
LIVING WITH AN OSTOMY: PERCEPTIONS AND EXPECTATIONS FROM A SOCIAL PHENOMENOLOGICAL PERSPECTIVE

Augusto Hernán Ferreira Umpiérrez¹

¹ Ph.D. in Nursing. Full Professor in the Department of Science of the School of Nursing and Health Technologies of the Catholic University of Uruguay. Montevideo, Uruguay. E-mail: auferrei@ucu.edu.uy

ABSTRACT: The aim of this study was to understand the life change events of a group of patients with a colostomy, as well as explore their nursing care expectations. Nine patients with a colostomy participated in this qualitative research, which was based on the social phenomenological approach of Alfred Schütz. The analysis of the interviews, using this frame of reference, identified the type of experience lived by these study subjects, whose life change contexts underscored the importance of the power of adaptation and the social and job environment. It also revealed their expectations regarding nurses as counselors during the transition period, their desire for compassionate care and the building of new horizons.

DESCRIPTORS: Colostomy. Nursing care. Quality of life. Life change events.

VIVIENDO CON UNA OSTOMÍA: PERCEPCIONES Y EXPECTATIVAS DESDE LA FENOMENOLOGÍA SOCIAL

RESUMEN: La finalidad de este estudio fue comprender la experiencia de vida de un grupo de pacientes portadores de colostomía develando sus expectativas en relación al cuidado de enfermería. Se optó por una investigación cualitativa, con el enfoque fenomenológico social de Alfred Schütz, en la cual participaron nueve pacientes portadores de colostomía. Del análisis de las entrevistas, a la luz del referencial, se identificó el tipo vivido de estos sujetos de estudio los cuales mostraron un contexto vivencial en el cual es de relevancia el poder de adaptación y el entorno socio laboral, mostrando expectativas respecto a la enfermera como asesora para la transición, el deseo del cuidado humanizado y la construcción de nuevos horizontes.

DESCRIPTORES: Colostomía. Atención de enfermería. Calidad de vida. Experiencias de vida.

VIVENDO COM UMA ESTOMIA: PERCEPÇÕES E EXPECTATIVAS À LUZ DA FENOMENOLOGIA SOCIAL

RESUMO: O objetivo do presente estudo foi compreender a experiência de vida de um grupo de pacientes com colostomia, revelando suas expectativas em relação ao cuidado de enfermagem. Optou-se por uma pesquisa qualitativa com abordagem da Fenomenologia Social de Alfred Schütz. Foram entrevistados nove pacientes com colostomia. A análise das entrevistas, à luz do referencial, identificou o modo de vida dos sujeitos do estudo que apresentaram um contexto experiencial em que a relevância é o poder de adaptação e o ambiente social e de trabalho, mostrando as expectativas para a enfermeira como consultora para a transição, o desejo do cuidado humanizado e a construção de novos horizontes.

DESCRIPTORES: Colostomia. Cuidados de enfermagem. Qualidade de vida. Acontecimentos que mudam a vida.

INTRODUCTION

The life change events of patients with a colostomy are a phenomenon that must be understood by professionals who are part of the nursing care process for people with this type of change. In this regard, the study was guided by the following concerns: What is it like to live with an ostomy? What are the expectations of patients with respect to nursing care? How is the future viewed?

The approach involving these types of patients must extend beyond the purely biological realm and include a bio-psychosocial focus, wherein nurses engage in a special field of action which highlights the importance of counseling and decision-making support in the overall care given to patients.¹

The results of the care process are substantially better when patients are encouraged to accept their stoma and participate in social life, by resuming their normal daily activities. Finding ways to achieve these objectives is the challenge that professionals face.²

The impact of an ostomy can be devastating, even in a postoperative period free from complications. Patients find themselves in uncharted territory with a segment of their intestine protruding through the abdominal wall. This is followed by a series of experiences that generate difficulties in adjusting, wherein depression is common.³ On top of this, hospital stays are shorter nowadays, especially where there are early discharge programs, thus leaving patients little time to adapt and adequately prepare to take care of their stoma upon release from the hospital.⁴

For these reasons, nurses play a fundamental role in providing support to ostomy patients until they, or if not, their families, feel capable of taking care of their stoma. It is essential to understand each patient's habits, perceptions and attitudes towards others, as well as their feelings and emotions, as manifested in a wide variety of situations.⁵ Therefore, taking into account their values and feelings, as well as the family's involvement, constitute basic factors in the approach used for these types of patients.⁶

Along these lines, as shown in studies on the subject,⁵⁻⁷ it is necessary for care-giving pro-

professionals to understand this phenomenon, since they contribute toward improving the quality of life, working with patients and their families from the preoperative period on.⁸

The approach and resolution of this type of health problem depend on the resources of patients, as well as on the professionals who care for them, in addition to the care structure available. Within this context, it is important to understand the patient in order to provide quality care and education that is framed within a pedagogical strategy that helps them exercise independence and autonomy.⁹

In light of the above and in an effort to reveal the concerns related to this phenomenon, the goal of this study was to understand the life change events of a group of patients with a colostomy and explore their expectations insofar as nursing care.

METHODOLOGY

This is a qualitative study, based on the premise that knowledge about individuals is only possible with a description of the human experience as it is lived and defined by its actors.¹⁰⁻¹¹ The phenomenological method¹² was selected as the theoretical and philosophical frame of reference for understanding the everyday reality in which the subjects are immersed.¹³

The approach chosen was the Social Phenomenology of Alfred Schütz, which provides a systematic method to better understand the social aspects of human action. This approach provides a way to articulate concepts of intentionality, intersubjectivity, human actions, social relationships, expectations and others, for the purpose of better understanding people's social worlds.¹² To understand the phenomenon, in terms of how it is lived in everyday life, requires an analysis of social behavior in relation to motives and purposes. Schütz distinguishes two types of motives in social behavior: those involving action and purpose are "motives in view of ..." or "in-order-to motives", and those involving the scenario of the actors, the environment or psychic disposition are "motives due to ..." or "because-motives".¹⁴

Key concepts in this frame of reference include intersubjectivity, based on the notion that our world is composed of fellow human beings. It

does not unfold in the private sphere, but exists in a shared intersubjectivity, where experiences are interpreted reciprocally. Another concept is face-to-face relationships, since there is always another person within reach of our direct experience in the sharing of space and time. Their experience flows alongside ours and a relationship develops between the two. Attitudes are influenced by the store of knowledge and the biographical situation of each subject, since previously-lived experiences are stored and will determine relevant elements of the social activity. These contributions are fundamental for understanding nurse-patient interaction processes and serve to help improve the nursing practice.¹⁵

Along the same lines, the world each person experiences, from the very start, is a social and cultural world in which the subject interacts with others. Having knowledge of this world is for practical purposes, where an understanding of the subject's behavior, motives, objectives and plans is rooted in certain biographical circumstances.¹⁶

The study, which is imbued with these concepts, was conducted in the city of Montevideo, Uruguay, and involved nine colostomy patients, of both sexes, between 49 and 72 years of age. Three of them had a temporary colostomy and six a permanent colostomy. All of them, within three months or more of having undergone surgery, were carefully and deliberately selected, from a database known by the researcher, since they had the means to provide thorough and detailed information on the subject of interest of the study.¹⁷ The data collection was conducted between February and May 2012, through in-depth interviews, which were mutually agreed upon with the participants, and the anonymity, privacy and confidentiality of the information provided was ensured. The ethical considerations set forth in Decree n°. 379/008 (Uruguay)¹⁸ for research involving human beings were respected, which requires informing participants of the study's objectives, its scope and all aspects related to free and informed consent.¹⁹ The study was approved by the Ethics Assessment Committee of the School of Nursing and Health Technologies of the Catholic University of Uruguay, under Protocol No. 004/2012.

Due to the nature of the study, the number of participants was not previously defined, and the data collection was considered over once the information needed to address the study objectives had been obtained and started becoming repetitive,¹⁷ showing signs that the phenomenon had been uncovered.²⁰ The subjects were identified by codes to respect their anonymity, and the letter I (Interview), followed by a sequential number from 1 to 9, were assigned to the conversations.

The interviews were guided by the study's directional questions, which were: what is it like living with an ostomy? What are your expectations regarding nursing care? How do you see yourself from now on? These questions were formulated on the basis of the theoretical and philosophical frame of reference chosen, in an effort to shed light on the phenomenon in question. The interviews were recorded on an electronic device and then transcribed. Their accurate transcription ensured the completeness of the process, as well as the phenomenological reduction, which sought to arrive at the essence of the forms that comprise the psychic experience of the other person.¹¹

The analysis of the interviews followed the steps suggested for qualitative data analysis methods²¹ and by researchers in social phenomenology²² which consists of: a careful reading of each interview, to grasp the global meaning of the experience lived by each subject; grouping of the significant aspects of the interviews in order to create specific categories; analysis of these categories, seeking after the life change events experienced by patients with a colostomy; discussion of the results based on the social phenomenology of Alfred Schütz and other references related to the subject.²³ The specific categories were comprised of descriptions which significantly depicted the experience of the subjects, categorizing them when finding convergences based on the frame of reference.

Efforts were made to understand the experience of the subjects from the perspective that comprehensive care invigorates this process and encourages their mobilization to move away from the paralysis that causes unfavorable health condi-

tions toward actions that open up new possibilities for their well-being.²⁴

RESULTS

A rigorous study of the interviews that were conducted resulted in five representative categories of the life change events and expectations of the study subjects, which were named: the power of adaptation, the social and job environment, the nurse as a consultant for the transition, the desire for compassionate care and building new horizons.

Taking into account the main concepts of the philosophical reference, there arose within each category "because-motives" (motivation contexts) and "in-order-to motives" (plans and expectations), based on the social phenomenological frame of reference. Following are different excerpts from the interviews that lead to the creation of the categories.

The power of adaptation (because-motives)

The study subjects demonstrate in their conversations that the experience is built on the ability to adapt to the new way of life. They consider it important, to a greater or lesser degree, to be able to adapt to the new relationship based on one's internal resources:

[...] I have to adapt, whether I like it or not. It's not easy because I've never gone through something like this before, obviously, or known anything about it, not even an acquaintance or a neighbor. It's hard, but if you adapt, you can make it (I2).

[...] I know I'm strong, I always have been, that strength that God gives me, and I have to get used to living with this. Yesterday I talked with my wife and told her not to worry, that I can get through this. I've already asked that they change my place at work and I put together a bag containing the things I need in order to manage the best I can (I6).

[...] for me it's hard, I know I have to get used to this, sort out my situation, adjust to a new way of life. It's no longer like it once was, where you could go out when you wanted, without having to worry about anything, but now I have to learn to live with this (I8).

The social and job environment (because-motives)

Information arises in the interviews related to the social and work context of the subjects, which indicates their special importance in the progress of patients and the acceptance of their problem.

Experiences in the social and job environment help subjects move forward:

[...] If it hadn't been for my family, I would have died, I wouldn't be here. My wife faced the whole situation and helped pull me through, as well as my older daughter, because the other one is in Spain and can't be here [...]. I have a neighbor who had gone through this before and it was a great support for me (I6).

[...] I think if you have help it's easier. In the benefit society, they gave me a big hand. The nurses helped my wife, explained it to her, told her everything [...]. At work they also helped me out, but I don't know, it seems like everyone is talking about you, you don't know if they're really helping you or just feel sorry for you [...] living with this [...] I don't know [...] it's rough to go out and not be thinking you might smell, and even more so at work, but they say you're not letting off any smell (I5).

The nurse as a consultant for the transition (in-order-to motives)

In the data reduction, the nurse is seen primarily as a consultant in the process and plays a fundamental role in the transition toward a new life.

The following expectations come to light in relation to the nurse-patient relationship:

[...] well, what I expect is that they'll provide good care, you have a lot of fear, you don't know what's happening to you, you've never gone through this before, so if you have someone that explains it to you, tells you how to do things, how to face things, it's much easier and you're more at peace [...] here, a nurse always comes and explains everything to you, she wrote things down for me, well, she gave them to my wife because at first I didn't want to know anything about it (I4).

[...] well, they took good care of me [...] Expectations? [...] and I have quite a few, that they tell me how to take care of this, although I already know now,

since the nurse explained to me how to change the ring and what I have to do if it comes off [...] she explained everything to me and told me to call her if I have any questions and that's it [...] it's very important for me to have someone who will help walk me through this very new experience (I8).

[...] this is like going into a tunnel [...] if you have someone guiding you, that's the ideal, someone who knows the way and can help you find the light at the end of the tunnel (I9).

The desire for compassionate care (in-order-to motives)

Another aspect that emerges in the interviews is the desire to receive compassionate, close, warm care. It is one of the aspects that the study subjects most desired:

[...] for me it's essential that they pay attention to you, receive you well, greet you and treat you decently, because sometimes you see that they've got so much work, and I understand their situation, but you're going through such a strange experience that you need a little pampering sometimes. Here, the nurses come and you wait sometimes because you know that they are more attentive than the doctors, speak in a clearer way [laughs] (I1).

[...] my daughter asks the nurses to speak in plain Spanish [laughs], well, jokes aside, this is what you hope for, that they'll be warm, one's already got enough problems [...] I want to be made to feel at home (I5).

[...] my expectations are the same as all patients, I think, that they treat you well, that they understand you. At times, it's not that you don't want to do what they ask, but you're struggling, so you expect some understanding, I mean, you're not a machine, in the end you're a human being and you need people to treat you with compassion (I8).

Building new horizons (in-order-to motives)

The information that emerged in the interviews shows that the subjects envision new horizons and wish to build for the future, resulting from their understanding of the phenomenon.

[...] and now you have to face it, the nurse told me that I can do everything I used to do before, even go to the beach she said, I don't know, but if that's

the case, it's a luxury I wasn't expecting, I have to be okay, that's what my daughter wants and that's what I'm going to do (I2).

[...] I have so many plans [...] one of them is to enjoy my granddaughter more than ever after having gone through this. You have to enjoy life because it slips by so quickly (I5).

[...] hereon in I want to return to work, it's not going to be the same, but I have to go back the best I can. They told me I can do anything I want, well, with some limits obviously, but I can live a normal life, or almost normal (I6).

[...] I have already adapted. The nurse told me that now I have to go and do the procedure before I go. But I've already adapted [...] I can see myself at home with my grandchildren and I've already explained to them what I have (I9).

DISCUSSION

The life change events of the study subjects reveal some aspects related to the motivation context, while others are tied to their expectations and how they envision the future. The analysis of the interviews, based on the theoretical and philosophical frame of reference revealed "because-motives" and "in-order-to motives" and has shown the way in which they experience the everyday world from a social phenomenological perspective.²⁵

The categories that emerged, related to "because-motives", encompass the prior history each subject has, from which they build their reality, showing that subjects place emphasis on the power of adaptation and the social and job environment.

With respect to the power of adaptation, it should be noted that it is built on the basis of what each person brings, with biographical circumstances, store of knowledge and previously lived experiences serving as a starting point.¹⁵⁻¹⁶ The absence of prior knowledge of this type of situation renders people more vulnerable, and lack of adaptation and depression are common results.³ From our point of view, and according to other authors, nurses play an essential role in facilitating this adaptation process, by assisting, educating and alleviating patients and their

families, which favors equilibrium with their environment.²⁶

In line with the above, the social and job environment is found to be a key element. Relationships with others, permeated with intersubjectivity, denote a world shared with fellow human beings.¹² The data from the interviews shows that subjects assign a prominent place to family and friends, as well as the importance of the nurse in the support process. This coincides with the contributions of Schutz's phenomenology, which emphasizes face-to-face relationships from the perspective that there are always others within the scope of our life experience and who share our space.¹⁶ The data is also consistent with other studies which highlight that the challenge of those sharing a space with these patients lies in finding ways to encourage their participation in social life,² wherein nursing professionals emerge as support figures in the transition toward new experiences.

In this regard, the subjects manifested clear expectations, related to "in-order-to motives", viewing the nurse as a consultant for the transition period, and showing a desire for compassionate care and the building of new horizons, which include their family and overall environment.

Understanding the expectations of patients contributes towards improving the nursing practice, infusing the support relationship with intersubjectivity and shared spaces,¹⁴ to provide comprehensive care.²⁴ People with a colostomy have to undergo the life change of accepting that they are different, which requires adjusting one's image and self-concept.²⁷ In this process, the nurse, through the support relationship, accompanies and educates. The data, which emerged coincides with other authors who emphasize the role of the nurse as an advisor, consultant and care manager in the therapeutic relationship.¹⁻⁵

The desire to receive compassionate care is an aspect highlighted by all the subjects. The need for warm and close care permeated all the interviews conducted in this study. The fact that this need ranks above others which could be of equal or greater concern for patients demonstrates the importance of understanding the phenomenon of this study. It also provides inputs for approaching individuals based on all their dimensions,

in accordance with studies that stress the values and feelings of people,⁵⁻⁸ thereby imbuing the care and nurse-patient interaction with the human element, as opposed to the focus placed on the biological model that permeates health institutions.

Finally, the projection patients make regarding the future and the building of new horizons is no less important, where they envision themselves in a shared world, which means embracing new lifestyles compatible with having an ostomy. In all the study cases, there is a desire for a world shared with others, involving social relationships, in principle with immediate family, based on the concepts that permeate the theoretical and philosophical approach of this study.^{12,14,16,25}

CONCLUSION

It was found that a part of the phenomenon studied exemplified the above, highlighting aspects that can contribute toward improving the practice of nursing care in relation to patients with a colostomy.

The findings that were analyzed on the basis of the theoretical frame of reference demonstrate the potential impact they have on the relationship established between nurse, patient and family. It would be desirable that nursing care and its management be focused on empowering nurses in their role of adviser, which particularly helps patients adapt to their new way of life, by restoring and enhancing their strengths and assisting them in overcoming their weaknesses. Care management, related to the reintegration of patients into their social and working environments, should be another goal of the care plan, while also engaging in actions directed toward providing compassionate, holistic care that stops being based on biological reductionism. In turn, as consultants in the transition process, nurses become part of the context of patients, assisting them and their families in responding to the new challenges they face.

In conclusion, it should be clarified that this study is limited to a specific field, in that generalizations cannot be made owing to the type of method used for addressing the subject. The purpose of this study was to delve deeply

into the particular experiences of each subject, as opposed to making generalizations based on the results. However, we believe that the findings constitute an important input for understanding the health care processes for these types of patients and open up opportunities for conducting new studies to further enhance the knowledge on this subject, by generating solid information that will contribute toward best practices in the support relationship that takes place in the nurse-patient interaction.

REFERENCES

1. Ferreira A. *Proceso de atención al paciente ostomizado: gestión de cuidados integrales*. Montevideo (UY): Ed. Psicolibros Waslala; 2011.
2. Kingsley L, Simmons J. Adjustment to colostomy: stoma acceptance, stoma care self-efficacy and interpersonal relationships. *J Adv Nurs*. 2011 DEc; 60(6):627-35.
3. Constantino L, Lázaro E, Sosa M. Problemática actual del paciente con ostomía. *Rev Cubana Med Milit*. 2001 Nov; 30(4):256-61.
4. Black P. Stoma care nursing management: cost implications in community care. *Br J Community Nurs*. 2009 Aug; 14(8): 350-5.
5. Arrais F, Souza P, Leite T, Giménez M. Assistência de enfermagem a paciente com colostomia: aplicação da teoria de Orem. *Acta Paul Enferm*. 2008 Mar; 21(1):94-100.
6. Maruyama S, Zago M. O processo de adoecer do portador de colostomia por câncer. *Rev Latino-Am Enfermagem*. 2005 Abr; 13(2):216-22.
7. Bellato R, Tao S, Moraes C, Castro P. A condição crônica e as repercussões que traz para a vida da pessoa e sua família. *Cienc Cuid Saude*. 2007 Jan-Mar; 6(1):40-50.
8. Bachelet V, Collet G, Ribal A. The role of the stoma therapy nurse in the preoperative period. *Rev Infirm*. 2012 May; (181):25-6.
9. Alvarenga P, Neide A. Perspectiva educativa do cuidado de enfermagem sobre a manutenção da estomia de eliminação. *Rev Bras Enferm*. 2011 Apr; 64(2):322-7.
10. Polit D, Beck CT, Hungler F. *Fundamentos da pesquisa em enfermagem: avaliação de evidências para a prática da enfermagem*. 7ª ed. Porto Alegre (RS): Artes Médicas; 2011.
11. Martins J, Bicudo MAV. *A pesquisa qualitativa em psicologia: fundamentos e recursos básicos*. 5ª ed. São Paulo (SP): Centauro; 2005.
12. Muñoz LA, Lorenzini A. La fenomenología en la producción de conocimientos de Enfermería. En: Prado M, Souza M, Carraro T. *Investigación cualitativa en enfermería: contexto y bases conceptuales*. Washington D. C. (US): OPS; 2008.
13. Terra M, Silva L, Camponogara S, Santos E, Souza A, Erdmann A. Na trilha da fenomenologia: um caminho para a pesquisa em enfermagem. *Texto Contexto Enferm*. 2006 Out-Dez; 15(4):672-8.
14. Schütz A. *Estudios sobre teoría social: escrito II*. Buenos Aires (AR): Amorrortu; 2003.
15. Camatta M, Nasi C, Schaurich D, Schneider J. Contribuciones de la sociología fenomenológica de Alfred Schütz para las investigaciones en enfermería. *Braz J Nurs*. 2008 Apr; 7(2):78-98.
16. Vollrath A, Angelo M, Muñoz L. Vivencia de estudiantes de enfermería de la transición a la práctica profesional: un enfoque fenomenológico social. *Texto Contexto Enferm*. 2011; 20(spe): 66-73.
17. Martínez-Salgado C. El muestreo en investigación cualitativa: principios básicos y algunas controversias. *Ciênc Saúde Coletiva [Internet]*. 2012 Mar [cited 2012 Aug 22]; 17(3):613-9. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232012000300006&lng=en
18. Uruguay. Decreto de Ley n. 379/008. *Investigaciones con seres humanos*. Diario Oficial n° 4573/08, diciembre de 2008.
19. Nunes E. Ethical aspects considered by researchers who use qualitative approaches in health. *Ciênc Saúde Coletiva [online]*. 2008 Apr [cited 2012 Aug 22]; 13(2): 351-60. Available from: http://www.scielosp.org/scielo.php?script=sci_arttext&pid=S1413-81232008000200010&lng=en
20. Noreña A, Alcaraz-Moreno N, Rojas J, Rebolledo D. Aplicabilidad de los criterios de rigor y éticos en la investigación cualitativa. *Aquichán Col*. 2012 Dic; 12 (3):213-27.
21. Lessard-Hérbert M, Goyette G, Boutin G. *Investigação qualitativa, fundamentos e práticas*. 4ª ed. Portugal: Stória Editores, Instituto Piaget; 2010.
22. Merighi MAB, Jesus MCP, Domingos SRF, Oliveira DM, Baptista PCP. Being a nursing teacher, woman and mother: showing the experience in the light of social phenomenology. *Rev Latino-Am Enfermagem*. [online] 2011 Jan-Feb [acesso 14 Out 2011]; 19(1):164-70. Available from: <http://www.scielo.br/pdf/rlae/v19n1/22.pdf>
23. Arias MM, Giraldo CV. El rigor científico en la investigación cualitativa. *Invest Educ Enferm*. 2011 Nov; 29(3):500-14.

24. Rivera M, Herrera L. Fundamentos fenomenológicos para un cuidado comprensivo de enfermería. *Texto Contexto Enferm.* 2006; 15(spe):158-63.
25. Wagner HR, organizador. *Fenomenologia e relações sociais: textos escolhidos de Alfred Schütz.* Rio de Janeiro (RJ): Zahar; 1979.
26. Coelho S, Mendes I. Da pesquisa à prática de enfermagem aplicando o modelo de adaptação de Roy. *Esc Anna Nery* [online]. 2011 Dez [aceso 2012 Ago 22]; 15(4):845-50. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1414-81452011000400026&lng=en
27. Souza PCM, Costa VRM, Maruyama SAT, Costa ALRC, Rodrigues AEC, Navarro. As repercussões de viver com uma colostomia temporária nos corpos: individual, social e político. *Rev Eletr Enferm* [online]. 2011 Jan-Mar [acesso 2013 Fev 21]; 13(1):50-9. Disponível em: <http://dx.doi.org/10.5216/ree.v13i1.7928>