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Perceptions of the social support for colostomized men in northern Portugal

Percepção sobre o apoio social do homem colostomizado na região Norte de Portugal

La percepción del apoyo social del hombre con colostomía en la región Norte de Portugal

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Abstract

Objective: To evaluate the perceptions of colostomized men concerning the social support received and to verify the relationship between perceived social support and socio-demographic variables, the information provided, the support they actually received, and educational sessions at the hospital. **Methods:** This is a descriptive-correlational, cross-sectional study, a quantitative approach with a sample of 112 men who had a colostomy for over a year, in three health units of northern Portugal. **Results:** The average age of participants was 59.9 years, 67.9% were inactive in terms of work, 49.5% perceive support as sufficient, insufficient support 36.2% and 14.3% neutral support. The perception of support is lower in older subjects (r = -0.166; *p* = 0.018). **Conclusion:** This study showed that the spouse is very important in the life of a colostomised man, particularly in times of difficulties inherent to the disease, representing his main support network.

Keywords: Men's health; Colostomy; Social support.

Resumo

Objetivo: Avaliar a percepção do homem colostomizado sobre o apoio social recebido; verificar a relação entre o apoio social percebido e as variáveis sociodemográficas, a informação prestada, o apoio efetivamente recebido, e a realização do ensino no hospital. **Métodos:** Trata-se de um estudo descritivo-correlacional, transversal, de abordagem quantitativa, com uma amostra de 112 homens portadores de uma colostomia há mais de um ano, em três unidades da região Norte de Portugal. **Resultados:** A média de idades dos inquiridos era de 59,9 anos, 67,9% encontrava-se não ativo perante o trabalho, 49,5% percepcionou o apoio social como suficiente, mas 36,2% apoio social insuficiente. A percepção do apoio social é menor nos sujeitos mais velhos (r = -0,166; *p* = 0,018). **Conclusão:** Este estudo permitiu perceber que o cônjuge é muito importante na vida do homem colostomizado, nomeadamente nos momentos de dificuldades inerentes à doença, sendo a sua principal rede de apoio.

Palavras-chave: Saúde do homem; Colostomia; Apoio social.

Resumen

Objetivo: Evaluar la percepción de los hombres colostomizados con relación al apoyo social recibido; verificar la relación entre apoyo social y variables sociodemográficas, información, apoyo recibido y educación para la salud en el hospital. **Métodos:** Se realizó un estudio descriptivo-correlacional, transversal, con enfoque cuantitativo, en una muestra de 112 hombres con colostomía, hace más de un año, en tres unidades de salud del norte de Portugal. **Resultados:** La media edad fue 59,9 años y sin ocupación (67,9%). El 49,5% percibió el apoyo social como suficiente, mientras el 36,2% lo considera insuficiente. La percepción de apoyo social fue más baja en los mayores (r = -0,166; *p* = 0,018). **Conclusión:** El estudio permitió concluir que la pareja es muy importante para el hombre con colostomía en lo que concierne a la relación personal, sobre todo cuando la enfermedad presenta complicaciones, siendo su principal red de apoyo.

Palabras-clave: Salud del hombre; Colostomía; Apoyo social.

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INTRODUCTION

An increase in chronic illnesses, many with no probable cure, such as colorectal cancer, continues to be a certainty for human beings. This is a reality in spite of socio-economic improvements among the population, as well as scientific and technological advancements which have contributed to an increase in the life expectancy and quality of life for patients[1].

This prevalence of chronic illnesses has followed the profile changes in morbimortality around the world, including Portugal[2]. The significant increase of people suffering from chronic illnesses is an ever present reality both at a national and international level.

According to the *Plano Nacional de Prevenção do Controlo das Doenças Oncológicas* (National Plan for the Prevention of Oncological Diseases) 2007-2010:

> "The decline in mortality rates from cancer, which is observed in many countries for the most frequent sites (lung, stomach, colon and rectum, breast, cervix and prostate), in some cases for several decades now, has not been translated in a generalized decrease in the absolute number of deaths from cancer"[3:8].

At present, there are 24.6 million people diagnosed with cancer and it is estimated that by 2020 there will be 30 million people, which is clearly a serious public health issue, not only for developed countries, but for developing ones as well[4].

On a global scale, every year there are 945000 new cases of colorectal cancer, making it the fourth most frequent cancer in the world and the second most common in developed countries[4]. In Portugal, the number of deaths caused by cancer is on the rise and colorectal cancer is the second main cause of cancer-related death, constituting a public health problem. In Portugal there are an estimated 14000 ostomised patients, 10000 of whom have been colostomised[1,3].

Colorectal cancer is a silent disease, which develops slowly and without any symptoms, at least not in its initial stage. The most visible clinical signs are the presence of blood in the stool and bowel movement changes (constipation and diarrhoea).

According to evidence from epidemiological studies, life styles are closely related to drastic changes in the level of health.

By working in close proximity with a limited number of local patients, the nurses who provide health care in the Basic Health Units have the duty and responsibility of knowing the needs of the population, so that they can participate with other professionals in the implementation of programmes which lead to solutions for these detected problems[1,5].

The nurse, as a member of a multidisciplinary team plays a key role as a source of knowledge concerning the existing support networks, as well as a source of information for the colostomized man in terms of the various resources, materials and interactions that the social support networks are able to provide in relation to the context and the environment to which they belong[5,6].

Most patients diagnosed with colorectal cancer undergo surgery, which frequently results in a temporary or permanent colostomy.

The word "colostomy" means a surgical procedure where an opening is made in the abdomen (stoma) to allow faecal drainage from the large intestines (the colon), bringing the viscera to the outside of the body.

Creating a stoma is one of the oldest types of surgeries carried out in the digestive system. This surgical technique consists of linking an internal organ to the body surface, creating a mouth or an opening to the exterior environment, allowing the elimination of the faecal matter from the body[7].

There are several pathological conditions which determine a colostomy, both temporary and permanent. The most common pathologies are caused by diverticular formations in the colon, fistulas and perianal abscesses, volvulus, intestinal occlusion and neoplasia of the colon and the rectum, which is one of the predominant ones in Portugal[7]. A review of the literature shows that most studies refer to colorectal cancer as the main cause for colostomies[8].

A colostomy for eliminating faecal matters constitutes a threat to the physical and psychological integrity of the colostomised person, due to the changes in the gastrointestinal physiology, with obvious consequences for family and social relationships. These changes in terms of self-image, self-confidence, personal, family and social relationships, often determine the insecurities and feelings of inadequacy in the colostomised man, making him incapable of establishing social connections[6,9].

In addition to experiencing physical, psychological and social transformations associated with changes in the body image and the consequences involved, the colostomised man is faced with several sources of negative feelings, often causing patients to feel incapable of returning to their daily routines, even leading them to isolate themselves from society. The return to productive activities related to work, allows the colostomised man to feel socially active and useful from an economic-financial point of view[7].

This is a highly valued aspect from the economic point of view because it creates a sense of usefulness and provides motivation to return to the social and family life, improving self-esteem and safety[8]. The lack of information for maintaining autonomy and personal independence concerning self-care may be the most frequent causes for perceiving the need for social support[9].

The perception of social support has proven to be a mediating factor for maintaining the health of colostomised men when facing the impact of disturbing and adverse situations which affect their physical and psychological well-being throughout their lives.

Therefore, social support must be seen as a multidimensional, dynamic and complex concept, allowing for the interaction between people and their social networks, aiming to satisfy social needs, promoting and complementing the existing personal resources, in order to face new changes that will aid and ensure survival[10].

Terms such as social support, social networks and social associations cover several concepts with different perspectives of the resources available in the community. In the field of health, the importance and relevance of social support has been the topic of great debates among politicians and specialists concerning the efficacy and implementation of interventions which are meant to promote this social support.

Most studies in the area of social support tend to focus on the perception people have of the different functions carried out by a group of people who are significant to the patient, depending on certain situations which occur in their lives.

Social support is a process involving the interaction with other people, which helps them cope with stress and other negative stimuli[11].

Social support can thus be seen as a multidimensional concept, referring to the help that people need during difficult times, especially in terms of emotional, instrumental and material support[11].

In the specific case of the colostomised man, the perception of social support is related to life experiences when confronting situations of crisis, which lead to severe emotional and psychological disturbances.

Nowadays, the role of social support has become more important in terms of cognitive and interpersonal aspects. The perception that each individual has of the social support they need depends on the various contexts and situations of their lives. Consequently, the perception of social support is defined as a subjective evaluation of the support relationships that each person has, as well as the different types of behaviour within each relationship.

Therefore, the social support functions carried out by groups or significant people (family, friends or neighbours), transmit a great sense of satisfaction, care, interest and affection in these relationships whenever they display interest and availability to help those in need[10].

We have chosen to divide the various means of providing social support into three categories: emotional support, which refers to behaviour that shows an interest and availability for listening, caring, trust and empathy, promoting affective well-being, making the subject feel respect and love; instrumental support, which covers the availability of material means in order to facilitate problem resolution of concrete issues related to everyday activities, as well as actions of support when facing perceived needs; information support, which refers to the process through which people receive both information and advice, helping them to understand and face the reality of difficult moments more easily, in relation to the changes that occur in their routines in terms of life styles and environment[12].

Therefore, social support is an important tool for dealing with the impact that a colostomy has on establishing relationships, as well as on the social interactions of the colostomised man[13].

In the specific case of the colostomised person, social support has often been considered a very important variable, taking into consideration the difficulties encountered after a colostomy, which require several types of support.

Due to the importance of social support for the colostomised man, it is important to create social support networks, based on a reciprocal social relations model from which positive effects may result, effectively built upon real relationships and supported by participation in society.

It is important to understand the perception of social support of the colostomised man when confronted with the life style changes caused by a colostomy, especially considering the exponential increase in the number of colostomised men in Portugal and the psycho-social repercussions related to the condition. In reality, social support is undoubtedly one of the most important needs felt by human beings, especially when experiencing a disease.

In order to achieve this understanding, the aims of this study have been the following: to assess the perception of the colostomised man concerning the social support in relation to his new living conditions with a colostomy; to confirm the relationship between the perceived social support and the socio-demographic variables, the information provided, the support that is actually received, and the educational sessions carried out in the hospital.

METHODOLOGY

This is a descriptive and correlational study, transversal and with a quantitative approach. The sample included 112 men. The selection criteria were the following: i) males; ii) over 18 years old; iii) have been colostomised for over one year; iv) Portuguese speakers; v) literate and able to understand the question on the form. The criteria for exclusion were the following: people in the terminal stage and/or those who had experienced neurological changes affecting comprehension of the questions on the form.

The instrument used for data gathering was a form, consisting of two parts: the first one was meant to gather information about the different socio-demographic variables and the second one included the social support scale from the Medical Outcomes Study Social Support Survey (MOSS-SS), which was originally developed by Sherbourne and Stewart (1991). This scale was validated and adapted to Portuguese in a sample of 2,987 patients suffering from chronic diseases: hypertension, diabetes and chronic disease[14].

This instrument evaluates social support in a multidimensional way, attributing importance based on the availability and quality of the social support functions. The scores are obtained by adding the points attributed to the questions in each category. Each answer was attributed a point from 1 to 5[14]. The higher the score, the higher the level of perceived social support.

In its original form, this instrument was created to originate five categories of social support. The affective category, which refers to people who display physical signs of love and affection (five questions); positive social interaction, which refers to having people with whom they can relax and enjoy themselves (four questions); the emotional category, which refers to the social network's ability to satisfy the individual needs in terms of emotional problems, such as dealing with confidential situations and providing encouragement when needed (four questions); information, which refers to having people who can advise, inform and guide them (four questions); and the economicl category, referring to the practical resources and economic assistance (four questions), making for a total of nineteen items evaluated on a scale similar to likert with five possible answers: 1 "Never"; 2 "Rarely"; 3 "Sometimes"; 4 "Almost always" and 5 "Always".

Since the author of the scale does not determine cut-off points, we chose to use the method of revised extreme groups[15], especially concerning method 1, which is applied when the variable distribution is approximately symmetrical and has no outliers, where the cut-off values provided by the formula were the following: average value ± 0.25 x standard deviation.

The categorization was divided into 3 types. The first one was classified as insufficient social support, covering the values of the average range -0.25 x standard deviation. The second one was classified as neutral social support, with the values between the two cut-off points. Finally, the third one was classified as sufficient social support, including the values of the average range + 0.25 x standard deviation.

Data was gathered between November 2010 and May 2012 in a Hospital Centre and at Basic Care Units in the north of Portugal. The research was approved and authorized by the Ethics Commission of the Regional Health Administration of the North, under protocol nº 34/2010, of 16 July.

This research was developed according to the principles of the Helsinki declaration of 1975, which was revised in 2004, and participation was entirely voluntary. Participants gave their free and informed consent after having the objectives and context of the study explained to them.

The software used for treating the data was the Statistical Package for the Social Sciences (SPSS), version 20.0. The statistical method employed was descriptive (minimum and maximum relative frequencies) and inferential, using the *t Student* and ANOVA parametric tests for comparing the averages between independent groups and the Pearson correlation coefficient for determining the correlation between variables.

In addition, the Kruskal Wallis and Mann-Whitney non-parametric tests were used when the variables did not follow the necessary criteria for using parametric statistics (normal distribution and homogeneity of variance) and when the groups consisted of under 30 people.

RESULTS

The participants in the study were differentiated according to age, educational level, marital status, address and employment status, current or previous job and socio-economic level (Table 1).

In relation to age group, a review of the literature shows that most researchers divide adulthood into the following stages: adult, from 20-40; middle-aged, from 40-64; and elderly, 65 and above. In our study we chose to combine the adult and middle-aged groups because there were few adult participants (between 20-40 years old), resulting in only two groups: adults 32-64 and the elderly ≥ 65.

The sample included 112 men who had been colostomised men for over one year, 69.9% belonging to the *Centro Hospitalar* and 33.0% to the Basic Care Units in the North of Portugal.

Of the colostomised men involved in the study, the majority belonged to the 32-64 age group (87.5%), most of them had primary school education (43.7%), most of them were married (83.9%), urban residents (42%), had been inactive in terms of work (67.9%). Of those who worked, many were drivers (35.7%), and belonged to the socio-economic level III (58.0%), which corresponds to the middle class, according to the Graffar scale (Table 1).

Concerning the distribution of colostomised men according to the categories of social support, we can see in Table 2 that the largest group of colostomised men are found in the category "Sufficient social support" (49.5%), but the second group also has a very high percentage, which is the group of men under the category "Insufficient social support" (36.2%), who have opposing views and which represents a relevant percentage.

In Table 3 we can observe the results of the tests that allowed us to verify the link between the points of the social support scale and the variables with which there could be a relationship of dependence, such as: age, marital status, educational level, socio-economic level, receiving an explanation about the colostomy prior to the surgery, health educational session by the nursing team, who provided support for caring for the colostomy, and the employment situation (active or not), as well as the results related to the different categories of social support.

There were no statistically significant observable differences between the social support and the variables of age ($p = 0.987$), educational level ($p = 0.949$), socio-economic level ($p = 0.268$), receiving an explanation about the colostomy prior to the surgery ($p = 0.897$), the educational session by the nursing team

Table 1. Description of the sample studied in the Northern region of Portugal 2010-2012. n = 112

Variables	Items	Nº	%
Age group	Adult 32-64	98	87.5
	Elderly ≥ 65	14	12.5
Marital status	Single	2	1.8
	Married/Common law	94	83.9
	Widower	12	10.7
	Divorced	4	3.6
Level of education	1st Cycle	49	43.7
	2nd Cycle	33	29.5
	3rd Cycle	17	15.2
	Secondary school	9	8.0
	University education	4	3.6
Residence	Village	44	39.3
	Small town	21	18.7
	Town	47	42.0
Work status	Active	36	32.1
	Inactive	73	67.9
Current or previous Profession	Bank directors	3	2.7
	Technicians	4	3.6
	Administrative staff	15	13.4
	Sales staff	37	33.0
	Drivers	40	35.7
	Farmers and farm hands	13	11.6
Socioeconomic level	Class I - Upper class	4	3.6
	Class II - Upper middle class	27	24.1
	Class III - Middle class	65	58.0
	Class IV - Lower middle Class	16	14.3
	Class V - Lower class	0	0.00

Table 2. Distribution of the participants according to categories of social support in the Northern region of Portugal, 2010-2012. n = 112

Levels of Social Support	N	%
Insufficient	38	36.2
Neutral	15	14.3
Sufficient	52	49.5

($p = 0.261$), whoever provided support for caring for the colostomy ($p = 0.540$) and, finally, the employment situation ($p = 0.166$).

The only statistically significant observable differences were seen in relation to marital status. The participants with the highest perception of social support were those who were married or in common-law marriage ($p = 0.000$), as opposed to widowers or divorced participants, with a higher average score (74.18).

The Pearson correlation test was used to verify the correlation between age, as a continuous variable, and social support. It showed a negative and weak correlation, though statistically significant, between age and social support ($r = -0.166$; $p = 0.018$). In other words, as age increases, the score on the scale decreases, meaning that the perception of social support is lower in older people.

DISCUSSION

When referring to the colostomised men who participated in our study, it is important to highlight the proportion of participants in the ≥ 65 age group (12.5%), their low educational level, 74.3%

Table 3. Results of the statistical tests related to the perception of social support in the North of, 2010-2012. n = 112

Variables	N	Average	Standard deviation	Test	Test value (F)	Degree of freedom (df)	*p*
Social Support x Age group							
Adults 32-64	91	72.37	11.705	*t Student*	-0.016	103	0.987
Elderly ≥ 65	14	72.43	11.413				
Social support x Marital status							
Married/Common law	90	74.18	11.060				
Widower	11	60.64	9.922	KW	16.283	2	0.000
Divorced	4	64.25	5.188				
Social support x Level of education							
1st cycle	45	72.82	11.947				
2nd and 3rd cycles	48	74.33	12.423	KW	0.357	3	0.949
Secondary school	9	71.56	11.642				
University education	3	74.33	12.423				
Social support x Socioeconomic Level							
Class I Upper class	3	74.33	12.423				
Class II Upper middle class	25	75.40	11.383				
Class III Middle class	62	74.00	10.928	KW	3.938	3	0.268
Class IV Lower middle class	15	71.47	14.628				
Class V Lower class	0	0.00	0.00				
Social support x Previous explanation about the possibility of having an ostomy							
Yes	83	72.51	11.123	MW	855.500		0.897
No	21	70.81	12.875				
Social support x Educational session?							
Yes	94	71.94	11.524	*t Student*	-1.131	101	0.261
No	9	76.56	13.584				
Social support x Who did support come from?							
Nurses	44	71.34	12.361				
Doctors	3	64.67	15.044	ANOVA	0.620	2	0.540
Family and friends	48	72.35	11.203				
Social support x job status							
Active	36	74.44	7.861	MW	969.00		0.166
Inactive	76	71.48	12.864				

N: Number of cases; MW: Maney Witeny; TS: *t student*; df: Degrees of freedom; *p*: Probability.

had completed between the 1st and 2nd cycle of education, 67.9% were inactive in terms of employment, and 14.3% belonged to class IV, or lower middle class, with the average age between 59.90 ± 5.071.

These results are similar to a study carried out in Portugal with a sample of 100 colostomized patients, where 68.0% were males, 54.0% had finished primary school, 78.0% were inactive in terms of employment, and 83.0% fit into the socioeconomic class III, or middle class, according to the Graffar scale[9].

In another North American study, including 140 colostomised men, the characteristics of the sample are very similar to the samples of our study, considering that the majority of the participants were over 50 (73%), had finished primary school (48.4%) and were retired (80.9%)[16].

Similar results were also found in another study from Brazil about the nurse's participation in the rehabilitation process of those with stomas, including a sample of 20 ostomised patients, where 50% of the participants had finished primary school and worked in the service sector in jobs requiring little qualifications[8].

In terms of the social support as perceived by the participants in our study, the average on the social support scale showed a minimum score of 43 points and a maximum of 95 points, with an average total score on the scale of 72.38 ± 11.613 points, or, with an asymmetry to the right. Therefore, the largest group of participants in the sample (49.5%) perceived the social support as sufficient even though there is an important percentage of over one third of participants who are unsatisfied with the social support they receive.

These results show clear differences in relation to the North-American study described above, which included 140 colostomised patients, 95.7% of which said they received social support when needed, which is a much higher percentage than the one in our study. This high percentage is explained by the author[17], by the fact that 78.6% of the patients belong to a support group or association and that 77.9% of the participants had established contact with other people.

This study corroborates the results of other qualitative studies, concerning the key role that social support networks have for the colostomised man. It is important to note that the emerging categories concerning the perception of social support were the support received by family and associations for colostomised people, which contribute to better accepting and adapting to the new life conditions[18].

Despite the importance of our study, we must acknowledge some of its limitations, such as the fact that it is a transversal study and that the sample is intentional, not random.

CONCLUSION

Our society has seen a significant increase in the number of people who live with a colostomy and who are confronted with the limitations and challenges that accompany this condition which they will have to live with for the rest of their lives.

Social support is a process which involves relating to other people, contributing to moderation and stability when experiencing stress, anxiety and other adverse stimuli.

Thus, social relations play a key role in the life of the colostomised man, fulfilling social, psychological and behavioural functions.

Evaluating the perception of social support among the participants in this sample leads us to conclude that the largest group has a sufficient perception of social support, although there is a group of men who disagree with this opinion and who feel a lack of a more effective type of social support for adapting to this new life condition.

When further analysing the proposed aims of this study, we observe that colostomized men who are married or in common law marriages show a higher perception of social support. This reinforces the idea that the affective relationship of the spouse is very important for most participants for dealing with the difficult moments during and after the critical phase of the disease.

When analysing other attribute variables, they did not prove to be discriminative in relation to social support.

Based on the results obtained, further studies should be carried out with a larger sample of participants, focusing on the role played by the spouse and the rest of the family on how the colostomised man perceives and recognizes social support when confronted with the changes that have happened in their new way of life.

Based on the results obtained in this study, we believe that the spouse plays an important role in the life of the colostomised man, especially during the difficult moments inherent to the disease. They constitute the main support network.

We also believe that promoting and facilitating social support must continue to be a part of the planning for nursing interventions geared towards the various forms of support, in order for the colostomised man to be able to overcome the difficulties of his newfound situation successfully.

This is also why we consider the role that social support plays in the life of the colostomised man to be very important because a colostomy deeply interferes with his social habits. Creating an emotional, affective, informative and instrumental social support network is an essential tool for fulfilling the specific social needs of men who live with a colostomy.

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