Emotions of people living with ostomies: existential comprehension

ABSTRACT
The objective of this study was to better understand the emotions of ostomy patients and to reinforce their own moral value as beings-in-the-world, through actions of humanized care. This qualitative study followed the existential phenomenology school of thought and was performed at a teaching hospital in Northwestern Paraná – Brazil. Interviews were performed with 15 ostomy patients receiving care at the stomal therapy outpatient clinic during the months of June and July, 2006. The guiding question was: What does being an ostomy patient mean to you? From the analysis, three existential themes emerged: finding oneself in the world of ostomy, daily life with an ostomy bag; and the importance of spirituality in understanding the situation. It was observed that ostomy patients, in their existentiality, express their vicissitudes differently, revealing how painful or pleasant life events can be to them. It is the nurse’s challenge to be mindful of their varying forms of expression.

KEY WORDS

RESUMO
Este estudo buscou compreender os sentimentos dos seres estomizados e resgatar seu próprio valor moral enquanto seres-no-mundo, por meio de ações humanizadas de cuidado. Trata-se de uma pesquisa qualitativa da linha fenomenológica existencial, realizada em um hospital-escola do Norte Este do Estado do Paraná, Brasil. Foi realizada entrevista com quinze indivíduos portadores de estomia, que estavam sendo atendidos no ambulatório de estomaterapia nos meses de junho e julho de 2006, tendo-se como questão norteadora: O que significa para você ser um ostomizado? Da análise emergiram três temáticas existenciais: descobrindo-se no mundo estomizado; a vivência cotidiana com a bolsa de estomia; a importância da espiritualidade para o entendimento da situação. Percebemos que, em sua existencialidade, o ser estomizado exprime de formas diferentes suas vicissitudes, desvendando quão dolorosos ou prazerosos são os acontecimentos da vida, cabendo ao enfermeiro estar atento às suas linguagens.

DESCRIPTORES
Ostomia. Acontecimentos que mudam a vida. Cuidados de enfermagem. Espiritualidade.

RESUMEN
Este estudio se enfoca a comprender los sentimientos de las personas estomizadas y a rescatar sus propios valores morales de seres humanos, a través de acciones de cuidado humanitario. Se trata de una búsqueda cualitativa de la línea fenomenológica existencial, realizada en un hospital-escuela del Noroeste del Estado de Paraná – Brasil, mediante entrevista con quince individuos portadores de estomía que estaban siendo atendidos como pacientes ambulatorios de estomaterapia durante los meses de junio y julio de 2006, teniéndose como pregunta orientadora: ¿Qué significa para usted ser un estomizado? Del análisis, surgieron tres temáticas existenciales: descubriéndose en el mundo estomizado, la convivencia cotidiana con la bolsa de estomía, la importancia de la espiritualidad para la comprensión de la situación. Percebimos que en su existencialidad, la persona estomizada expresa de formas diferentes los cambios de sus circunstancias, mostrando cuántos dolorosos o placenteros son los acontecimientos de la vida, quedando a cargo del enfermero estar atento a sus diferentes modos de expresarse.

DESCRIPTORES
Ostomía. Acontecimientos que cambian la vida. Atención de enfermería. Espiritualidad.
INTRODUCTION

In Brazil, it is estimated that there are approximately 50,000 ostomy patients; 1,000 of them are users of the Brazilian national public health system, the Unique Health System (UHS), in the state of Paraná\(^1\). In the region around Maringá - PR, there were 113 known ostomy patients in 2005\(^2\).

The history of ostomy procedures dates back to the XVII century when Lorenz Heister described intestinal battle wounds from soldiers in combat. He noted that these men were only able to survive because they underwent an enterostomy\(^3\). The terms ostomy and stoma are conjugated from Greek, meaning mouth or opening, and are used to describe any externalization of a hollow organ in our body\(^4\). The reasons that lead to the necessity of the creation of a stoma are varied, but the most frequent are neoplasms, firearm and bladed weapon wounds. The two latter causes sometimes result in a temporary ostomy, depending on the wound and patient condition\(^5\).

The experience of being an ostomy patient due to cancer tends to alienate people from their normal cultural interactions and severely affects the meaning they give to themselves, to the disease, to the treatment and to their own existence. In the context of becoming ill, two important cultural meanings can be determined: cancer - a disease that carries the stigma of death and suffering - and stoma: a physical mutilation that even though concealed, carries innumerable consequences for the patient\(^6\).

When the patient is faced with the prospect of having a stoma, he must begin to deal with a new reality and is overwhelmed with a torrent of sentiments, reactions and behaviors\(^7\). The impact of being an ostomy patient and the fact that it is caused by cancer not only affects the patient, but also his entire family and his closest friends.

In addition to all of these changes, living with the stoma also demands that the patient embrace new habits and readjust their daily activities, including the learning and adoption of new actions of self-care for the stoma and peristomal areas, as well as learning how to handle and deal with the ostomy bags\(^8\).

In reference to the ostomy bags, it should be noted that even though there is a Health Ministry decree that grants their supply to all UHS patients, this decree has not been carried out due to high material costs; therefore, supply usually falls much shorter than the patients’ needs. Due to this fact, each patient must try and obtain within his own means the basic materials that our Public Health System cannot supply them with\(^9\).

In our opinion, the existing-in-the-world of an ostomy patient is extremely difficult for the individual and his family, bringing about feelings of uncertainty for the present and the future, feelings that involve their own life perspectives. Thus, when living with a stoma, the Being is taken by the sensation of being different because, in addition to facing all of the problems post-operative patients have to deal with, they also experience vicissitudes associated with physical, psychological, social and spiritual dimensions.

The physical aspects refer to the ostomy condition itself, which means that the patient will have to live with physiological changes in terms of defaecation and with all that it implies, such as the odor and the compulsory use of an ostomy device. When it comes to the psychological aspects, one of the concerns relates to the corporeal image changes, which leads to the sensation of mutilation and rejection of oneself. The social consequences may arise from the insecurity caused by the poor quality of the equipment used, making the patient feel vulnerable and, thus, isolating himself from family and social environments\(^10\).

Finally, yet importantly, there is the spiritual aspect that is translated as religiosity and the hope of being cured. It caused us much unrest when these patients were followed by us in a teaching hospital in the Northeast of the state of Paraná, because of their extreme difficulty in personal and social relationships, their insecurity in fulfilling common daily tasks and their preoccupation with accepting a new corporal image. It was observed that these patients experienced within themselves all of the emotional misfortune of living with this new condition; of being directly connected to the ostomy bag.

OBJECTIVE

The aim of this study was to gain an understanding of the feelings of ostomy patients surrounding their condition. We believe that the results of this study will allow professionals to help these individuals to redeem their moral value as beings-in-the-world, in order to prepare them to face their existential conditions, to build and live their authentic self, and, mainly, to shed some light into directing our actions and transforming their harsh reality.

METHOD

This is a qualitative analysis study following Martin Heidegger’s existentially phenomenological school of thought. In an Heideggerian\(^11\) view, phenomenology shows, ontologically speaking, the matter of the Being, for the essence of man resides in his existence, and only through the existence of the individual it is possible to analyze the Being to reveal and unroot his mysteries. Thus moves a hermeneutic phenomenology of the human towards a fundamental ontology of the Being-there\(^11\).

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\(^{1}\) Sales CA, Violin MR, Waidman MAP, Marcon SS, Silva MAP.
This study was carried out in a teaching hospital in the Northeast of the state of Paraná. Fifteen ostomy patients were interviewed between the months of June and July of 2006 in a stomal therapy outpatient clinic of the aforementioned institution. During our meetings at the clinic, we explained the aim of the study and requested their collaboration. After being granted permission from the patients and their having signed the terms of privacy and agreement, we started the interviews in their homes, to capture both their feelings and corporeal expression during their reports.

The meetings were purposely not timed because we were attempting to comprehend their existential time and from there, seek the answers to our inquiries. We thought that their experiences should encompass thoughts, feelings and actions in terms of their reality. Therefore, while we were pondering over the daily life of ostomy patients, we were also considering a question that would not be casually answered, but one which would require in-depth thought and answers from the interviewees spontaneously. Therein, we have inquired of the interviewees the following question: What does being an ostomy patient mean to you?

In order to capture the cornucopia of thoughts expressed by the interviewed subjects in their own language, we opted for the individual analysis of each discourse, following these steps: a priori, we carried out attentive readings of each report after having completed their verbatim transcription, and separated excerpts or units of interest (UI) which pertained to the question asked. A posteriori, we read each unit thoroughly, highlighting the feelings that arose more than others in each discourse in which existential themes were mentioned, expressing their existential presence.

Because the research involves human beings, this study had to abide by the ethical and disciplinary parameters established by Resolution 196/96 of the CNS - MS, and the project was approved by the Ethics Committee for Human Research of the State University of Maringa (protocol number 167/2004). The participants were verbally asked to take part in the study, and at the same time they were informed of its purpose, the extent of participation that would be expected, and the length of the interviews. They were also assured there would be no connection between their participation and any changes in their medical care. They were also assured of the possibility of giving up their participation at any time. They were granted absolute secrecy of their identity whenever their opinions were divulged in our study. They were named s1, s2, s3, and so on to preserve their identity.

RESULTS

After analyzing the reports three existential themes arose, which were then interpreted using some of the ideas from Martin Heidegger: discovering oneself in the ostomy world, daily life with an ostomy bag, and the importance of spirituality in understanding this situation.

DISCUSSION

Discovering oneself in the ostomy world

Human beings live within a limited number of possibilities, and thus become both the creator and dominator of its history, the planners and idealists of their own life projects. They care about their own health, perfection and dynamism. When they find themselves inserted into a world where something may destroy their lives and their will to live, their vanity, their hope, their self-trust and control, they feel destroyed before the world.

When faced with this type of situation, human existence can become the object of questioning, especially when man is faced with a new reality which he can not comprehend. At these moments, the human being shrugs himself down and cannot grasp his own existential condition, denying the truth which faces him squarely. When stricken by this situation, we analyzed that the urge to revolt, rebelliousness and embarrassment invade them when they find themselves inserted into the ostomy world, a condition that had not been foreseen by any of them. Under this perspective, the following lines of speech ought to be highlighted:

The sensation is that life is going to change completely, a great change in my daily life (s2);

I only accepted having the surgery done when there was no other alternative. It was very hard; I was indeed enraged (s3);

In the beginning, it was really hard. After having the surgery and becoming an ostomy patient, I’ve felt really insecure and worried about the use of the bag. Never in my life had I thought I’d use this... I had never seen someone using this... I had no idea about it (s1).

The person that falls ill is not isolated and living alone, because others are also co-present. The being-with-the-other during the disease process can become significant when others express solicitude and offer patience and consideration for the person who is ill. Obviously, one of the functions of the nursing professional is this very one, a role of caring for the other, which implies co-existing and participating. Notwithstanding, we have learned from the accounts of some ostomy patients that this was not the reality they were presented with, experiencing unprofessional care from these care-takers who were not concerned about offering any sort of clarification regarding the procedure that was about to be carried out or that had been carried out.

When I woke up after the surgery, after staying in the ICU for three days, I saw that I had something attached to my belly, something really weird and I thought - Oh My God! What is this? (s6);

In the beginning it was really hard, I was apprehensive because I didn’t know what it was going to be like. It took a long time, but I got used to it (s7);

Nowadays, I’ve already gotten over it, but at first I was really hard to accept the disease and the surgery. I’ve had
radiotherapy and chemo and I was very weak. I had never heard of a colostomy; I didn’t even know this existed. I was taken to surgery but I still didn’t know what it would be like afterwards. No one told me I’d have a bag attached. And no one thought to explain what that bag did, and how things would be after I was discharged from the hospital. I was enraged, for not a single person had explained to me what that bag was for (s4).

Geez, when he told me my rectum was going to be removed and that I’d forever have to use that bag I was desperate. I knew what that bag was for because a friend of mine had gone through that, otherwise I wouldn’t have known (s5).

When it comes to interviewees’ feelings, we cannot forget to mention how important the presence of the nurse is to the patient during these moments:

The teaching-learning process of the adult ostomy patient starts during the pre-op period, when the nurse must establish a firm bond with the patient and the family to assist them to learn what the situation will be like, concretely speaking, so they can better adapt to the changes in their life-style they will surely undergo(12).

Fear represents an unnerving feeling about an unknown situation with which we have to cope, unexpectedly generating an intense sensation of agony(10). Therein, we inferred from some of the interviewee’s reports that changes in the social context of the patient, particularly in their bodies, have deeply affected their self-esteem and triggered feelings of discrimination from others around them.

The phenomenology of perception does not analyze the body as merely a physical organism, but contemplates it as a whole, a structure which interacts with all that is in and around them; in other words, the meaning it has is something that happens within the body itself. Therefore, the body is a work of art and all of our tactile, visual and auditory perceptions are always related to a gesture. The body is a gathering of lived significance aimed at its own balance: a new knot of signification(10).

Concerning this reflection, we have noted from the interviewees a feeling of profound sorrow and desolation when they felt different from others, as if they denied their own existence and their own body.

The elements of symbolic order are the ones that govern our relationship with our body and that also organize the relationship with the image of the body and, from it, the image of the ones similar to us(14).

The instant I knew, right after the surgery, I was really sad. Many times I thought that it was better to stop living. It’s very hard, because your whole life changes; we suffer from prejudice from other people and from ourselves because we feel different from the others (s8).

I struggle to get over it and try to have a normal life, even though being totally normal is an impossibility because of this bodily alteration. Even if I try really hard, my self-image compromises my social life (s9).

In the impoverishment of senses and meanings, man experiences the not well-being, the emptiness and the existential annihilation(15). Therefore, we realize within the words of interviewee number 10 the expression of her existential emptiness from inside her being. In her language, she expressed her fear of death and the possibility of not having the strength to continue living with her loved ones.

When I saw my body for the first time, I almost passed out. I cried a lot. It’s a feeling of mutilation. It seemed like the surgery had worsened it and not treated it. I really thought I was going to die. The suffering took over me, my image; I was not the same; I thought I was not going to see my daughters getting married (s10).

**Daily life with a colostomy bag**

The authentic existence of man, under the Heideggerian philosophy, is characterized by living according to a singular way of life, because we are aware of our own limitations, and so we assume the condition of being-cast-in-the-world, which means to live aside from the daily ongoingness(10). However, this condition of being given to yourself, without knowing who and what you have come here for, does not mean that the human being should remain passive given the ups and downs of life, but should actually fulfill his desires and not just sit and wait for the end to come.

In that respect, we observe that in their daily lives, the interviewees try to transcend their pain and project themselves in their daily routine to adapt to their new existential condition. We exemplify this line of thought with the following reports:

I don’t think my job is going to cause me pain, and for that reason I work and have fun... In my opinion, there’s no difficulty in carrying this bag. I’ve already travelled to Porto Alegre by bus three times to my sister’s house and I feel safe, because these bags are pretty resistant and practical (s1).

Only after some time had passed did I begin to start to feel normal, so now I go to church, I sing in the choir, I travel, I fish and I am able to have fun. I have been doing everything that I feel like doing and I try to lead a normal life. Today, I feel bad for not being able to work, not to be able to work out and sometimes I want to leave home. However, it’s all just a phase, I have dreams and I am happy (s6).

In their daily lives, we have also noted that these patients manifest their fears towards the awkwardness of living with the ostomy bag, especially because it deals with the elimination of their excrements, and this surpasses any biological grounds and reaches into their social life and their existing-in-the-world. For them, the breach of these codes, when observed by others, always causes feelings of shame and embarrassment(16).
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Ostomy is a big problem for single people. In our intimacy, when it comes to sex, it is very hard. I've spent a long time without having an erection. Things change and you can't be as comfortable as before; taking a shower requires a lot of care. We always depend on the bag. We always need to have another bag at our reach for an emergency substitution, which might occur at anytime when we're far from home (s2).

The bag makes me really upset, but I try not to keep thinking about it. What bothers me is that they get filled up at the wrong time and you can't control it, you can't control gases and sometimes I am around people when it comes. When it happens I get terribly irritated, I apologize immediately and explain that I am an ostomy patient, and that things are different now. Appearance doesn't bother me, and I try to wear loose outfits. Of course it's not the way it used to be, that's simply impossible, I have to wear something looser to be more comfortable (s4).

We have also noted that not even time itself can totally make up for a plentifully comfortable situation, as seen in the following accounts. These interviews show how hard it is for an ostomy patient to eliminate his bodily waste using the bag. In Heideggerian meditation, this behavior represents a scream of inauthenticity, of not assuming your responsibilities of being-with an ostomy patient; it is a way of existing that is not based on its primitive sense of pure possibilities(10).

It has been almost nine years since I have become an ostomy patient, but it still isn't easy and I feel fragile. I am afraid of going to certain places, like night clubs or the beach; I am afraid of being amongst people and the ostomy bag produces noises with the release of gases; I am afraid of traveling, of going to relatives’ and friends’ houses, because I am embarrassed when cleaning the bag because of the odor it leaves. I can’t wear all the clothes I’d like to, because the bag shows under the clothes. I don’t have the freedom to say to everyone that I am an ostomy patient. There is also the special diet which restricts me from certain foods (s5).

But time has passed and there’s nothing to be done, only to accept and see that, despite all my difficulty, life goes on, living is good because God allowed me to continue living with my family who accepts me as a completely normal person (s14).

There are two distinct forms of time perception(15); the objective time (years) and subjective time (the intensity with which these years have been lived). In this perspective, we realize in the following passage that the interviewee experienced an existential temporality with the stoma and, in principle, it was not counted in years, but as a situation that intensified her existential condition.

[…] Only with the passing of time was it possible to realize that I could still lead a normal life. Today I see that nothing impedes me from living and doing what I like. What's important to me is not to feel pain; and there is a God, isn't there? Then here I am today, I’ve accepted it and God has blessed and helped me […] (s11).

When discovering oneself as a being-in-the-world, man always discovers himself as a being-with (Mit Sein), being-the-other (Mit Dasein) and also a being-in-the-world; in other words, a being for the others, or a companion. It is in this being-with-another that man visualizes the possibility of staying with someone not only for the purpose of caring, but to be with someone in an involving and meaningful way(15). In that respect, we inferred from the following accounts that being-with with a family member during the learning process on how to use the bag strengthens them to face their existential reality.

At first I needed help to change the ostomy bag. Everything is hard in the beginning. The man from CREA helped my sister and me as well. During chemo I was dependent on others… yeah… it was not easy… but I had a lot of support from others and today I am fine […] (s3);

My wife helped me a great deal. I’ve needed professional psychological help, but I’ve gotten over it with my family’s help, so I believe that if we have some kind of psychological support all of us will be greatly helped (s7);

At first, my daughter was the one that changed the bags, because I couldn’t sit because of the surgery. After about a month or so I started changing it by myself, I started driving again, and thanks to God I have never had any complication and never had any skin rash, so no special care was necessary. I didn’t have to change anything with my diet. I eat just about everything. I don’t bother much with the smell; only when I have to change the bag does the smell bother me. I even said that I was going to build a bathroom outside because of the smell, then my children told me that I shouldn’t worry about it because the smell wears off […] (s10).

Affectionate relationships under Heideggerian philosophy are filled with solicitude which encompasses the basic characteristics of being considerate and patient with others and for others. Therefore, from interviewee number 9 we have learned of the importance these feelings have in her existing-in-the-world as an ostomy patient.

When I have to use someone else’s bathroom I always say it, I try to be a good sport. I don’t hide what I have from anyone because at some moment I may need them (s9).

In Heideggerian philosophy(15), the expression being-cast denotes the responsibility of giving yourself to the task of what is and of what has to be. However, in this same philosophy, the imminent possibility of suffering, which brings to man feelings of fear and anguish, also gives him the conscience for his ontology of can-be whole and authentic, because after foreseeing his pain, the human being can start existing authentically for himself; that is, worrying about himself and not about the others that surround him.

Today I deal with it very well and even try to visit people that may need my assistance. I tell them my story, so they can better accept their existential condition (s13).

The importance of spirituality to understand the situation

Under Heideggerian meditation, the authentic existence of man is that which makes him a true revealer for himself,
based mainly on anguish. Anguish is an ontological possibility, which reveals the ontic horizon of man as a being, for it emerges from man himself, as he perceives he is a Being-cast-in-the-world\(^{[10]}\). Hence, anguish does not represent only a colloquial feeling, experienced within the daily life of human beings, but it is actually placed among all feelings and forms of human existence, that it may reduct man to encounter his totality as a being and join the pieces into which he is reduced from the immersion in monotony and in nondifferentiation within daily life. Aguish would make man elevate from all committed treason against himself, when he is no longer dominated by day to day stinginess, up until his self-knowledge is completed in his most profound dimensions\(^{[17]}\).

Anguish, if analyzed this way, is the only feeling capable of bringing a human being back from his daily ruin, transcending his condition of being cast-in-the-world and assuming his essential project; that is, to be transformed into a being of cure, manifesting it through preoccupation about himself and about the others around him, becoming free to assume all concrete responsibilities of his existence.

For the human being, faith is an important tool for pain relief. Faith, or the quest for divine help, hurls the person into a search for resources that could help him face his daily difficulties. In this context, we observe accounts from patients that approached God who brought them strength to endure their vicissitudes. The patients have reported the following:

- It’s too much anguish. We have to search for God to tolerate and support us in all that’s possible... nurses, psychologists and other more experienced colleagues. Thanks to God and to these people, I’ve been able to recover (s2).
- I didn’t get angry as many other people do. I’ve accepted my condition. If this is the way God made me be, and that can allow me to linger a little while longer here, then I have to accept it, and let’s make the best of it. That’s how I’ve been living. I don’t think this is going to hamper me from living (s5).
- I never thought it was going to happen to me because in this world we get ready to get married, to have children, but never to die, to get sick. That’s why we have to be prepared for anything. Saying this to others is just too easy; the hard part is when it happens to us, because if we have no faith, we have no strength to fight back, and thank God I am fine now (s7).
- My embracing of spirituality helps me push away any kind of defeating thoughts. I definitely don’t think like that. I have a small ranch and I do all kinds of things there. People even say I can’t work, but I feel fine [...]. (9)
- What I’d like to say to other ostomy patients is that I have a lot of faith in God and I thank Him everyday for being alive. We are not different from anyone, and if so, we are just special. Which one would you choose? Being an ostomy patient and living or having nothing and not having a life? (s15)

These accounts show how great the suffering of these people is. However, through divine contact with their faiths, they have found the strength they need to live and to fight with dignity for better life conditions.

The mystic experience would reveal to man the existence of God and would lead to the discovery of necessary, eternal and immutable knowledge existing in our soul. It implies the conception of a transparent being which would give purpose to truth. God, when found, is, at the same time, an internal reality and it transcends our thoughts\(^{[18]}\).

**CONCLUSION**

When we began this study, we tried to investigate not only the meaning of a person living as an ostomy patient, but also to learn about the changes this procedure imposes on their daily lives. Thus, we comprehended that in the process of living with their stoma, the being-in-the-world hears, sees, knows, imagines, waits, rejoices and anguishes because of his facticity.

In the interviewees’ messages, we have distinguished that the interviewees, through their own language, manifest feelings that reveal the essence of their existence, opening themselves up to people and/or situations in the world of caring. Such feelings are translated into fear, anguish, guilt, accomplishment and satisfaction which comprise their way of being.

Thus, in the narration of some patients, we have realized that care also manifests through dialogue, for they express their desire to be understood in their own state and of sharing their thoughts with others. For them, care must be expressed as living harmonically, in which every being shares his thoughts and feelings in a reciprocal process in which speaking and hearing arise as forms of caretaking. *When we hear the words attentively, we are actually hearing the calls that bring us closer*\(^{[18]}\).

In this perspective, we have also observed in their accounts that the essence of living with the stoma and using an ostomy bag is not an experience cherished by the caretakers, since the world as they see it remains obscured, tangled by their conflicts and discomfort, feelings that are frequently noted by the ones close to them who take care of them. It is within this world that the patient perceives his existence as a deterioration of his own autonomy, of his self-care ability and his individuality. Therefore, it is imperative that the conduct of Being-there of the caretaker be of caring for the patient from the perceptions that the latter has of the lived situations and not only from the experiences of the caretaker, for this experience is often altered by the contact the caretaker has with his surrounding world, in which humanity is frequently forgotten.

We have also concluded from this study that, in his existentiality, the ostomy patient expresses his vicissitudes in many different ways, showing how painful or pleasant...
are the occurrences in their lives, leaving to the nursing professional the role of comprehending such language. Ultimately, we share life stories with each interviewee and mainly we have learned that caretaking is an art to be rescued. The comprehension of this truth urges us to reflect about the process or caretaking in the nursing practice and to think existentially and beyond the technical-scientific knowledge, for caring conducts us to a broadening process with other people around us, experiencing the authenticity of being-with.

REFERENCES


