



INFOGRAPHIC



Adjustment to an Ostomy

An Integrative Literature Review

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ABSTRACT

This integrative literature review summarizes recent literature relating to patient adjustment to stoma. The search strategy included 5 databases (CINAHL Plus, PsychINFO, Web of Science, Scopus, and MEDLINE); 65 articles meeting criteria were retrieved. Eleven were removed as duplicates, and a further 29 were removed when read in full, yielding 25 elements. Three were randomized controlled trials; 2 were prospective descriptive studies; 15 were cross-sectional descriptive studies; and 5 were qualitative studies. The quality of studies was evaluated using the Mixed Methods Appraisal Tool (MMAT). The calculated mean quality score was 97%, and no studies were excluded on quality grounds. Limited evidence suggests that adjustment occurs over time and provides some insight concerning how rehabilitation leads to resumption of an altered normality. Some evidence suggests that long-term adjustment is associated with demographic and pre- and postoperative factors. A knowledge gap was identified regarding the role of support groups, which in other fields has been shown to positively benefit psychological well-being. This review revealed a paucity of interventional studies seeking to test ways to address adjustment-related problems. Longitudinal studies are recommended as ostomy care nurses work to facilitate adjustment in the person with a stoma over time.

KEY WORDS: Adjustment, Integrative review, Ostomy, Psychosocial, Stoma.

INTRODUCTION

Adjustment to life with an ostomy is an individualized process with clinically relevant effects on health-related quality of life (QOL). Health-related QOL is an implicitly subjective construct best defined by the patient. The World Health Organization defines health-related QOL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.”^{1(p1)} Validated instruments used to measure QOL tend to incorporate these domains: physical and social role/function, vitality, pain, and emotional/mental health.²

Adjustment is a psychosocial construct that is also best defined by the patient. Unlike QOL, it comprises postintervention or postdiagnosis factors that must be met and overcome when faced with a challenge to health such as creation of a new ostomy. Like health-related QOL, instruments measuring adjustment have been developed and validated.³⁻⁵ In the case of ostomy formation, adjustment focuses on acceptance of the ostomy. Additional factors have been shown to influence ad-

justment; they include independence with ostomy care, location of the stoma, personal resilience, stomal and peristomal complications, depression, sexual difficulties, knowledge retention after education, treating nurse’s knowledge of self-care, and spousal relationship quality.⁶⁻⁸

Adjustment was linked to QOL in a Norwegian study.⁹ This cross-sectional study used 3 instruments (Ostomy Adjustment Scale,⁵ Short Form-36,¹⁰ and Quality of Life Scale¹¹) to assess the relationship between ostomy adjustment and health-related and/or general QOL, among 158 participants with permanent ostomies. The time since ostomy creation ranged from 3 months to over a year. Results indicated that ostomy adjustment scores were a significant predictor of both QOL and health-related QOL; better adjustment to a stoma resulted in improved QOL and health-related QOL.

In the context of stoma formation, QOL can be understood as a more generalized health outcome, which is influenced upon by adjustment. It is generally accepted that QOL will change over time as adjustment to the stoma changes over time.¹² Adjustment appears to be a continuous dynamic process, which is dependent on multiple factors and situations.^{13,14}

While evidence concerning adjustment continues to grow, evidence related to the process of adjustment over time and how resumption of normality occurs is limited. Research supports that long-term adjustment is influenced by preoperative factors including receiving useful information from an ostomy (stomal therapy) nurse, having a cancer diagnosis, and information related to obtaining stoma supplies.¹⁵ Nevertheless, there is a lack of interventional studies seeking to test ways to address adjustment problems, which are common among this patient group.¹⁶ This integrative literature review seeks to inform practice by determining what is known about adjustment to stoma formation and establish where existing knowledge gaps occur.

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DOI: 10.1097/WON.0000000000000895

SEARCH STRATEGY

The guiding question for this review was: What is known about the adjustment trajectory for a person following ostomy surgery? Five databases were searched: CINAHL Plus, PsychINFO, Web of Science, Scopus, and MEDLINE. The following search terms were applied: “stoma” OR “ostomy” OR “colostomy” OR “ileostomy” AND “adjustment” AND “rehabilitation.” Inclusion criteria were empirical studies published from 2010 to 2020; all studies were published within 10 years of the literature search.

The search of these electronic databases identified 66 potential elements. Following removal of duplicates ($n = 11$) there were 54 elements. A further 17 were excluded as commentary or clinical education. The remaining 37 elements were read in full; 12 were excluded due to the focus of the study not being directly related to adjustment, resulting in 25 elements used in this review. We then reviewed reference lists of the 25 elements but found no additional elements. A summary of our search based on the PRISMA is provided in the Figure.¹⁷

Twenty-four of the 25 studies were from peer-reviewed sources. Three were randomized controlled trials, 2 were prospective, descriptive studies, 15 were cross-sectional, descriptive studies, and 5 were qualitative studies. The quality of the studies was evaluated using the Mixed Methods Appraisal Tool (MMAT).¹⁸ This instrument appraises the methodological quality of empirical studies. Elements were scored either 0 or 1 for each of the 7 appraisal items in the MMAT. The calculated mean quality score was 97%, and no studies were excluded on quality grounds.

DISCUSSION

Longitudinal evaluation of adjustment to living with an ostomy has not been studied extensively. Time since ostomy surgery among participants in longitudinal adjustment studies ranged from 6 months to 25 years.^{12,14,19} Several instruments have been developed to measure adjustment to an ostomy (Table).

Two quantitative studies measured adjustment at multiple time points post-stoma formation among people with a temporary or permanent stoma.^{12,14} Karadag and colleagues¹⁴ tracked adjustment at 1 and 6 months after stoma formation in a multisite study that enrolled 135 participants. Smith and colleagues¹² assessed adjustment in 107 participants at 3 time points: 1 week, 1 month, and 6 months after hospital discharge. Despite using different instruments, they established similar findings. Both studies found that patients who had a permanent ostomy adjusted better over time than those who had a temporary stoma. The poorest adjustment was found to exist among those who had an ileostomy and those who had cancer. Karadag and colleagues¹⁴ reported that overall scores on the Ostomy Adjustment Inventory (OAI-23) did not improve between 1 and 6 months. Nevertheless, individual factor analysis showed significantly improved scores for female, partnered, and unemployed participants. Adjustment improved in those who had a permanent stoma, had undergone emergency surgery, or had experienced complications.

Two cross-sectional studies were retrieved that evaluated psychosocial adjustment; findings from both suggest that adjustment improved in relation to time living with an ostomy.

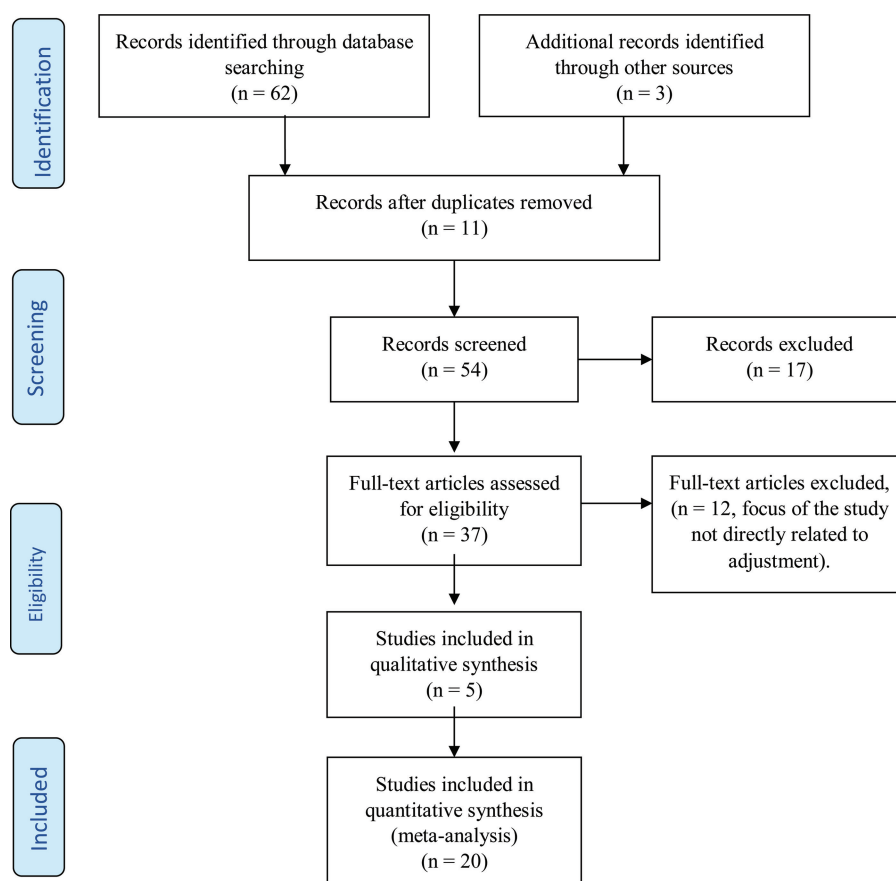


Figure. PRISMA diagram.¹

TABLE.**Integrative Review Results^a**

Author/Study Setting/Nation	Research Design	Sample Size	Stoma Type and Duration	Data Collection (Including Name of Tools Used and Time Points)	Intervention	Findings/Results
Adjustment and quality of life						
Indrebø et al, ⁹ Norway	Cross-sectional survey	n = 158	Permanent stoma >3 mo	Sociodemographic questionnaire, Short-Form 36 (SF-36), Quality of Life (QOL) Scale, Ostomy Adjustment Scale (OAS)	N/A	Ostomy-specific adjustment appears to be an important predictor of health-related quality of life (HRQOL) and overall QOL. Average QOL similar to general population. Ostomy patients scored lower on the SF-36 domains of physical role functioning, general health, vitality and MCS (mental component summary)
Adjustment over time						
Fingren et al, ²¹ Sweden	Prospective, exploratory study	n = 144	Colostomy or ileostomy	Ostomy Adjustment Scale (OAS) translated, visual analog scale (VAS) plus a QOL question and 2 open-ended questions (qual) 1 y after surgery	N/A	<i>No difference in adjustment for gender or diagnosis.</i> Worse adjustment in ileostomy + cancer than colostomy + cancer differences. Low adjustment also in sexual activities, attractiveness, participation in sports and physical activities. <i>High adjustment scores related to ostomy nurse contact, feeling well informed and knowing how to manage stoma. Ileostomy lower adjustment</i>
Thorpe et al, ²³ UK	Longitudinal, phenomenological, qualitative study	n = 12	Colostomy or ileostomy	In-depth unstructured interviews 3, 9, and 15 mo after stoma surgery	N/A	3 categories identified: participation in the social environment, interpersonal relationships, changes and challenges, setting and achieving goals. <i>Talking to others with a stoma helpful</i>
Thorpe et al, ²² UK	Phenomenological, qualitative study	n = 12	Colostomy or ileostomy	One-to-one interview 3, 9, and 15 mo after stoma surgery	N/A	9 themes including mastery of self-care and leakage associated with disruption of body function. Stoma formation causes a disconnect between the body and self, making them feel different, leading to negative feelings. Time does help them reconnect with their bodies but not to how things were.
Gautam and Poudel, ²⁶ Nepal	Descriptive, cross-sectional	n = 130	All stoma types >6 mo	OAI-23 translated	N/A	Lower psychosocial adjustment in perceived lack of family support, total dependence on others for stoma care, unemployment Higher adjustment = time Acceptance associated with better adjustment
Karadag et al, ¹⁴ Turkey	Prospective Quantitative descriptive	n = 135	Colostomy or ileostomy	Sociodemographic characteristics, stoma-related attributes Ostomy Adjustment Inventory (OAI) translated and validated 1 and 6 mo after stoma formation	N/A	Higher adjustment scores for permanent stoma, those who could self-care (19%) women, married Those who experienced <i>stoma and peristomal complications (14%) had lower adjustment at first measure</i> . Those who had someone else attend their stoma care scored lowest at the first measure then increased significantly.
Sun et al, ²⁴ USA	Qualitative	n = 33	Colostomy or ileostomy for 8-19 y	Focus groups	N/A	13 themes Persistent issues focused on clothing restrictions and adaptations, dietary concerns, equipment related, self-care, bowel function constant need to find solutions to adjust and readjust to living with a stoma

(continues)

TABLE.
Integrative Review Results^a (Continued)

Author/Study Setting/Nation	Research Design	Sample Size	Stoma Type and Duration	Data Collection (Including Name of Tools Used and Time Points)	Intervention	Findings/Results
Smith et al, ¹² USA	Prospective Quantitative descriptive	n = 74	Colostomy or ileostomy	"Satisfaction With Life Scale" and "Ladder Scale" (QOL) plus additional information about stoma-related problems, demographics, and reason for stoma Interviewed in hospital then survey mailed at 1 wk, 1 mo, and 6 mo after discharge	N/A	Hypothesis strongly supported for better adaption for permanent stoma. Permanent group increase in life satisfaction over time, not in temporary group. Increase in QOL for permanent group over time, not temporary group. Ostomy symptoms a negative predictor in QOL across both groups.
Correlates of adjustment						
Ayik et al, ⁴⁶ Turkey	Cross-sectional, descriptive	n = 95	Colostomy or ileostomy Stoma >2 mo	Sociodemographic Characteristics Form, Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-Sp) OAS-23 Stoma Quality of Life Scale (SQOL)	N/A	Spiritual well-being and QOL were both found to be associated with adjustment to stoma.
Xu et al, ³⁵ China	Correlational study	n = 118	Colostomy Stoma <6 to >37 mo	Sociodemographic, Social Impact Scale (SIS), OAI translated into Chinese	N/A	Stigma closely related to stoma adjustment <i>Degree of self-care important part of adjustment.</i> Those who are able to communicate with health professionals such as ostomy nurse after discharge adjust better. Social isolation and economic insecurity have a negative effect on adjustment. Higher patient level of stigma the lower the level of ostomy adjustment.
Sun and Lee, ²⁵ Korea	Cross-sectional, descriptive study	n = 156	Stoma type or duration not reported on	Face-to-face interviews, Modified Post-Traumatic Growth Inventory for cancer survivors, Revised Health Promotion Behaviour Scale, Psychosocial Adjustment to Illness Scale plus general characteristics	N/A	Level of psychosocial adjustment lower in those who could not hold down a job due to their cancer treatment. <i>Low adjustment also in difficulties in activities of daily living, having a stoma, not attending the support group.</i>
Nam et al, ³⁸ Korea	Quantitative descriptive	n = 125	All stoma types Stoma >6 mo	OAI-23 translated Social Support Scale Self-efficacy and instrumented developed and used in unpublished thesis	N/A	Adjustment increased as level of medical support increased Adjustment decreased as family support increased, may be due to medical expertise. Influenced by culture.
Xian et al, ³³ China	Descriptive, cross-sectional	n = 1010	Colostomy or ileostomy Stoma >1 mo	Demographic, 10-item Social Support Revalued Scale, 20-item Chinese version of the OAI via online survey platform	N/A	Ostomy adjustment scores higher in those with higher educational levels, not self-paying, lived in urban areas, <i>no peristomal skin conditions</i> , regular defecation pattern, no history of leakage, <i>independence in stoma care</i> , and <i>frequent communication with medical staff about their stoma and used social support.</i>

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TABLE.**Integrative Review Results^a (Continued)**

Author/Study Setting/Nation	Research Design	Sample Size	Stoma Type and Duration	Data Collection (Including Name of Tools Used and Time Points)	Intervention	Findings/Results
Gautam et al, ¹⁹ Nepal	Descriptive, cross-sectional	n = 130	Stoma (type not reported on) >6 mo	OAI-23 Clinical characteristics Sociodemographic characteristics	N/A	Men lower psychosocial adjustment score in All domains. Men lower social engagement—explained by perceived lack of family support, total dependence on others for stoma care. Adjustment in men improved over time. As women's age increased so did psychosocial adjustment.
Scardillo et al, ⁷ USA	Quantitative, descriptive	n = 48	Colostomy, ileostomy, and ileal conduit Time since stoma 3-300 mo (mean 182.3)	OAI-23 and the Resilience Scale, demographics	N/A	Found a statistically significant relationship between adjustment to stoma and resilience. <i>Higher levels of adjustment correlated with higher levels of resilience.</i> Women and employed participants described greater anxious preoccupation and social engagement than men and unemployed people
Riemenschneider, ⁴¹ USA	Descriptive, correlational study	n = 41	Colostomy, ileostomy, or ileal conduit Half had stoma <1 y; other half >1 y	OAI and Mishel Uncertainty in Illness Scale, demographic	N/A	The more <i>uncertainty a person experiences following stoma surgery the more difficult it is to adapt</i>
Hu et al, ³² China	Cross-sectional study	n = 129	Colostomy >1 mo to 37 y	General information questionnaire, Ostomy Adjustment Scale (OAS), Exercise of Self-care Agency Scale (ESCA), Perceived Social Support Scale (PSSS)	N/A	Overall adjustment was moderate. Adjustment was influenced by occupation, health insurance provider, and <i>independence with self-care. Peristomal skin complications and not participating in a support group also affected adjustment negatively.</i>
Cheng et al, ³⁴ China	Prospective, quantitative, descriptive	n = 54	Colostomy	Sociodemographic data questionnaire, Psychosocial Adjustment Scale (PAS) (translated), Stoma-related Knowledge Scale	N/A	<i>Stoma knowledge</i> positively correlated with psychosocial adjustment. <i>Self-care also important in factor in psychosocial adjustment</i>
Li et al, ⁴⁵ Taiwan	Descriptive, cross-sectional exploratory study	n = 45	Colostomy Stoma 2-17 y	2 validated tools: Chinese version Spiritual Well-Being Scale (SWBS) Psychosocial Adjustment to Illness Scale (PAIS)	N/A	Spiritual well-being strongly associated with psychosocial adjustment. Predictors for adjustment accounted for 53% of the variance (income change after surgery, self-related disease severity, spiritual well-being) Participants reported strong extended family relationships and poor adjustment in sexual relationships
Grant et al, ²⁸ USA	Qualitative	n = 33	Stoma type not reported	Focus groups	N/A	Food, resuming physical activity, sleep issues. Men identified little about adjustment, both groups identified use of humor to cope. Body image, depression only mentioned by women in low HRQOL group. Many comments about social well-being. Sexuality and the challenge of travel mentioned by both groups.

(continues)

TABLE.
Integrative Review Results^a (Continued)

Author/Study Setting/Nation	Research Design	Sample Size	Stoma Type and Duration	Data Collection (Including Name of Tools Used and Time Points)	Intervention	Findings/Results
Simmons et al, ⁴⁴ UK/Japan	Comparative, cross-sectional	n = 948	Colostomy, ileostomy, or ileal conduit Stoma 2 to over 10 y	OAI plus demographic data	N/A	Suggests culture influences psychosocial adjustment to life with a stoma. <i>Age, gender, ostomy type no relationship with adjustment.</i> The UK adjusted quicker. Time since surgery and country of residence predictors. Culture impacts on adjustment.
Altschuler et al, ⁸ USA	Qualitative	n = 30 women	Colostomy Stoma 5-30 y	City of Hope QOL for ostomy survey, semistructured interviews	N/A	<i>Only women with husbands reported as giving positive support.</i> Support was described as central to their psychosocial adjustment to having a stoma. Women reported that withdrawal of support from husbands or male partners experienced a negative impact on their adjustment to having a stoma and their lives generally.
Adjustment-promoting interventions						
Wang et al, ⁴⁷ China	RCT	n = 203	Colostomy, ileostomy, or ileal conduit New stoma	Demographic and clinical characteristics, OAI-23, Stoma Self-Efficacy Scale (SSES), stoma complications 1, 3, and 6 mo after discharge	Study group had a mobile app for follow-up with ostomy nurse	Follow-up via a mobile app improves psychosocial adjustment and self-efficacy 1, 3, and 6 mo higher OAI scores Between-group difference in self-efficacy was significant. No difference in stoma complication.
Hamidi et al, ⁴⁸ Iran	RCT	n = 64	Stoma type not reported New stoma	Demographic, disease information, Olbrisch Ostomy Adjustment 6 text messages every wk for 6 wk about their stoma. Third- and fourth-week education session with ostomy nurse. Third, seventh, 23rd, and 27th-day follow-up phone call from ostomy nurse to answer questions and check texts received	Text/phone follow-up	After the intervention ostomy adjustment scored different in both groups. The <i>adjustment mean score increased in the experimental group after each intervention</i>
Zhang et al, ⁴³ China	RCT	n = 103	Colostomy New stoma	Five instruments: demographic and hospital length of stay, OAI, Stoma Self-Efficacy Scale, satisfaction with care and stoma complications Phone call from ostomy nurse 3-7, 14-20, and 23-27 d after discharge	Structured, individualized educational and supportive phone follow-up program	At 3 mo, study group had <i>better adjustment, higher stoma self-efficacy, higher satisfaction with care, and less stoma complications</i> than control group Top 3 complications skin irritation, stoma retraction, and stenosis

Abbreviations: N/A, not available; RCT, randomized controlled trial.

^aWithin each category, studies organized in reverse chronological order; *italicized* text identifies key points of findings/results.

Gautam and coworkers¹⁹ used the OAI-23²⁰ to measure psychosocial adjustment in 130 Nepalese persons living with an ostomy from 6 months to 25 years. Lower psychosocial adjustment was associated with perceived lack of family support, dependence on others for ostomy care, and poor acceptance of the ostomy. Even though higher psychosocial adjustment was established over time, the study findings differed from findings reported by Karadag's group, who reported lower

adjustment in unemployed respondents.¹⁴ Differences in these findings may be attributable to differences in study design, the large timeframe since ostomy creation in the study by Gautam and coworkers, and country of origin. Fingren and associates²¹ evaluated adjustment among 144 participants with an ostomy a year after stoma surgery using the Ostomy Adjustment Scale-23.⁵ Lower adjustment was found among those who had an ileostomy and those who had cancer. Low adjustment

scores were linked to lower levels of sexual activity, perceived attractiveness, and participation in sports and physical activities. Higher adjustment scores were associated with contact with an ostomy nurse, feeling well informed, and knowing how to manage the stoma.

The 2 qualitative studies included in this integrative review provided further insights into ostomy adjustment over time. Two studies evaluated adjustment over time using a phenomenological approach with a focus on social adaptation and adjusting to body change.^{22,23} The 3 main categories linked with disrupted social worlds among respondents were “participation in social environment,” “interpersonal relationships,” and “setting and achieving goals.” Partner support influenced acceptance of their ostomy, specifically positive partner support facilitating self-acceptance and adaptation. For some participants, it took up to 9 months to establish stable routines or strategies to manage the unpredictability of their ostomy output and develop a sense of mastery over their stoma care.

Beyond 5 years, colorectal cancer survivors living with an ostomy reported having to make adjustments related to ongoing issues in a qualitative study set in Korea.²⁴ These identified in this qualitative study were adapting clothing, dietary concerns, appliance (pouching system) management, self-care, and bowel function. Existing findings regarding lower adjustment among people with cancer were highlighted in Sun and Lee’s study of colorectal cancer survivors living with an ostomy.²⁵ Similar to other researchers, they found that respondents with an ostomy had lower psychosocial adjustment than those without one.²⁵

Considered collectively, findings from these studies suggest that adjustment to an ostomy is a multifaceted and ongoing process, which is impacted by acceptance and the availability of support. Reestablishment of body image and self-image is likely to be linked to acceptance. Mastery of ostomy care and elimination functions may be linked to ongoing adjustment and this process may continue for a year or longer following ostomy surgery.²²⁻²⁴

Correlates of Adjustment

Adjustment to an ostomy is a dynamic process influenced by multiple intrinsic and extrinsic factors. Extant findings regarding key correlates of adjustment are outlined next. In most cases, correlates have been established via cross-sectional, descriptive study designs.

Although age and adjustment were not associated in any of the abstracted studies, sex was shown to be of some potential importance in 2 cross-sectional studies using the OAI-23.²⁰ Gautam and Poudel²⁶ demonstrated that Nepalese men had lower psychosocial adjustment and lower social engagement scores than women. Males also reported more negative emotions and lower acceptance that appeared to be related to perceived lack of family support, and the need for employment among males. Interestingly, adjustment scores among both men and women were lower when they were dependent on others for their stoma care. Another study⁷ used the OAI-23²⁰ with a Resilience Scale²⁷ to evaluate the relationship between resilience and adjustment in a group of 48 peer support group members with permanent ostomies. Even though the studies reported on different aspects of adjustment, both identified that males, particularly if they were unemployed, experienced lower psychosocial adjustment levels than females.

The one qualitative study among long-term survivors of colorectal cancer located for this review²⁸ identified women as

more likely to describe specific psychosocial adjustment issues than men such as body image, depression, coping, and adjustment. Commonalities reported between genders related to managing diet, physical activity, social support, and the challenges around intimacy, sexuality, and travel.

Ostomy Self-care

The task of establishing independent stoma care dominates the postoperative period, with length of hospital stay impacting on the time for this process to occur.²⁹ With enhanced recovery programs becoming more commonplace, the average hospital length of stay following elective stoma surgery has decreased in recent years.³⁰ Study findings suggest that preoperative ostomy education plays an integral part in an enhanced recovery program and contributes to reducing delayed discharge and length of stay in people having elective stoma surgery.^{30,31} A 2018 Australian study reported a median time to reach independence with ostomy care of 7 days. Factors enhancing independence in ostomy care were younger age, male sex, preoperative stoma site marking, and treatment in a public hospital.²⁹

Achieving independent in ostomy self-care is an important part of positive adjustment, and multiple studies have found that those who are not independent in self-care do not adjust as well as persons who master ostomy self-care.^{14,19,32-35} Four cross-sectional studies were retrieved that analyzed independence in ostomy self-care; all were conducted in China and all used a Chinese language version of the OAI-23.³⁶ Sample sizes ranged from 54 to 1010; a majority of participants had a permanent colostomy.^{33,34}

Cheng and colleagues³⁴ explored associations between ostomy knowledge, self-care ability, and adjustment in a male population with a permanent colostomy ($n = 54$). Higher ostomy knowledge and ostomy-related self-care were positively associated with adjustment. Using a cross-sectional approach, Hu and coinvestigators³² explored contributing factors to adjustment in 129 participants with a permanent colostomy; 69.7% were male. The vast majority ($n = 50/93.03\%$) of study participants reported being independent in ostomy care and just over a third ($n = 19/35.66\%$) had experienced a peristomal skin condition. Independence with self-care was positively correlated with increased adjustment. Additional factors influencing adjustment to an ostomy were spousal acceptance of the ostomy, aversion to the stoma, and the occurrence of peristomal skin complications. Attending an ostomy support group enhanced adjustment whereas lower insurance coverage (less than full coverage of ostomy-related costs including supplies) reduced adjustment.

A larger cross-sectional study set in China enrolled 1010 participants with a temporary or permanent colostomy ($n = 823/81\%$) or ileostomy ($n = 187/18.5\%$).³³ Low adjustment was associated with less independence with ostomy care, persistent leakage from the pouching system, peristomal skin complications, irregular defecation, lack of communication with medical staff, lower levels of social support, lower educational level, living in a rural community, and inadequate insurance coverage. Similar to studies with a smaller sample, this study also found that lower socioeconomic status is associated with reduced levels of adjustment to an ostomy.

The most recent study identified self-care as an important aspect of adjustment and evaluated stigma with stoma adjustment.³⁵ One hundred eighteen participants participated in the study; those experiencing leakage scored lower on adjustment to an ostomy while those who communicated regularly with

medical staff were able to better self-care. Stigma was negatively associated with stoma adjustment; the authors recommended ongoing support post-discharge to facilitate adjustment long term. Stigma is defined as a mark of disgrace associated with a person, a personal quality, or a personal circumstance; a mark on the skin³⁷; it is associated with disgust and feelings of shame.

Support From Healthcare Professionals

Variability exists regarding the level of medical and nursing support available between hospitals, and more widely, between communities worldwide. Nam and colleagues³⁸ published findings of a descriptive study that investigated the relationships among social support, self-efficacy with adjustment to an ostomy in 125 participants living with an ostomy for an average of 10 years. They administered the OAI-23,²⁰ Social Support Scale,³⁹ and an instrument developed and used in an unpublished master's thesis⁴⁰ and found that support from healthcare professionals is time dependent and viewed by participants as essential to successful adjustment to an ostomy. They also found that adjustment improved as the level of medical support increased, but deteriorated when reliance on family support increased. The authors attributed this to the perceived burden and guilt that older participants may feel after being supported through cancer treatment. Korean culture identifies the eldest of the household as holding direct responsibility for the welfare of the family. They further concluded that access to medical support over time was the most important factor contributing to adjustment of all they evaluated.

Access to an ostomy care nurse in particular has been shown to be a key driver of adjustment to living with an ostomy; ostomy nurses provide essential services to these patients including education about ostomy care, psychosocial support, and counseling related to living with a stoma.^{21,41} Contact with an ostomy care nurse and feeling well informed about how to care for the stoma were the strongest predictors of adjustment in a 2018 Swedish study.²¹ A North American study⁴¹ that enrolled 51 participants reported an association between uncertainty and adaptation among participants with a new ostomy; specifically, the involvement of an ostomy nurse reduced uncertainty related to the new ostomy and enhanced adjustment.

Support From Others (Nonhealthcare Professionals)

Our search found no quantitative studies that exclusively examined the effect of support from others (nonhealthcare professionals) on adjustment to an ostomy. Nevertheless, spousal acceptance of an ostomy was identified as a predictor of adjustment in a cross-sectional study set in China.³² A qualitative study was also retrieved that explored this important issue. The role of partner support was described as central to adjustment in a qualitative study that enrolled 22 adult females with colorectal cancer and a permanent ostomy created more than 5 years prior to data collection.⁸ Study findings suggest that emotional and psychosocial support from family and others is central to adjustment and feeling "normal" again. This study also examined respondents' experiences with physical support with pouching system changes and its influence on adjustment. Partners' assistance with ostomy pouch changes enhanced empathy and adjustment to their ostomy. In contrast, withdrawal of support from partners prompted negative impacts on adjustment and health-related QOL.

Evidence regarding the role of attendance at peer-to-peer support groups on adjustment is limited. A single study was

found that reported on attendance at a support group was associated with improved adjustment.²⁵ Nevertheless, evidence suggests other benefits of participation in ostomy support groups such as ability to share experiences and challenges when living with an ostomy.⁴² One study was located that described peer-to-peer support as integrated into usual practice in the postoperative period. Unfortunately, no evaluation of this process on psychosocial outcomes such as adjustment to an ostomy was reported.⁴³

Culture and Spirituality

Culture and spirituality are integral to health-related QOL and ostomy surgery has the potential to impact the individual's spirituality, cultural beliefs, or behaviors. Few studies were found that explored the culture and spiritual impact of an ostomy. The largest study compared psychosocial adjustment among British (n = 464) and Japanese participants with an ostomy (n = 484).⁴⁴ Participants from the UK were found to adjust faster than their Japanese counterparts. British people were more accepting of the ostomy and more likely to participate in social activities after stoma surgery. This was particularly noticeable among those who had had their stoma for more than 2 years. The authors postulated that traditional Japanese cultural beliefs about disease and implications of self-infliction and avoidability may have contributed to the prolonged adjustment period among Japanese participants.

Spiritual well-being was found to be associated with psychosocial adjustment in 2 cross-sectional studies. A study of 45 Taiwanese participants living with a colostomy and colorectal cancer reported a significant association between spiritual well-being and psychosocial adjustment.⁴⁵ Positive adjustment was more common among those who reported strong extended family relationships. More recently, a cross-sectional study of 95 Turkish respondents with various types of ostomies found that spiritual well-being and health-related QOL were associated with adjustment.⁴⁶

Adjustment-Promoting Interventions

Three randomized controlled trials were found that evaluated interventions designed to provide adjustment to an ostomy.^{43,47,48} Researchers evaluated telecommunication-based clinical support modalities: phone call, mobile app, and text messages. The first study evaluated adjustment among 103 Chinese participants with a permanent colostomy.⁴³ The intervention group (n = 52) received 2 nurse phone calls in addition to the standard follow-up care after discharge. The intervention group had fewer stoma complications at 1 and 3 months post-surgery, and their self-rated adjustment was significantly higher at 3 months, than the control group (n = 51). These findings were supported by a later randomized controlled trial that enrolled 203 participants with recent ostomies; the intervention group (n = 100) receiving a mobile phone app.⁴⁷ The app provided appointment booking, photographic diagnosis, consultation, and a contact link for support from the ostomy care nurse. Significantly, higher adjustment was found at all follow-up time points at 1, 3, and 6 months after discharge for those in the intervention group. Finally, a trial of 64 Iranians living with an ostomy evaluated the use of text messages in conjunction with an interactive follow-up program.⁴⁸ Findings revealed higher levels of adjustment at 6 and 12 weeks after discharge among participants receiving the experimental intervention.

Considered collectively, findings from these trials indicate that follow-up beyond face-to-face clinic visits using phone-based technology improves adjustment to an ostomy. We assert these interventions are efficacious because they offer frequent access to an ostomy nurse, previously identified as associated with adjustment.^{21,33,41}

KNOWLEDGE GAPS AND RESEARCH IMPLICATIONS

A significant identified gap in the adjustment literature is a paucity of evidence concerning the role and importance of support groups and peer-to-peer support. Peer-to-peer support group participation has been studied most extensively in other fields; potential benefits include sharing experiences, insights and challenges among persons with an ostomy, along with giving and receiving support.⁴⁹

Our review also found a paucity of studies set in North America, Europe, and Australasia on this topic; studies published in the past 10 years are primarily set in Asia. In addition, many studies are cross-sectional in design, which limits our ability to evaluate the effect of time on adjustment to an ostomy. Additional research using a longitudinal design is needed to more clearly describe the adjustment trajectory following an ostomy, the effect of various facilitators and barriers on adjustment, and the efficacy of interventions designed to promote adjustment following stoma surgery.

CONCLUSIONS

An integrative literature review located evidence suggesting that adjustment to an ostomy is enhanced by knowledge of the ostomy and its care, independence in stoma care, and access to health professionals and ostomy care nurses in particular. Support takes many forms, and partner support has been identified as especially important. Sex, cultural, and spiritual factors also influence adjustment to an ostomy.

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DOI: 10.1097/WON.0000000000000919