender identity, and surgical impacts, with many children requiring continuous multidisciplinary care into adulthood. The shortage of specialized stoma nurses and limited access to medical resources in remote areas further exacerbate caregiver burden.

2. Assessment Tools for Caregiver Burden

Validated assessment scales are crucial for evaluating caregiver burden and the effectiveness of nursing management in pediatric colostomy care, enabling monitoring of burden levels across different stages and informing the timing and nature of interventions. The Distress Thermometer for Parents (DT-P) is a reliable validated tool for assessing burden in parents of pediatric colostomy patients, encompassing six dimensions: practical, social, emotional, physical, cognitive, and parenting (for infants or toddlers). Each dimension is scored from 0 (no distress) to 10 (extreme distress), with scores ≥ 4 indicating significant caregiver burden. This scale demonstrates good correlation with other psychological assessments, including the Self-Rating Scale for Posttraumatic Stress Disorders (SRS-PTSD), Self-Rating Anxiety Scale (SAS), and Self-Rating Depression Scale (SPS). Additionally, the Caregiver Burden Scale, Three-Dimensional Psychological Pain Scale (TDPPS), Quality of Life Scale, and Social Support Rating Scale show sensitive responsiveness in evaluating caregiver burden.

3. Nursing Management Measures

Since the 1980s, the United States has published toolbooks for home care of pediatric ostomy patients, providing caregivers with practical and psychological guidance. A Utah study demonstrated that multidisciplinary collaboration reduced readmission rates to 52% within 120 days post-discharge compared to 63% in the control group ($p=0.04$). Similarly, a European consensus emphasized the importance of multidisciplinary care and communication between healthcare providers and caregivers. Online-assisted health education for caregivers effectively improves their nursing competence, reduces caregiver burden, and decreases postoperative complication rates. Video-based learning enhances caregivers' skills, attitudes, and confidence. Increasing social support and reducing disease-related uncertainty positively impacts psychological burden. Thus, home care interventions and nursing management can substantially alleviate caregiver burden.

Recommendations for Practice

4.1 Developing Specific Assessment Tools

Currently, no specific assessment tool exists for evaluating caregiver burden following pediatric colostomy, yet the physical and psychological burden on caregivers represents a critical factor affecting home care quality. A specialized assessment instrument could incorporate key influencing factors such as family social support, education level, quality of life, and anxiety evaluation, while also including healthcare system factors. Such a tool would enable timely monitoring of caregiver burden throughout the hospital-to-home care continuum, allowing for personalized nursing management strategies that enhance education effectiveness while reducing time and personnel costs.

4.2 Enhancing Online Management Platforms

With rapid advances in information technology, online training and continuous home care are continually improving. Online education-based home care models effectively enhance family care capabilities and self-efficacy for ostomy patients, promoting better quality of life and psychological well-being while reducing post-discharge complications. Caregivers require ongoing multidisciplinary home care and management support from healthcare providers after discharge, primarily through online and video-based training. This approach further improves caregiving competence and alleviates burden in both theoretical knowledge and practical skills.

4.3 Improving Specialist Nurse Competence

Research by Zhang Jie et al. indicates that stoma specialist nurses require enhanced capabilities in psychological care and information management, along with improved teaching and training in nursing procedures and theoretical in-

struction to elevate care quality. Domestic research has established competency evaluation indicators for stoma nurses in home care, comprising three primary domains: knowledge and technical skills, comprehensive abilities, and personal attributes. These indicators enable quantitative assessment of specialist nurses' home care competencies, promoting professional development and facilitating more professional, comprehensive, and timely in-home care for pediatric colostomy patients, thereby reducing caregiver burden.

5. Conclusion

Caregivers of pediatric colostomy patients constitute a special population requiring greater attention. Current evidence shows that some international caregivers have limited knowledge of basic home care for pediatric colostomies and need further education on topics such as stoma appliance selection and use, care techniques, and complication recognition. These caregivers also experience varying degrees of psychological stress. We recommend that domestic researchers draw upon international experiences, adapt or develop assessment tools, consider Chinese cultural contexts, address caregiver psychological stress, understand caregiver needs, and employ appropriate training methods to improve home care management and reduce caregiver burden.

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