

# The role of coping strategies on health-related quality of life in adults with anorectal malformations

C. Grano<sup>1</sup> · M. Fernandes<sup>1</sup> · D. Aminoff<sup>2</sup> · S. Bucci<sup>1</sup> · F. Lucidi<sup>3</sup> · C. Violani<sup>1</sup>

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## Abstract

**Purpose** Coping strategies have been acknowledged as crucial for the well-being and for health-related quality of life (HRQoL). The main aim of the present study is to determine whether different types of coping strategies predict HRQoL in patients born with ARM, above and beyond the variance explained by fecal and urinary continence.

**Methods** 71 adult patients from the Italian Parents' and Patients' Organization for Anorectal Malformations (AIMAR) participated in the study. Participants completed measures of fecal and urinary continence of the Hirschsprung Disease/Anorectal Malformation Quality of Life (HAQL) (Hanneman et al. in *Dis Col Rect* 44:1650–1660, 2001), the Short Form Health Survey (SF-36) (Apolone and Mosconi in *J Clin Epidemiol* 51:1025–1036, 1998), and the Brief Coping Orientation to Problems Experienced (COPE) Inventory (Carver in *Int J Behav Med* 4:92–100, 1997), which measures different coping strategies: maladaptive, problem-focused and emotion-focused.

**Results** Hierarchical regression analyses showed that fecal continence ( $\beta = 0.53$ ,  $p < 0.01$ ) and urinary continence significantly predict ( $\beta = 0.23$ ,  $p < 0.05$ ) Physical HRQoL. Fecal continence ( $\beta = 0.36$ ,  $p < 0.01$ ) and maladaptive coping strategies significantly predict ( $\beta = -0.27$ ,  $p < 0.05$ ) Mental HRQoL.

**Conclusion** Besides considering the importance of fecal and urinary continence for Physical HRQoL, these findings indicate that maladaptive coping strategies are associated with worse Mental HRQoL. Interventions aimed at enhancing the patients' HRQoL should target coping strategies by reducing denial, behavioral disengagement, substance abuse, and self-blame.

**Keywords** Anorectal malformations (ARM) · Health-related quality of life (HRQoL) · Coping strategies · Adult patients · Fecal continence · Urinary continence

## Introduction

Anorectal malformations (ARM) are congenital diseases of the rectum with an incidence across the world of 2.0–2.5 per 10,000 live births [4]. As a chronic disease, some sequelae of the malformation often continue into adulthood, and patients have to cope with the long-lasting consequences of the disease, including fecal and urinary incontinence [5], which may affect and impair their health-related quality of life (HRQoL) [6].

In the last decade, a number of studies has shown an increasing interest in the role that personal and social resources (e.g., social support, self-efficacy, resilience) may have in enhancing or in impairing quality of life. In line with a number of health regulation models (e.g., Leventhal et al. [7]), health-related quality of life is not

✉ C. Grano  
caterina.grano@uniroma1.it

D. Aminoff  
aimar@aimar.eu;  
http://www.aimar.eu

<sup>1</sup> Department of Psychology, Sapienza University of Rome,  
Via dei Marsi, 78, 00185 Rome, Italy

<sup>2</sup> AIMAR, Italian Parents and Patients Organization  
for Anorectal Malformation, Via Tripolitania, 211,  
00199 Rome, Italy

<sup>3</sup> Department of Developmental and Social Psychology,  
Sapienza University of Rome, Via dei Marsi,  
78, 00185 Rome, Italy

only directly influenced by the illness itself (present symptoms), but it can also be significantly influenced by the individual's personal and social resources [8]. Among these resources, coping strategies have been acknowledged as a psychological construct crucial for individuals' adaptation outcomes [8], such as subjective well-being [9], perceived quality of life [10], health satisfaction [11] and health outcomes [12].

According to Lazarus and Folkman [8], coping can be defined as “cognitive and behavioural efforts to meet specific requirements, internal and/or external, which are assessed as exceeding/or being within the limits of the individual's resources”. Individuals may use different coping strategies when facing stressful situations, which are characterized as problem-focused (e.g., planning, seeking support) or emotion-focused (e.g., denial, avoidance, seeking emotional support, accepting). Problem-focused coping strategies are aimed to change the stressor and solve the problem, while emotion-focused coping strategies are used to regulate and reduce the emotional distress [13]. In addition, some of these coping strategies can be considered adaptive (e.g., seeking emotional support, planning) or maladaptive (e.g. denial, avoidance) [14]. For example, getting emotional support from others, taking action to try to make the situation better, and planning strategies to solve the problem are generally considered as adaptive strategies. Conversely, using alcohol or other drugs to feel better, criticizing oneself, not believing in what is happening, or giving up in dealing with the situation, are examples of generally maladaptive coping strategies.

Numerous studies have been shown an increased interest in the role of coping strategies in chronic disease health outcomes [15–21]. For example, Knowles et al. [21], on a sample of adult patients with a stoma, found that illness perceptions and maladaptive coping strategies (e.g., ignore problems) exacerbated depression and anxiety symptoms, while self-efficacy and emotion-focused coping strategies (e.g., seek advice) decreased depression but not anxiety. In two studies conducted with patients with inflammatory bowel disease (IBD), adult patients who used adaptive coping styles perceived higher QoL compared with those who used maladaptive coping styles [15, 18].

Similarly, Petrak et al. [10], in a cross-sectional study with 1322 patients suffering from IBD, have shown that active coping strategies (e.g. actively seeking information and actively undertaking efforts to solve problems) were negatively related with patients' Physical HRQoL during an active inflammatory phase. Furthermore maladaptive coping strategies (e.g. social withdrawal, self-pitying, pessimistic thinking) were strongly and negatively associated with Physical and Mental HRQoL.

Nevertheless, to our knowledge, no studies have considered the role of coping strategies in the QoL of adult patients with ARMs. In line with this premises, the aim of the present study is to investigate the role of different types of coping strategies on health-related quality of life in a sample of Italian adults born with ARM.

## Method and materials

Participants, at least with 16 years old and who underwent surgical procedures to correct anorectal malformations, were recruited in 2013/2014 through the Italian Organization for Anorectal Malformations (AIMAR). A battery of questionnaires and a letter describing the aims and the procedures of the study were sent by ordinary mail to all adult patients ( $\geq 16$  years old) who were in the AIMAR registry, for a total of 160 sent questionnaires. The study was approved by the ethical committee of the Department of Psychology of the “Sapienza” University of Rome. All participants signed an informed consent before answering the questionnaires. The informed consent was signed by the patient if he/she was at least 18 years old and by parents (most typically mothers) if the patient was under this age.

### Sociodemographic characteristics

The questionnaire asked each participant to provide sociodemographic information including age, gender, and education level (primary school, secondary school, or further/higher education).

### Type of fistula

To identify the type of malformation, patients were asked to choose one alternative from a list of anomalies based on the Krickenbeck classification system on fistulas [22].

### Fecal and urinary continence

Fecal continence and urinary continence scales of the Italian version of the Hirschsprung Disease/Anorectal Malformation Quality of Life (HAQL) [23] questionnaire were used to assess the degree of fecal and urinary continence. The HAQL is a 42-item disease-specific QoL questionnaire developed by Hanneman et al. [1]. It assesses eleven areas of QoL. For the purpose of the present study, only fecal continence (e.g., soiling during the day or night), and urinary continence (e.g., loss of urine before reaching the bathroom) subscales were used. For each item, respondents were asked to indicate the frequency of occurrence in the past week using a 5-point scale ranging from 1 (never) to 5 (always). Responses to all of the items

of the HAQL were first recoded and linearly transformed into a 0–100 scale, with higher scores indicating more fecal and urinary continence. Then, scores for the two subscales were calculated by averaging the items of each subscale. In the present study, the reliabilities of the fecal continence and urinary continence subscales were excellent, with alpha values, respectively, of 0.91 and 0.92.

### Measure of coping strategies

Coping strategies were measured through the Brief Coping Orientation to Problems Experienced (Brief COPE) [3], which is a 28-item self-report questionnaire subdivided in 14 subscales that assesses a number of different coping behaviors and thoughts: (1) active coping; (2) planning; (3) use of instrumental support; (4) use of emotional support; (5) venting; (6) behavioral disengagement; (7) self-distraction; (8) self-blame, (9) positive reframing; (10) humor; (11) denial; (12) acceptance; (13) religion; and (14) substance use. Each item is rated on a 4-point Likert scale, ranging from 1 (“I haven’t been doing this at all”) to 4 (“I’ve been doing this a lot”). For the present study, in line with Carver et al. [14] and with recent studies by Knowles et al. [21, 24], three interrelated coping strategies were derived: problem-focused, emotion-focused and maladaptive coping. Problem-focused coping is measured by eight items taken from the following subscales: active coping, planning, seeking for instrumental support, and self-distraction. Emotion-focused coping comprises ten items taken from the subscales: seeking emotional support; positive reframing, acceptance, humor, and turning to religion. Maladaptive coping strategies include ten items from the following subscales: denial, substance use, venting, behavioral disengagement, and self-blame. These three subscales have demonstrated a satisfactory internal reliability, with an alpha coefficient of 0.77 for problem-focused coping, of 0.74 for emotion-focused coping and of 0.79 for maladaptive coping.

### Measure of health-related quality of life

Health-related quality of life was assessed using the Italian version of the Short Form Health Survey (SF-36) [25]. The SF-36 is a 36-item self-reported health questionnaire and includes eight subscales: physical functioning, social functioning, role limitations due to physical problems, role limitation due to emotional problems, mental health, energy/vitality, pain, and general health perception. These scales can be summarized in a physical functioning score and the others in a mental functioning score, both ranging from 0 to 100, with lower scores indicating worst health functioning. For the purpose of the present study, only the physical and the mental functioning scores were used.

### Statistical analyses

Reliability analyses for each scale considered in the study were calculated by means of Cronbach’s alpha. Secondly, Pearson correlation coefficients were conducted to examine the relations between fecal continence, urinary continence, coping strategies and the dependent variables (Physical and Mental HRQoL).

Finally, to analyze which variables predict Physical and Mental HRQoL, two sets of hierarchical regression analyses were performed considering as outcome variables, respectively, Physical HRQoL and Mental HRQoL. In both regressions, problem-focused, emotion-focused and maladaptive coping strategies were considered as predictors, once the impact of fecal continence and urinary continence was taken into account. *P* values lower than 0.05 were considered significant. Analyses were conducted using SPSS v21 for Windows.

### Results

The questionnaires were completed by a total of 71 patients, for a response rate of 44.4 %. During the preliminary analysis, seven questionnaires were excluded due to missing data in critical items. Of the final sample, 38 (59.4 %) were males and 26 (40.6 %) were females. Age ranges from 16 to 46 years with a mean age of 25.32 years (SD = 8.32). Patient characteristics are presented in Table 1.

The type of fistula (using the Krickenbeck classification system) is summarized in Table 2. In the present sample, the number of surgical procedures ranged from 1 to 40 with a mean of 5.12 (SD = 5.41).

Prior to consider regression analyses, correlations among fecal continence, urinary continence, coping strategies, and the HRQoL scales (Physical and Mental HRQoL) were performed (Table 3).

**Table 1** Patient characteristics

	<i>N</i>	%
Gender		
Males	38	59.4
Females	26	40.6
Education level		
Middle school	18	28.1
Higher school	27	42.2
Degree	17	26.6
Marital status		
Single	53	82.8
Married	8	12.5

Physical HRQoL was negatively and significantly correlated with problem-focused coping strategies ( $r = -0.27$ ,  $p < 0.05$ ) and with maladaptive coping strategies ( $r = -0.30$ ,  $p < 0.05$ ), but did not significantly correlate with emotion-focused coping strategies. Moreover, Physical HRQoL was positively correlated with fecal continence ( $r = 0.57$ ,  $p < 0.01$ ) and urinary continence ( $r = 0.29$ ,  $p < 0.05$ ).

Mental HRQoL was significantly and negatively correlated only with maladaptive coping strategies ( $r = -0.37$ ,  $p < 0.01$ ). Moreover, Mental HRQoL significantly and positively correlated with fecal continence ( $r = 0.45$ ,  $p < 0.01$ ).

To analyze whether problem-focused, emotion-focused and maladaptive coping strategies might predict Physical and Mental HRQoL, two sets of hierarchical regression analyses were conducted, with the three styles of coping strategies as predictors of the two different components of HRQoL (Physical and Mental HRQoL), which were considered, respectively, as outcome variables in each

analysis. In both analyses, we controlled for fecal continence and urinary continence.

In the first hierarchical regression analysis, considering Physical HRQoL as the outcome, fecal continence and urinary continence were entered at the first step, and problem-focused coping, emotion-focused coping and maladaptive coping strategies at the second step. The results indicated that in the first step, fecal continence and urinary continence were significant, explaining 38.1 % of the variance in Physical HRQoL. At the second step, the total variance explained by the model as a whole was 38.5 % [ $F_{(5,58)} = 7.27$ ,  $p < 0.01$ ], and coping strategies did not significantly contribute in explaining Physical HRQoL. In the final model, only fecal continence ( $\beta = 0.53$ ,  $p < 0.01$ ) and urinary continence ( $\beta = 0.23$ ,  $p < 0.05$ ) were significant, with higher levels of fecal continence and urinary continence predicting better Physical HRQoL.

Following the same rationale, in the second hierarchical regression analysis, considering Mental HRQoL as the outcome, fecal continence and urinary continence were entered at the first step, and problem-focused, emotion-focused, and maladaptive coping strategies were entered at the second step. The results indicate that in the first step, fecal continence was the only significant predictor, explaining 20.0 % of the variance in Mental HRQoL. At the second step, fecal continence ( $\beta = 0.36$ ,  $p < 0.01$ ) and maladaptive coping strategies ( $\beta = -0.27$ ,  $p < 0.05$ ) significantly predicted Mental HRQoL, with lower levels of fecal continence and higher use of maladaptive coping strategies predicting worse Mental HRQoL. This final model explained 26.4 % of the variance in Mental HRQoL [ $F_{(5, 58)} = 4.15$ ,  $p < 0.01$ ]. The results of the hierarchical regression models for Physical and Mental HRQoL are reported in Table 4.

**Table 2** Classification on the type of fistula

	<i>N</i>	%
Imperforate anus	16	25.0
Perineal fistula	7	10.9
Rectobulbar urethral fistula	3	4.7
Rectoprostatic urethral fistula	5	7.8
Rectobladder neck fistula	3	4.7
Vestibular fistula	5	7.8
Vaginal fistula	4	6.3
I do not know	5	7.8
Other type of fistula	7	10.9
Did not give an answer	9	14.1

**Table 3** Pearson correlation among fecal continence, urinary continence, coping strategies, Physical and Mental HRQoL

	1	2	3	4	5	6	7	Mean	SD	Range
1. Gender	–									
2. Fecal continence	–0.01							80.12	20.23	0–100
3. Urinary continence	0.09	0.08						83.79	24.57	0–100
4. Problem-focused coping	–0.21	–0.29*	–0.25					2.47	0.66	1–4
5. Emotion-focused coping	0.05	–0.11	–0.03	0.50**				2.23	0.54	1–4
6. Maladaptive coping	0.04	–0.38*	–0.24	0.43**	0.21			1.65	0.48	1–4
7. Physical HRQoL	–0.09	0.57**	0.29*	–0.27*	–0.06	–0.30*		51.23	7.75	0–100
8. Mental HRQoL	–0.18	0.45**	0.02	–0.16	0.01	–0.37**	0.33**	44.56	10.39	0–100

\*  $p < 0.05$ , \*\*  $p < 0.01$

**Table 4** Hierarchical regression analyses for Physical and Mental HRQoL

Predictors	Physical HRQoL, $\beta$	Mental HRQoL, $\beta$
Block 1 $\Delta R^2$ ( $R^2$ )	0.38** (0.38)	0.20** (0.20)
Fecal continence	0.55**	0.45**
Urinary continence	0.25*	−0.02
Block 2 $\Delta R^2$ ( $R^2$ )	0.004** (0.39)	0.06** (0.26)
Fecal continence	0.52**	0.36**
Urinary continence	0.23*	−0.08
Problem-focused coping	−0.07	−0.01
Emotion-focused coping	0.04	0.11
Maladaptive coping	−0.03	−0.27*
$R^2$ model (adjusted $R^2$ )	0.39** (0.33)	0.26** (0.20)

\*  $p < 0.05$ , \*\*  $p < 0.01$

### Discussion

The role of coping strategies in HRQoL outcomes has been little studied in adult patients with ARM, despite being considered an important psychological construct in chronic illness management [8]. Therefore, the main aim of the present study was to determine whether different types of coping strategies predict HRQoL in adult patients born with ARM, once the variance explained by fecal and urinary continence was taken into account. More specifically, we were interested in investigating whether coping strategies influence two components of health-rly physical and mental functioning, measured through the SF-36, a widely used health-related quality of life questionnaire.

Considering Physical HRQoL, our results suggest that the only significant predictors were fecal continence and urinary continence, that is, higher scores in fecal and urinary continence predicted better physical functioning and lower role limitation due to physical symptoms (e.g., less problems with work, fewer daily activities restrictions). This result is in line with the findings of previous cross-sectional [26–28] and longitudinal [23] studies conducted with ARM patients, which found that QoL was affected by fecal and urinary incontinence.

Considering Mental HRQoL, our findings highlighted a significant positive effect of fecal continence and a significant negative effect of maladaptive coping strategies on Mental HRQoL. In other words, lower levels of fecal continence and higher use of maladaptive coping strategies were associated with worse levels of Mental HRQoL. It seems that fecal continence is very relevant for Mental and Physical HRQoL, possibly due to the high prevalence among patients with ARM and probably because in adulthood, the lack of defecation control may also have

consequences related to other crucial aspects, such as sexual functioning and sexual well-being [26, 28].

In our findings, the other important determinants of Mental HRQoL were maladaptive coping strategies. Specifically, maladaptive coping strategies, such as thinking that the situation is not real (denial), giving up trying to deal with the situation (behavioral disengagement), using alcohol to feel better (substance use), or criticizing oneself (self-blame), were associated with worse mental functioning, that is, with worse levels of emotional well-being, less energy and more fatigue, and with a higher role limitations due to emotional problems. These results are in line with previous research that reported links between maladaptive coping and increased anxiety and depressive symptoms in other chronic diseases [19, 20]. For example, Danesh et al. [15], considering a sample of patients with IBD, have shown that maladaptive strategies (e.g., fatalism and venting) were inversely correlated with QoL.

Differently from other studies, we did not find a significant effect of adaptive strategies, namely problem-focused and emotion-focused coping strategies neither on the Physical nor on the Mental HRQoL.

Regarding the problem-focused strategies, in a systematic review by McCombie et al. [29] in IBD patients, the link between these strategies and psychological outcomes was weakly positive. Indeed, in our study, although problem-focused strategies did not exert a significant contribution on Mental and Physical HRQoL in the regression analyses, they were significantly and negatively correlated with Physical HRQoL, indicating that those patients who used more problem-focused strategies were also those who had worse perceptions of their physical functioning. It may be possible that patients who perceived a worse physical functioning recurred more frequently to the use of problem-focused strategies (such as following a special diet and seeking advice from other people regarding what to do) in the attempt to change their situation, even though, these attempts may be ineffective in enhancing their physical quality of life.

In our findings, emotion-focused strategies, as mentioned before, did not significantly influenced HRQoL. Nonetheless, in the study of Danesh et al. [15], the authors reported that emotion-focused strategies (e.g., seeking support and optimism) were positively correlated with QoL. Similarly, in another recent research with stoma patients [21], an association between emotion-focused coping and the decrease of depression feelings was found, with individuals adopting more emotion-focused strategies being more likely to report higher levels of perceived health status. More research is needed to clarify this association.

Our study presents some limitations that should be addressed. A first limitation is that the sample is limited,

although it includes the 44.4 % of the entire adult patient population registered at the Italian association of ARM patients. Another limitation is the cross-sectional design of the study that cannot give assurance regarding the direction of the associations. Therefore, future longitudinal studies are necessary to explain better the observed relations and to evaluate how coping strategies may change along time. In fact, different problems may appear across the diverse moments of the life span, and alternative coping strategies may be more or less effective in facing these specific problems. The selection and adoption of one strategy over another may also change as patients acquire more skills and knowledge regarding their condition [30]. At this respect, it may be particularly interesting to explore also coping strategies in children and adolescents with ARM and in their parents.

Nonetheless, to our knowledge, the present study is the first one that has measured coping strategies in adult patients with ARM, and our findings strongly suggest that maladaptive coping strategies are associated with worse Mental HRQoL. Since how individuals cope with their symptoms is an important aspect of HRQoL, psychological interventions aimed at enhancing the patients' HRQoL may target maladaptive coping strategies by reducing denial, behavioral disengagement, substance abuse, and self-blame.

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#### Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethical approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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