

FAMILY CAREGIVER OF A PERSON OSTOMY

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ABSTRACT

This paper aims to understand the experience of family caregivers of people with stoma. This qualitative study had as an outpatient context of ostomy, a reference in Cuiabá, State of Mato Grosso, whose participants were eight relatives of these patients. The strategy for data collection was Integrative Community Therapy (ICT), between April and November 2012, which were seized by shooting. After thematic analysis, results are structured into two categories: 1.Care within the family, that is related to what happens domestically, its relationships with family members, involving home maintenance care, financial demands and care for the other family; 2.Care within the general public, with respect to daily health care, social security and care maintenance. The outcome shows that the family caregiver experience involves social and cultural issues and should be recognised by health professionals, especially nurses.

Keywords: Family Nursing. Caregivers. Professional-Family Relations. Family Health.

INTRODUCTION

Being taken ill affects the biological, psychological, social and cultural universe of each and every being, and also adds new demands for health care. When the illness is chronic, then the care provided by the family members for the ill person could be intensified⁽¹⁾. In the light of this situation, family members are an important pillar of support, constantly seeking solutions to take care of the family member in the multiplicity of diligences as required, especially in the case of chronic ostomy. Among people with chronic ailments, those with ostomy have been the focus of our study, due to the social and cultural repercussions that affect them as a result of urinary or faecal incontinence. The ostomy consists of an operation which performs an opening in the abdomen for the elimination of feces and urine to the external environment⁽²⁾. People with stoma do indeed show some biological alterations, as the eliminations become incontinent and through the abdomen. There are also some important cultural changes, as the sphincter control learnt in infancy is largely concerned with hygiene issues, meaning that ostomy is a challenge to the shape and function of the body. There is also the need for certain devices such as boards and collection bags, which are technologies that have been

developed to offer a better quality of life, which is essential for daily living.

In the light of this context, it is in the family that these people have found the support they need to face this situation. In the family unit, we appreciate the understanding of a group that is bonded together by love and affection⁽³⁾. The relative that is fuelled by these bonds of affection recognises the condition and situation of the family member who has been taken ill. For the nursing area, the family has been recognised as a caretaker, responsible, the element that gives support to the person who has been taken ill, but we believe that the context of this family member is something wider in scope, full of demands and needs arising from the historical and social situation. The visibility of the caretaker relative started when we co-ordinated group therapies at the ostomy nursing department of a state-run hospital and we observed how the people behave and also talk in detail about fragments of their lives, as a person within the family and also as a caretaker for people with stoma, allowing us to ask: How does the caretaker family experience this context, and the care for people with stoma? This study seeks to understand the family member taking care of the person with ostomy and, thus, contribute towards the construction of awareness of the family unit and care from the standpoint of the family member, within his or her context of life and care.

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The search for people's meanings, values, creeds and references leads us to understand social and cultural aspects. In this way, the study is based on core concepts of culture. For interpretative anthropology, culture is like a web or several webs of meanings constructed by human beings themselves⁽⁴⁾. Culture is linked to actions and behaviour that people take on, and whose meanings show their values and creeds. We stress that the intention is not to look at family members from the viewpoint of professional care, and for this reason we defend the use of 'caretaker relative' as more appropriate to refer to the family member than 'relative caretaker'. In the first expression, the fact that the person is within the family is highlighted, while in the second expression caretaking is prioritised. The visibility of the family as a person, within this context, leads us to care in the extended sense. Care, in the view defended by Ayres⁽⁵⁾, can be understood as being movement, interaction, identity and alterity, plasticity, projects, desires, temporality, non-causality and responsibility between people seeking each other's well-being. Care is not restricted to therapeutic resources or procedures, as we see in the relationship between the professional person, the family member and the patient, that being the reference for this study. In order to know the experience of the family member taking care of a person with stoma, we seek to show the relationship between behaviours, creeds and values, their meanings, social and cultural issues, as important aspects of health care, seeking the production of meanings for humanisation, which is still so expensive within current practices by health professionals.

METHODOLOGY

This is a qualitative research study, as we intend to exploit the way in which a group of relatives of people with stoma think, give meaning to events, and establish their values and beliefs about caretaking. This approach seeks to establish a relationship between the events of the social world and the meanings that are assigned by the people who experience such events; in other words, there is a quest to absorb the way people understand the world, nature, health, illness, what meanings they assign and

reassign⁽⁶⁾, which fits in well with the general purpose of this study. The study was conducted in a nursing treatment room for people with stoma, owned by the state and a reference in the Brazilian State of Mato Grosso, which serves an average of 650 patients per month. Among the actions carried out, we highlight medical appointments, demarcation of the stoma, and provision of devices. There is also group therapy, including the Integrative Community Therapy (ICT), once a month, with the participants including not only patients but also patients' relatives, and nursing professionals and students. The ICTs normally take an average of 60 minutes, and this was the strategy used for data collection. The ICTs were filmed, but the main focus was the audio of the narration by family members. This made it possible to access the life experiences of the participating relatives. ICT allows welcoming, mutual hearing, sharing of suffering and ways of overcoming it, with the basic stages being: welcoming, choice of theme, contextualization, establishment of the problem or sharing experiences, reflexive closure and final analysis⁽⁷⁾. This strategy was considered appropriate, allowing access to the narrative statements made by family members, including anguishes of life and care, and, in an expanded manner, the person's existence as a person.

The participants were invited and also informed, at the start of each ICT, about the research: there would be no harm caused if they decided not to take part, and there would be filming with assured confidentiality and anonymity. The names of the participants were replaced by adjectives suggestive of moral qualities. The participants have also signed an Informed Consent Form (ICF), as recommended by Ruling No. 466/12 of the National Health Council (*Conselho Nacional de Saúde – CNS*), with approval in document No. 792/CEP-HUJM/10. The data was collected at six ICTs between April and November 2012. There was participation of eight different family members taking care of people with stoma, as the wife, daughter, aunt, grandmother, granddaughter, sibling, and two mothers, with the respective patient status being husband, mother, nephew, grandchild, grandmother, brother and two stomatised daughters, who live with the ill person. Regarding the basic characteristics of

family members: the average age was 34 years, the people were all female and are caretakers, and 80% take care of adults with stoma, while a mother takes care of a two-year-old child and another one nurses a teenager aged 12; 90% live in urban areas. ICT makes it possible for the people to talk about themselves and their experiences. For this reason, it is useful to take in the experiences of being taken ill and permanent care, which occur within the family⁽⁸⁾. In this regard, ICT allows the expression thereof through statements and narratives, and also listening by those people who live with illness within the family, to understand the context, their anguishes, and also to make it possible to share different ways of overcoming similar situations of distress which other participants may already have experienced. The statements or narratives have made up the corpus of data within this study. Thematic analysis seeks the nuclei of meaning that comprise an instance of communication⁽⁹⁾. With fluctuating reading and after new readings, we find the details and highlight them in different colours, according to the affinity with the following core themes: care overload, social needs, psychological support, routes for searches, technologies and equipment, rights, and shared experiences. The theme of 'Caretaker relatives of people with stoma' has allowed the establishment of two broad categories: **Care within the family and care within the public**.

The process of construction of results has led us to think about how the caretaker relatives, taking care of someone with stoma, show themselves within this context of specific care. It is important to ensure the commitment with the experiences of people which seeks to understand, so the researcher should make decisions during the research aiming to protect its ethical commitment with the research⁽¹⁰⁾. Based on narratives of family members, there is evidence of demands and care.

RESULTS AND DISCUSSION

The narratives themselves show doubts and expectations about caretaking in the very voice of the relative caring for people with stoma, as also concerns about how to face the situation,

solve problems, obtain technologies and also seek health services. They also show the need to share experiences with other people who have had similar experiences or those who clarify doubts, such as health professionals. The round of ICT in a reference infirmary specialised in ostomies makes it possible to share experiences, and also to have interaction between them. The caretaker relative stands out as that provider of care, instigator of actions, manager of demands, responsible for the organisation of routines within that family unit.

Care within the family home

The family members show how care occurs within the home and also shed light on their context and the meaning they have to the members. The meanings regarding the families were obtained with reports of positive feelings, shown as happiness, this being the normal meaning of a family marked by greater closeness between the family members. The 'narrative of happiness' places this family member in his or her relationship with the rest of the family, based on generations, and mediated by feelings such as *pleasure, liking, loving and wanting*, in relationships with *children, senior citizens, offspring, grandparents, babies, parents, husband*, who share spaces and meetings, giving support and caring:

I have the pleasure of liking and caring for children. (Coherence)

I also really love my elderly people. [...] Wherever they are, I want to be with them! I think that without them I lose my footing, and do not wish to smile. This, because every day, I have my mother who is now 81 years old, and every day she says good morning to me. She comes along in that playful mood. For me, the day is enough and the children too, I really like children. I have 12 children, can you imagine it? (Sweetness)

I went with her to Curitiba in January. Then there is my husband, who is in good health and not ill, but I also have three children. The two boys stayed [...] with my mother, with my grandmother. He was just going round and round [...] And I went with my baby, to have surgery (Altruism).

{Taking care of} My husband, my father, my granddaughters, this is what I do with most pleasure (Self-Confidence).

It is in the household unit that the caretaker relative establishes closer paternal and marital ties, with friendship, mutual commitment, showing that there is movement and also interaction between the family members, which is shown in temporality evident through the use of verbs such as *like, love, be, play, have, do* with the other, whether *husband, child, mother, grandmother*. The caretaker relative, within the household unit, can, through family ties, establish identities like those of the narratives where there is the presentation of relationships with family members - *child, father, mother, husband, grandmother, granddaughters* - through actions such as *caring, loving, playing, and travelling together*. Thus, the interactions reinforced by ties of kinship identities are constructed of each one. The existential identities constitute the act of interactions ⁽⁵⁾. The family that cares doesn't limit the role in this group, but in the dynamic that your family moves. The relationships enable links between them, it is marked by the recognition of mutual rights and obligations ⁽¹¹⁾.

The narratives show concreteness in the meaning of the family, with the evidence of the relationship of belonging to the other in its alterity. The feelings that involve relationships come out as something *pleasant, wanting to be together, smiling with the other, sufficient for well-being and counting on help*. The feelings are fragments of meanings. In the relation between professional of health - ill and their family, the care as happiness project is built, shared and responsible; it seeks to understand that the illness and your family are seeking, at the same time, it enables them to understand that professionals intend, mediated by authentic dialogue ⁽¹²⁾.

Thus, care in the household environment may be taken in by health professionals, thereby facilitating the interaction between nursing professional and relative of the patient, as also making it possible to share the different ways of caretaking. If the household space is the one encircling the family, any situation that threatens one of the family members is indeed a challenge to the family's very integrity, life reference, project for happiness, and can be established as suffering and affliction. Giving an opportunity for family members to talk about these

afflictions is not standard practice in health services, meaning that the rounds of therapy also have the purpose of giving this family member voice and also visibility. In the round of treatment, the participants could state 'what makes them sleepless', and also reveal the challenging and significant situations of their daily activities and family life:

[...] I have affliction, yeah! One thing takes my sleep away: since my husband died, passed away, they killed him, I went six months without any sleep [...] And now that the boy is ill, I am also a bit like this again, there are nights when I didn't sleep (Coherence).

What takes my sleep away is the fact that we are owing money. We are in rented housing and are not going hungry, but we are going through difficulties! (Sweetness).

The threats are shown below:

[...] even though the doctors say he is still young [...] but as I am a grandmother, I would like him {a paraplegic grandson with stoma} to at least move something! This is something that makes me restless (Sweetness).

[...] my daughter {child with syndrome and colostomy} will need heart surgery, which will be performed in Curitiba, Campo Largo. I am a bit worried because this is surgery with an element of risk. I am going outside the state, I don't know anyone, and I am a bit anxious, sometimes I even start shaking (Bravery).

In their narratives, the family members mention issues such as illnesses, surgery, need for treatment, progress of state of health, the need for care, social and economic limitations, that need care. These demands are threats to the relative and also a challenge to this person's project for happiness, which is something personal, but shared collectively when experienced within the household. A threat to autonomy could come from illness and conflicts within the family environment ⁽¹³⁾. The family and relatives are a single complex integrated unit which can be threatened by chronic illness. Thus, when the family is not fully understood and is excluded from the planning of assistance, they could diverge from the care provided by the professional people ⁽¹⁴⁾. The caretaker relative needs some space to be heard by the health services. In the reports made by family members

about the context of the caretaking operation, the life of the family member is not limited to caring for their loved one with stoma, but also brings several other demands. The demands for the caretaker relative are added to the demands that already exist, bringing a situation of overload:

[...] It's a daylong battle, because I am alone to do things at home. [...] I have crops to take care of, I have the house because I wash clothes alone, a lot to be done. Then I have my husband who has Parkinson's disease and is not very well. He has his intestines at the side, and is using a colostomy bag, so he depends on me. [...] In addition, he shall have a new operation on the thirteenth of May, and I have no-one to take care of my father so I can go along (Self-Confidence).

The demands for care refer to life at home and also the role within the family, including care for house maintenance, the health of the husband and the father, both of whom have health problems. This means that Self-Confidence is responsible for taking care of the very existence of other people, as she mentions in her narrative. Taking care of the existence of self and others means that the caretaker relative often gets overloaded:

I get really tired as he is a person who does not like to see anything dirty. I wash clothes every day, and I have to get the clothes clean and tidy [...] so I get tired (Sweetness).

Overload is marked by caring for the home and also for the people who belong to that space. In the narrative, we find grounds for understanding context and explanations, and also rationality about family relations and means of caring. For Sweetness, this rationality comes out in mobilisation and promotion of comfort, hygiene, food, distraction, rest, showers, changes of clothes, and provision of care in line with need. This rationality also includes provision of health care at institutions, and understanding of demands on professional care, information about possible services, such as taking to the service, following the appointment of service, and then going back home. This needs the interpretation of the problem, raising of new alternatives, and also mobilisation to demand efforts to access, move and establish itineraries in search of treatment, and have good relationships with health professionals. These needs are highly complex situations managed by

the caretaker relative, often alone. These demands bring physical consequences, as also psychological and emotional problems and psychosomatic illnesses for the caretaker relative⁽¹⁵⁾, as shown in the following narrative cases:

[...] Despite my age, I am a person who doesn't complain about everything, however I do think that this real mother should come along and help at least once in a while, right? Then the other siblings of his, they never show up. I do not complain because if I am alone, I still do things myself, as I am always doing, right? [...] I sometimes feel lonely, because it is a lot! (Sweetness)

[...] There are relatives of my husband, but it is not like my family. They never help, just when it is time for the barbecue, at party time! (Bravery).

Now there is my father, I need to bathe him, and he makes me very worried. [...] No, he does not walk, he stays in the wheelchair. I take him from bed and put him in the wheelchair, and then from the wheelchair to the hammock (Self-Confidence).

The family member who takes care of the sick patient has been commonly linked to the female figure, and also to characteristics such as not complaining, I do it myself and get worried, execution of hygiene and movement of the ill person, distinction of relatives and family, also being responsible for managing the household. This way of being brings overload and also requires care, a fact not normally recognised within the professional practice of the specialised professional people. ICT is a space that allows these people to state their feelings, and also provides a view of care by horizontal communication, by listening to others, free from any judgements and prejudice of any kind, which helps with the understanding of the context. In addition, ICT is a technology for caretaking, to face situations of suffering arising from daily activities⁽¹⁶⁾. The family members are, in relation to the patient with ostomy, in a certain family position: daughter, mother, grandmother, granddaughter, aunt, wife and sibling.

My nephew is like this (Coherence).

Apart from the father and husband, we have the granddaughters and also my daughter (Self-Confidence).

I have four, but my first drowned to death in a river; so I only have three children now, two boys and one girl (Fluency).

He is my grandson, but he is like a son to me (Sweetness).

"[...] My daughter is a baby and also picks up bags (Altruism).

The construction of care based on gender is the consequence of a historic culture perpetuated by generations but which, in our current reality, is worthy of thought, as the context of families is transformed in its form and dynamics. Even though caretaking has been traditionally considered a woman's role, we highlight that the main motivation of care is concern for others. Another aspect of overload is the overlap of positions as family members within the household: Coherence is an aunt; Sweetness is a grandmother; Fluency is wife and mother; Altruism is a wife and also mother to three children, one of whom has a colostomy; and Self-Confidence is a wife, grandmother, mother and daughter:

[...] I just live with my husband, my father and three granddaughters. One of them was 12 on 28 March, while the others are 10 and 8. In fact there are four! There is another one who is 4 years old, and shall be five on 8 May (Self-Confidence).

The caretaker relative tries to organise the daily routine seeking the management of demands for care. Thus, apart from the maintenance of the household, there are also the demands for caretaking of the ill relative and, having ostomy, the main concern is for the adaptation of the environment and the domestic space, food, bathroom, and also the need to learn about how to tend the stoma, what a stoma is, handling and provision of devices such as boards, bags, folders and clips, and also a concern with the social implications, as this is a person with stoma. The caretaker relative gives value to the household dimension as a space for care. The value of the family members is expressed to the extent that it is pleasant to do things for and with them, but one can also see affliction amidst threats within this environment space. ICT has proved to be a powerful instrument for taking care of the person with stoma, in a health institution, as it made it

possible to recognise the relative, his or her narratives, and also context for care.

Caretaking in the public

The demands for the caretaker relative go well beyond the household dimension. In their narratives of their paths, the relatives state how they have perceived their loved one being taken ill, and specifically the ways in which they have understood the illness, its symptoms, and the execution of the colostomy procedure. In their narratives and interpretations, they even incorporate biomedical language, which is different from the daily language used, but typical of health professionals, and which has been learnt in the process of monitoring their loved one:

She was born with an imperforate anus. [...] Then, the trip was scheduled for 8 January because apart from the colostomy she was also born [...] with kidneys in horseshoe configuration and a syndrome that has not yet been diagnosed. [...] But when she was born, there was no atresia of the oesophagus, there was only one membrane, there was only one obstruction there, it was not atresia. [...] They suggested colostomy because they saw that it was at the bottom rather than at the top (Bravery).

This one that has haemodialysis [...] It is for him to have this transplant soon, as he is here and in good health right now, but suddenly his immunity falls. It is like someone with diabetes, who goes a long time without eating and then needs to eat something quickly (Fluency).

He has had Parkinson's disease for 15 years. After having this surgery (colostomy), he improved [...] And now, it has been one month since he had the surgery. Now, he is starting to do something unaided, like having a shower. He also eats and dresses himself unaided (Self-Confidence).

He became paraplegic and uses a colostomy bag (Sweetness).

The family members also use terms that include affected organs, including the anus, kidneys, and oesophagus. Pathologies such as imperforate anus, horseshoe kidneys, syndrome, atresia, obstruction, diabetes, Parkinson's Disease, also require significant knowledge of physiology, and the appropriation of biomedical language. This process turns the family member into a specialist for the mediation between the patient, his or her family, and also professional

people and their health institutions, as there is keeping of history right from the first symptoms, different interpretations for the disease and forms of care as executed, and also the paths through the services, the suffering experienced by the patient and related events, and the context. They have the narration of history as a relative of the patient, which favours mediation between this patient and the family, and also between the patient and the health professionals. The incorporation of biomedical language for the events and happenings within the context of the life of the caretaker relative makes it possible for him or her to understand the disease and explain it, as also to acquire the ability to coherently understand and justify the treatment and the appraisal thereof, marking their life and contributing with the true meaning of what it is to be a caretaker relative. Demands outside the home make the caretaker relative promote actions towards mobility, effort and accompaniment of demands, also requiring the interpretation of the context that is presented, seeking care. Thus, they pass through public spaces seeking attention, with a particular movement, marked by dates, times, health problems, monitoring and progress of symptoms, which are ordered to give meaning to the narratives. They also show a path with the description of efforts for movement, means of transport, states of health, degree of dependence for mobilisation, eating and getting dressed. This effort, this movement, requires visibility by the institutions and also by health policies, but also on the part of professionals, as, within this effort, there is demonstration of suffering and overload arising from the structure available, also limited to what refers to full assistance, accessibility and humanisation. The overload on the relative, related to structuring and organisation of health services, associates the relative's need to work with the need to seek health services and professionals, not always in compatibility:

Very nervous indeed! I am alone, there are a lot of things to be done, my granddaughter, with my daughters, I do not sleep well, as I have an older cousin who is mentally challenged yesterday I felt ill (Enhancement).

I work three times a week. I work on Thursday, today is just a quick whip-round at the office. So I leave at 9 a.m. and I cannot work every day

because she is monitored by several doctors and then it is bad for me to take her to the doctor because I need to be absent at work (Bravery).

The caretaker relative needs to meet the demands for appraisals and appointments with the health services. So, this requires a search for booking return appointments, examinations, consultations, and also having to learn how to deal with the public health system, whose organisation is not always accessed by the population. This demand becomes much more complex when the family does not reside at the location where the health services are located, meaning a need for travel, transport, housing, piling extra burdens on the relative:

Sure, it is very important, on 13 May I need to bring him to Cáceres for another operation (Self-Confidence).

She already has other problems. She has horseshoe kidneys which have not caused any problems as yet, but there is a good chance that this could lead to problems, as they are fused. Joined one to the other, and she also has a problem with her spine, she walks a bit bend but now I am unable to deal with this problem (Bravery).

The caretaker relative, on mentioning a commitment towards the date of the surgery and accompaniment of the development of the symptoms, also reveals how 'care' extends beyond the household, as he or she takes care of the patient also within health institutions. Another public space where they have transit is the venue of rehabilitation:

He needs a wheelchair [...] because he weighs over one hundred kilos. The wheelchair that he is currently using is no good, as it has gone wrong. This wheelchair, for one year and five months we have been asking for it here at the rehabilitation centre and they never received this wheelchair {to pass on} and we are in no condition to make the purchase thereof (Sweetness).

The family member narrates the necessary interlocation with the rehabilitation service seeking the equipment that is essential for their loved one and also concern at lack of service and the fact that due to financial constraints it is impossible to provide such services. In the report that follows, the relative shows concern in carrying out the recommendations of the physiotherapy professional in their home, and

also due to health problems afflicting the caretaker relative:

The physiotherapist told me: "When night-time falls, you repeat what I am doing here, you do it at home. I shall do it in the box bed? I shall do it with my bed over there, the large one? [...] I have problems with my spine. I cannot stay on it to do this, and his legs are really thick, like tree-trunks! Another issue, what about having a shower? We bath him on the string chair because we do not have a real bath chair, as here at the rehabilitation centre they have not found a chair for me. He is really heavy, I am already spoiling the floor (Sweetness).

The professional people in these spaces do not always recognise the limitations of the family relative, and neither have the preparation to maintain the care that is recommended. This aspect shows that professional people do not analyse the social and cultural situations, the efforts made by the family relatives, the financial constraints, and even the health of that family member. The chronic condition known as ostomy is considered a physical handicap, meaning that those with the condition shall fall under the protection of Law No. 5,296 of 2 December 2004. The person with stoma is entitled to receive illness assistance. However, access to this benefit is by no means easy, and often there is a need for assistance from Government institutions in order to acquire it:

I had to use the services of public lawyers because the National Social Security Institute (INSS) said that he was able to work. (Fluency).

Oh, mine has also approached the Government lawyer service. (Flexibility).

The services of provision of attention to people with stoma are also often accessed by caretaker relatives, especially for the acquisition of the devices that are assured by Law, which allow the qualification of the life of their loved one. However, these devices are not available in most health services and also in most locations of the state, meaning that there is a need to go to distant locations, of the state. This right is not always known to the family members and needs to be learnt, and there is the inclusion, in the care, in the public dimension, of knowledge of social rights and assurance thereof to their loved ones, as stated in the following narrative:

Ah! Look, for example, when I didn't know that it was available here, that such bags were given, I would buy them for him. I would buy bags, boards, everything I would buy, things were difficult then! (Fluency)

Among the different demands on the family member, we highlight the movements that they make as their loved one is a person with stoma. The journeys in seeking health, social assistance and legal services are the formal support⁽¹⁷⁾, which is loss-making, bureaucratic and prescriptive. Along this route, the person also manages the family, arranges transport, money, board and lodgings, food and other financial expenses.

For me to come here today, I had to leave for Mirassol yesterday, take my father and husband and also the granddaughters, who stayed with my daughters [...] I came here at two o'clock in the morning. The next day I take a bus, and then arrive home at ten o'clock at night [...] Three days for me to come here, to pick up the bags (Self-Confidence).

The narrative of the caretaker relative, while also showing the protagonism of the loved one who has been taken ill, also becomes a protagonist as well, as he or she not only accompanies, but also shows concern, makes, searches, teaches, learns, appraises, interprets, establishes paths, and decides a process in which the person is cared for while also caring; and as the person reveals new meanings throughout this shared experience, he or she gets reconstructed as a person. Among the concerns with public spaces, social interaction outside the home is shown as a focus area of the care provided by the relative. This aspect relates care with the ostomy, with gases, bags, and hygienisation:

When I went to travel with my baby, he gave me 10 more bags, and I get 20 myself. I went to Curitiba [...] I didn't know if there would be any bags over there, so he or she released a lot, there were 30 bags in all (Altruism).

[...] there were those bags that had to be washed and he would get disgusted and not do it. This meant that I had to do it. But now it is like the one who has nothing to wash, he is the one who does it! (Fluency)

[...] She keeps grabbing [...] I like this bag that does not wash, that is grabbed and thrown away. (Bravery)

They fill up so much with air [...] that I tell him: "Oh, oldie, go there and take out the air!" because removing the air does not force [the bag] too much (Self-Confidence).

The relative taking care of the person with stoma needs to plan regular visits to the health services, which is an intercity trip for some, and also a search for means of transport for others. Both situations of travel bring additional burdens on the family:

[...] I took advantage of the fact that I left early [...] I take a trip just because that to bring her at this time she even feels bad (Bravery).

I went to the secretariat for health to discuss things with them. Then she said no, because I had to come because the men of the ambulance are not picking them up any more (Self-Confidence).

The caretaking relative is also aware of specificities and particularities of their loved one, as they are aware of the most appropriate devices, their routines, habits, as they have already shared the home and public spaces with them for a long time. The family context has a repercussion on the act of caretaking, as the knowledge and the practice of maintenance of the stoma are acquired within the home⁽¹⁸⁾. The meaning of the care is in the sharing of the condition of the other person and show concerns with the other. The reconstruction of care means the development of attitudes and spaces of the intersubjective meeting⁽⁵⁾. Because of this, we see the need for the public health spaces to be reconsidered and reorganised so as to recognise the importance of the caretaker relative for health care, and also to give them the necessary support. There is physical, psychological and social wear on the family member because of the lack of connections between the services, which leads to psychological and social losses, arising from this process⁽¹⁹⁾. In this study, ICT made it possible to visualise the family of the person with stoma, on giving this person the chance to speak out. During the process, we could show fragments of its regular daily complexity and, even though this is not the focus of this study, visualise it as technology for taking care of family members with chronic conditions. The cultural results of this care, such as songs, strengthen values, knowledge and individual competences⁽²⁰⁾, favouring the consideration of the self-starting out from the social context:

[...] I really liked participating, so I am taking a little piece of every one of you (Self-Confidence).

To unwind a bit, and return a bit lighter [...] as I have support. (Altruism).

Experience (Sweetness).

The satisfaction, the opportunity to speak out, lightness, experience and support are some points that remain in the mind of the caretaker relative participating in the ICT which, in turn, was shown in the hug, in the handshake, in smiles and tears. Therefore, the use of the ICT showed itself to be a type of technology for care, for caretaker relatives of the person with stoma.

FINAL COMMENTS

This study allows us to understand that the coexistence between the caretaker relative and the person with stoma refers to the context of family life. The physiological change of intestinal elimination, which in turn is incontinent and through the abdominal wall, in the chronic condition of ostomy, threatens exposure on social interactions and leads to dependence on health devices and services. Here we visualise that, for the caretaker relative, care includes two key spaces, home and public spaces. In the former, the caretaker relative takes care not only of the loved one, but also of other family members amid a diversity of needs, moved by the ties of affection with each and every one of them, and also take care of maintenance of the home and its organisation. This means the family is understood as its reference and there is concern with any threat as may affect it, as it is already part of the project for life and happiness. Regarding care for the loved one with stoma, the family learns how to cope with this change, and also shows concern with the social implications that this chronic condition shall have. In public space, the caretaker relative goes beyond home life, needing to learn biomedical language, rally round in search of health professionals, health institutions, and devices, and manage means of transport and housing. Also in this context, other services and the search for rights in the health area are demands presented to the family members. Here we highlight the relationship between the caretaker relative and the feminine

figure which has been historically constructed in our society. The results point to an overload with repercussions in the form of suffering, particularly due to the current social structure, which is presented with limitations on full attendance, accessibility and humanisation. The findings show the protagonism of the patient with stoma and the caretaker relative, who shows concern, does, searches, teaches and learns, appraises, interprets, establishes paths and also decides, while also taking care and is cared for, and also gets reconstructed as a person to the extent that he or she unveils new meanings

through mutual existence. TCI allows one to absorb the experience of the caretaker relative in a wide way, mentioning social and cultural issues. In addition, it opens the opportunity for the caretaker relative while this is a type of group therapy. Therefore, it becomes necessary that medical and nursing professionals accept and recognise the reality experienced by the caretaker relative, so that they include actions towards interaction and care. We recommend more studies about the caretaker relative from this person's own standpoint, and with reference to life.

FAMILIAR CUIDADOR DA PESSOA COM ESTOMA

RESUMO

Este estudo objetiva conhecer a vivência do familiar cuidador da pessoa com estoma. De abordagem qualitativa, teve como contexto um ambulatório de estomias, referência em Cuiabá - MT, cujos participantes foram oito familiares destes pacientes. Utilizou-se como estratégia para coleta de dados a Terapia Comunitária Integrativa (TCI), feita de abril a novembro de 2012, por meio da filmagem. Após a análise temática, os resultados foram estruturados em duas categorias: 1. Cuidado na dimensão domiciliar, que relaciona ao que acontece no âmbito doméstico, suas relações com os familiares, envolvendo os cuidados de manutenção da casa, as demandas financeiras e os cuidados aos demais familiares; 2. Cuidado na dimensão pública, que diz respeito à assistência em saúde, previdência social e à manutenção do cotidiano de cuidado. O desfecho aponta que a vivência do familiar cuidador implica questões sociais e culturais, que devem ser reconhecidas pelos profissionais de saúde, em especial de enfermagem.

Palavras-chave: Enfermagem Familiar. Cuidadores. Relações Profissional-Família. Saúde da família.

FAMILIAR CUIDADOR DE LA PERSONA CON ESTOMA

RESUMEN

Este estudio tiene el objetivo de conocer la vivencia del familiar cuidador de la persona con estoma. Se trata de un abordaje cualitativo, que tuvo como contexto un ambulatorio de ostomía, referencia en Cuiabá- MT, cuyos participantes fueron ocho familiares de estos pacientes. Se utilizó como estrategia para la recolección de datos la Terapia Comunitaria Integradora (TCI), conducida de abril a noviembre de 2012, con la grabación de los trabajos. Después del análisis temático, los resultados fueron organizados en dos categorías: 1. Cuidado en la dimensión domiciliar, que se relaciona a lo que sucede en el ámbito doméstico, sus relaciones con los familiares, involucrando los cuidados de mantenimiento de la casa, las demandas financieras y los cuidados a los demás familiares; 2. Cuidado en la dimensión pública, en lo que concierne a la asistencia en salud, previsión social y el mantenimiento del cotidiano de cuidado. La conclusión es que en la vivencia del familiar cuidador implican cuestiones socioculturales que deben ser reconocidas por los profesionales de salud, en especial, de enfermería.

Palabras clave: Enfermería Familiar. Cuidadores. Relaciones Profesional-Familia. Salud de la familia.

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