

TELLING STORIES TO CARE AND TRANSFORM

CONTANDO HISTORIAS PARA CUIDAR Y TRANSFORMAR

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Mirliana Ramírez-Pereira

University of Chile

mirliana@uchile.cl

ORCID:0000-0003-1439-4162

Esmerita Opazo Morales

University of Chile

ORCID: 0000-0003-3061-1390

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Abstract: Postmodernity has arrived bringing individualism, globalization, and fragmentation of the social fabric. Nursing, in its holistic care conception, must look after the health of the person, the family and the community without losing the connection with itself. The aim of this work was to reflect about the emotions, feelings and thoughts that arise in the nurse-researcher when exploring about the care and the social representations of patients with renal disease. The method used was the interpretative autoethnography, as a methodological proposal that sets apart from the traditional dynamic of nursing. Our conclusion was that there is a connection between the experience of the disease, the qualitative research and the care from the point of view of patients and nurses, confirming the chosen methodology as a proper way to improve the understanding of the phenomena associated with nursing care.

Keywords: Nursing, Renal Insufficiency, Qualitative research, Chronic disease.

Resumen: La postmodernidad ha traído consigo individualismo, globalización y fragmentación del tejido social. Enfermería en su visión holística debe mantener el cuidado integral de la persona, familia y comunidad, sin perder la conexión consigo misma y con el entorno social. El objetivo de este ensayo fue reflexionar acerca de las emociones, sentimientos y pensamientos que emergen en la enfermera-investigadora, cuando se explora el cuidado y las representacionales sociales de las personas con enfermedad renal. Como metodología se usó la autoetnografía interpretativa, como una propuesta metodológica que rompe con la dinámica de enfermería tradicional. Como conclusión hemos podido observar el vínculo existente entre la experiencia de la enfermedad, de la investigación cualitativa y del cuidado desde la perspectiva del paciente y la enfermera, validando la metodología de la autoetnografía interpretativa como una forma de mejorar la comprensión de los fenómenos asociados al cuidado de enfermería.

Palabras Clave: Enfermería, Insuficiencia renal, Investigación Cualitativa, Enfermedad crónica.

Resumo: O pós-modernismo trouxe consigo o individualismo, a globalização e a fragmentação do tecido social. A enfermagem em sua visão holística deve manter o cuidado integral da pessoa família e comunidade, sem perder a conexão consigo mesma e com o meio social. O objetivo deste ensaio foi refletir sobre as emoções, sentimentos e pensamentos que emergem no enfermeiro-pesquisador, quando se exploram os cuidados e representações sociais de pessoas com doença renal. Como metodologia, utilizou-se a auto-etnografia interpretativa como proposta metodológica que rompe com a dinâmica tradicional da enfermagem. Em conclusão, vimos a ligação entre a experiência da doença, a pesquisa qualitativa e cuidado do ponto de vista do paciente e a enfermeira, validando a metodologia de autoethnography interpretativa como uma maneira de melhorar a compreensão dos fenômenos associados cuidados de enfermagem.

Palavra chave: Enfermagem, Pesquisa qualitativa, Insuficiencia Renal Cronica, Doença Cronica.

INTRODUCTION

The stories of nurses are lost in the care of the sick and the neglected. Not because they do not have any value, but because the stories are not written, they are only left in the memory of those who had the privilege of being served with love and wisdom, thus forgetting the small story, the one that is the story of all and that is built with the events of life. When we nurses rescue and narrate the stories of our patients, which are unavoidably intertwined with our own, we defy the traditional research standards, that of a research which starts with the premise of an objective reality, that it can be captured and measured.

But, what happens when the story goes beyond that, when it not only rescues the narrative of the other but also our own? When the researcher does not deny, but, on the contrary, claims the subjectivity and her own experience, emphasizing the social aspects that accompany the disease? It is in that instance of being recognized in the other, on the understanding of that nurses and patients are bonded by the same dignity and humanity, that we all share experiences, history and culture, when we can envision nursing as a tool for social transformation.

In this road of social transformation Interpretive Autoethnography emerges as a method and a chance to meet with the Me-nurse, to deliver humanized care that patients require from the health professional, especially nurses, who must possess skills to relate to them, to welcome them with humanity, to understand their fears, identifying themselves with their pain, offering security; nurses who are able to observe and allow to be observed (1).

In a broader sense, if we understand qualitative research as a multi-sided crystal, with an energizing discourse, rebel, where art and science are mixed and in which both are combined in an infinite variety of forms, substances and transmutations, we will be able to understand that the reality is much more than what we see with an illusion of capturing the objective reality. In this multidimensional, multiphase and of multiple approach to reality (Ellingson, 2011) context,

nursing science is positioned in an integrative interface from humanistic, social, political and spiritual views, as an alternative of holism and transversality (2).

Lyotard argues that, at present, the Western world is in the condition of post modernity, that is, dissatisfaction with the systems, a disbelief in regards to the grand narratives of unifying type on which modernity was based (3). Postmodernism is set by globalization, marked by communication and the use of new technologies, with an emphasis on social and multicultural homogenization, which has caused the disappearance of the conception of the human being, family and traditional community of the pre modern era, understood as holistic, focusing on the being and obedient to natural cycles (4). These changes that neoliberalism has imposed involve all western countries. One of the most affected is Chile, a laboratory of a neoliberal model (Saavedra, 2014) that was imposed during the military dictatorship of Pinochet and which consolidated social, economic and political transformations that remain to this day, where social inequality has deepened with a Gini index of 0.5, one of the highest in the Organization for Economic Cooperation and Development (5,6).

The renal disease is a world problem. It overloads health systems and generates millions of deaths and years of life lost. Epidemiological changes worldwide are also reflected in the health of Chileans, with a significant increase in the prevalence and incidence of chronic noncommunicable diseases (7). Within these renal disease has increased considerably, as the diseases that are risk factors for it, such as diabetes and chronic hypertension. The V-Stage Renal Disease affects 19,071 dialysis patients, with 45.5% of women and 51% of the total are over 60 years old. 88% of them are dialyzed in private dialysis centers and 12% in public hospitals and clinics (8).

Chronic renal disease not only affects a specific organ of the body; it chooses the body itself as a means of expression with the world, without being able to separate the healthy parts thereof (9). This disease results in an important personal, family and social cost with high levels of anxiety, depression, suicidal thoughts and self-contempt (10). This is worsened by the low employment rate of patients in renal replacement therapies. According to Julian-Mauro, only 33.3% have some kind of remunerated job (11).

The processes mentioned and the characteristics that they imprint on people, families and communities generate huge changes in different dimensions of their daily life, influencing and making all the sciences more complex. However, certain changes in the understanding of the human being have been occurring during centuries. According to Le Breton, the rupture in the integral conception of the human being occurs with the first anatomists, who, by dissecting the body, transformed the person in an object (12).

This article derives from the field notes, experiences and memories of interviews with people with chronic renal disease, as part of the research "Humanizing care: understanding the social representations of renal disease in people on dialysis", rescuing in this way the intersubjectivity of the nurse-patient relationship, as well as the voice of those who suffer from the disease.

METHODOLOGY

Its purpose is to reflect on the emotions, feelings and thoughts that emerge in the nurse-researcher, when exploring care and social representations regarding the condition of people with renal. Social representations are understood as "systems of opinions, knowledge and beliefs of a culture, a category or a social group and in regards to objects of the social context" (13).

The methodology used was qualitative, since it allows to understand the meanings, granting a contextual importance and taking into account the particular aspects of the situation to be studied. This is fundamentally related to the idea of a search for meaning in order to achieve the whole understanding of phenomena, being even more important than the explanation of a particular phenomenon (14).

The paradigm used was the constructivist. According to this paradigm, people interpret phenomena according to their own history and culture. The constructivist paradigm recognizes that the real world is built on the basis of social interactionism and representational resources (15).

The perspective used was interpretative autoethnography, which is the use of the experience and personal writing to comment or criticize cultural practices, to contribute to existing research, to expose the vulnerability and to create reciprocal relationships with the reader in order to achieve an identification with the story (16-17). According to this, people create their lives through stories of who they are and who the others are, interpreting their lives according to these stories (18).

This research is based on Habermas's principles of communicative ethics, according to which interlocutors are validated as equals, in which both have a voice and stories to tell (19). The participant signed an informed consent authorizing the interview, its recording and transcription, as well as its use in academic publications, safeguarding her anonymity. The interview was conducted in her home, with an approximate duration of 90 minutes.

DEVELOPMENT

Traveler, there is no road; you make your path as you walk

(Proverbs and songs (XXIX), Antonio Machado)

I am a nephrologist nurse. I have worked for a long time in the care of people with renal disease, in conjunction with the teaching of undergraduate and graduate students. During all these years I have tried not to forget that human beings are whole beings. In this path I have been in contact with the suffering of my patients, knowing how hard it is for them to suffer this disease, how difficult it is to enter the labor and social worlds, and the problems that arise within the families.

After completing my Master's degree in Community Psychology I decided to study the Doctorate in Nursing and to inquire about the care and social representations of people with renal disease, so as to visualize from the common sense of patients how they understand this disease, how it affects them emotionally and which is its field of representation.

Often, in the care of renal disease patients the biological aspect is prioritized, downplaying the importance of the psychological, social and spiritual aspects to the point of seeing the person as a machine, forgetting about the whole and the suffering of both, him and his family.

After reviewing numerous documents, articles, book chapters, analyze and reflect on new ideas, I spent hours locked up in my office, trying to link humanized care and social representations, reflecting and thinking in order to translate them into a research project.

A pleasant feeling of joy overwhelms me, at the time of field work. It is the chance to get out of the long hours of confinement and isolation to get closer to the patients, intentionally knowing their reality, their lives. In a Chile where social inequality is part of our lives, this instance becomes a possibility to leave my comfort zone as a nurse, a wife and a mother and get to know my patients more deeply, exploring their concerns about their illness. All this leads me to imagine a disturbing and encouraging scenario. For a long time, while preparing the project, I imagine that the fieldwork will be very enriching for me and I hope it is also the same for the people who suffer from this disease. Research will be conducted in Coquimbo, a small town where I live, which is located 471 kilometers north of Santiago, capital of Chile.

I look up on a map the address of my first interviewee, Mrs. Maria (pseudonym). I have to enter an area of the city that I did not know. There are very humble wooden houses, but clean and tidy. I notice some young people chatting in the street, with loud music. It is 3 PM, I think of the lack of opportunities that in my country start from the cradle, in the sense that children grow marginalized in ghettos of poverty with poor education, no green areas where then can play, or safe public spaces.

I knock on the door, and a woman of about 70 years old welcomes me, sweet and affectionate. I introduce myself and she gives me a kiss on the cheek. It is customary in my country greeting with a kiss, even though you are just getting to know the person for the first time. Her house is small, with ornaments and paintings everywhere, family photographs and gifts. She tells me that she lives with a grandson who works all day and that her daughter lives nearby, so she sees her often. I tell her about the purpose of the interview; she unabashedly accepts and signs the informed consent, which authorizes me to do the interview.

She tells me that despite her illness she is a happy person, who feels loved and cared for by all, especially by the nurses at her dialysis clinic. She tells me that they are always looking after her: if her blood pressure lowers or if she suffers from cramps; they ask her about her family and also tell her about aspects of their lives outside of nursing. She insists that all of this is with "great respect". While she is talking I observe her. Her face sunburned by the sun in northern Chile, a little pale, with deep wrinkles covering her face, but with a wonderful smile that fills the room. From my perspective I consider dialysis to be a terrible experience: attend three times a week, lose 4 hours each time connected to the machine that keeps her alive. I observe her arm, her arteriovenous fistula, somewhat edematous, her working woman hands, her humble clothes, which is a testament of her social origin. I listen to her words always lit with a smile. I ask her: tell me your story. I remember the words of one of my teachers who emphasized that the best interview is the conversation between friends; I leave aside my white uniform and with it the costume of an expert, and I listen to her:

"I only got to 4th year of primary education. I was orphaned at age 8; my dad raised me. It is sad to grow without a mother, without anyone to guide you and take care of you. In the search for love, I got pregnant at age 14 from my husband. I was very badly treated by him, he beat me up every day. When I widowed at 46 years of age, I decided to never have a partner again. I raised my five children alone".

"Llegue sólo a 4to año de educación primaria, quede huérfana a los 8 años, me crio mi papá, es triste crecer sin madre, sin nadie que te oriente y cuide. En esa búsqueda de amor, quedé embarazada a los 14 años, de mi esposo. Fui muy maltratada por él, me golpeaba todos los días. Cuando enviudé, a los 46 años, decidí no tener nunca más una pareja, crie sola a mis cinco hijos".

The words of my interviewee sprout without difficulty, she seems to have waited a long time to tell her story. I cannot help but feeling compassion for her and for many other women who bear the stigma of loneliness and poverty and seek refuge in their partners to feel loved, tolerating physical and psychological violence.

She continues with her words, sometimes as if I were not present. She tells me she is a Catholic and that she used to attend Mass every Sunday before she got sick. Currently, she cannot do it, arguing that she does not have either courage or strength to go, though she stresses that she still is a firm believer:

"I have a picture of Jesus next to my bed, I cross himself before going anywhere. I ask Him for strength. I only live for Him. Diseases are things that God commands; they are tests that our Lord sends us for us to believe that He exists. I'm already resigned; it is what I had to go through and if He has not taken me with Him yet, it is because I am still useful down here".

"Tengo una imagen de Jesús junto a mi cama, me persigno antes de salir a cualquier lugar, le pido fuerzas, solo vivo por él. Las enfermedades son cosas que manda Dios, son pruebas que manda nuestro señor para creer que el existe, yo ya estoy resignada, es lo que me toco y si no me ha llevado es que todavía sirvo acá".

As a nurse I have heard this explanation many times. This way of understanding the disease as something sent by God, sometimes as tests, others as punishment. I observe myself and I remember that many times throughout my life I have explained the events under the same precepts; as something necessary to become stronger or as a test from life itself in order for me to grow. I recall the cold winters in Santiago, when my little son suffered bronchopneumonia; I would look at his face with an oxygen mask and thought: if God sent me this child, He will not allow him to die; it may be a test from Him, to see if I have faith, if I still believe in Him. I think that in one way or the other this way of understanding diseases and events provides us with peace and comfort within all the suffering that means to be sick. Latin America is deeply religious. Christianity is part of everyday life and it guides the lives of the people; it is part of our culture to accept suffering and sacrifice as a part of life.

Maria says: *"My lady," my life has been full of suffering; when I was 25, I suffered from a very severe form of diphtheria, which left me bedridden for 8 months. I had to learn how to walk and move again. I was treated in Santiago, there were no medical means here to help me heal. Then I worked on shifts in the fishing business that used to be in Coquimbo. In the very cold winter I had to work canning seafood and fish; maybe that's why my kidneys stopped working"*. She goes on with her story: *"I have not misbehaved; I have not been a bad person. I was never a woman to go out with friends to have fun at night"*.

"Mi señorita, mi vida ha estado llena de sufrimientos; cuando tenía 25 años, me dio una forma muy grave de difteria, que me dejó postrada por 8 meses en cama, tuve que volver a aprender a caminar y moverme. Me trataron en Santiago, aquí no había los avances para curarme. Luego trabajé por turnos en la empresa pesquera que había en Coquimbo, en invierno con mucho frío debía enlatar los mariscos y pescados, quizás por eso dejaron de funcionar mis riñones". Continúa con su historia: *"yo no me he portado mal, no he sido mala, nunca fui una mujer que saliera con las amigas a divertirme en las noches"*.

I listen to her and again I think about the stereotypes and prejudices that surround being a woman "bad women go out at night with friends; the good ones stay at home". I reflect on this last sentence and the memory of the research we and some other Latin American countries are developing about the social representations of gender in children of school age emerges. The discourses of 10 year-old girls are the same as 70 year-old women in Chile: *"good girls stay at home and help mom in household chores"* / *"las niñas buenas se quedan en casa y ayudan a la mamá en los quehaceres del hogar"* (20).

Maria continues her story: *"I have been on dialysis for one year and five months"*. She tells me she came to the emergency department, *"with breathing problems and high potassium"* / *"hace 1 año y 5 meses que estoy en diálisis"*, me cuenta que llegó al servicio de urgencia, *"con problemas para respirar y el potasio muy alto"*. She tells me that she knows there is no cure and that because of her age it is difficult for her to get a transplant. Maria is well informed. We Chileans are very supportive when it comes to disasters and we are all donors due to a law that so dictates; however, in practice people wait for a miracle to save their loved ones and very valuable hours are lost than cause transplantation to become impossible. I saw it happen many times in the Intensive Care Units, when the procurement team dedicated time and love to their work without results. I observed, while I would haemofiltrate patients, trying to give some comfort to the family, without interfering with the work of the transplant nurse and without judging the family, in order to not hinder my care.

She tells me she is happy when she has to go to the clinic to dialyze. She feels accompanied by other patients and nurses, for her they are her family and shelter. They listen to her, welcome and accompany her. She says she tries not to be a burden to anyone, and that only when she feels very bad she alerts the health staff, trying not to create conflicts and lead a quiet life.

She exclaims: *"Miss, thank you so much for coming to visit me and listen to my story! Sometimes I feel so alone, only the television accompanies me"* / *"Señorita le agradezco tanto el que haya venido a visitarme y que escuche mi historia, a veces me siento tan sola, solo la televisión me acompaña"*. She offers me to have a cup of tea with her. I feel a bit of shame and guilt. Older

adults in Chile receive a very low pension. I accept it and smell the freshly brewed tea. I approach the cup to my lips and while I drink a sip, I observe her, with her wonderful smile, despite her hard life; I see her mixture of resignation and the desire to continue living. I remember her words: *“Why should I be angry with life if it is what the Lord wanted for me”* / *“para qué voy a tener rabia con la vida y es lo que el señor quiso para mí”*. I thank her for her time, her joy and the cup of tea. I must leave her to go to visit two nephropathy patients in intensive care unit. I turn away from her home, as she says goodbye waving her hand. I see her happy and quiet. As I drive to the hospital, my feelings of frustration and sadness for not being able to do more for her fade away. I relax. A few tears drip down my face, ephemeral, but full of strength, and as our great Violeta Parra says; I give "thanks to life that has given me so much".

FINAL REFLECTIONS

Human beings are social beings and dependent on other people. This dependence requires a human response in the form of care, becoming aware that being with the other generates reactions in both persons. According to this the care situation is contextual, emotionally charged and particularistic in its nature, understanding care as a material being, present in a relationship with our senses and our bodies (21).

On the other hand, Waldow says that nurses are not aware of the power of care, or the power of nursing activities based on the action of caring. This is due, in part, to an underestimation of care by the nurse herself. Knowledge is linked to power, to act with knowledge and to do better. From that perspective, care can be political and emancipatory (22).

Pires points out an emancipatory trihedral of caring: knowing to care better, caring to confront and caring for emancipation. The articulation between knowledge, power and autonomy is clear (23). The transformative power of the nurse arises from the possibility of caring rescuing subjectivity, empowering and emancipating the person, giving a space to the voice of the silenced and invisible ones, as the "patients" from biomedicine have always been considered.

The disease leaves a dark mark on Maria's life; it is a chain that keeps her in the shade that the person does not want to see. After a life determined by neglect and abuse, suffering from chronic renal disease and dialyzing is just one more step, even becoming an instance to reduce her loneliness and lack of companionship. Maria is far from the democratization of knowledge that the Internet provides. She does not even know how to use a cell phone. She belongs to the generation of women who grew up under the yoke of poverty, an abusive husband and now she faces a disease that brings many consequences in all aspects of life. Despite the clouded outlook, resilience as the own capacity of women to succeed, raise their children and see the positive aspects of life arise.

I am also a woman; our paths might have been alike, just out of date in the time. The only big difference between her and me is that I was able to study at the university and that opened a door to a very different life to that of most Chilean women.

When I write interpretive autoethnography and check my processes on the face of what I am living as a woman, mother, nurse, I show myself, I expose myself. I perhaps become weaker in the eyes of others. However, for me it is an instance in which I get humanized and I heal myself and I can be a better nurse. Also, I have my own voice, silenced by hundreds of years of submission, a voice that understands the citizens, community, social and historical processes of my country that are part of my own history. I can do located narrative, defying the traditional canons of doing academia and nursing which for years has been built from a biomedical, positivist and under powers that be perspective. In this story there is a stimulus to create a new nursing, which is being born without permission, along with the pressing need for social transformation that explodes in every corner of Chile. In the violent times that we live, social injustice, forced silences to avoid conflicts, not to recognize the other as an equal, nursing is waking up and losing their fear of speaking, with a humanist, social and committed voice with the historical processes of the peoples.

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