

Pressure ulcers: representation of life and death for wheelchair users

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Abstract

Pressure ulcers can significantly affect the quality of life and social inclusion of wheelchair users, in addition to delaying the rehabilitation process and compromising the health-disease process. The aim of this study is to analyze the representation of pressure ulcers in the perception of life/death for wheelchair users. The methodological design of this research is applied, descriptive and participatory, with analysis and discussion of data under a qualitative paradigm. Seven collaborators who are wheelchair users of the Association of Spinal Cord Injuries in Rio Grande do Sul/Brazil (LEME) participated in the interviews. Data analysis was performed by using data categorization and triangulation. The results show the negative impact pressure ulcers have on users' health and social inclusion. The fear of appearance of pressure ulcers and the associated possibility of death, overlaps other situations that may result from the condition of being a wheelchair user. Users are aware that injuries associated with a bacterial infection can lead to death. The need for constant care and dressings, in addition to the body's own odor, become important limitations in social life. The importance of the prevention of pressure ulcers is emphasized as a way to promote social inclusion and physical and emotional well-being of users.

Keywords: pressure ulcers; fear; death; wheelchair users.

1. Introduction

In terms of contextualizing the theme of this research, the World Report on Disability, states that more than one billion people worldwide live with some type of disability, that is, about 15% of the world population, among which about 200 million experience considerable functional difficulties [1]. According to Kang et al. [2], worldwide, the incidence of spinal cord injuries varies between 13.0 per million to 163.4 per million people, the majority being male. In the coming years, the incidence of disability will continue to increase due to the aging of populations and the greater risk of occurrence in the older population, including the global increase of chronic diseases. For people with spinal cord injuries and other people with reduced mobility, the use of a wheelchair is essential for mobility. It assists the participation of people with disabilities in numerous activities and it provides greater independence both at home and in the community [3].

The wheelchair plays an important role for the social inclusion of wheelchair users, as it allows the right to independence and to move in the social space, being a part or extension of their body. It also makes possible the manifestation of the corporeality of the person with physical disabilities. It is through the wheelchair that users feel and use the body as a tool for interacting with society, thus allowing their insertion in the socio-cultural context [4]. When it comes to wheelchair users, they spend most of the day in a sitting position, which makes the seat an extremely important structure for the users' comfort.

In the sitting position, the body comes into contact with the seat through the ischial tuberosities that are composed of two rounded bones that resemble an inverted pyramid [5]. As a result, most of the total body weight is supported on these tuberosities, causing this load to be distributed over a relatively small area, thus creating great pressure efforts. To relieve this pressure, people change their posture periodically. However, wheelchair users, in most cases, do not have this feature of postural change, nor the sensitivity to feel the pressure produced by the body, which is translated by discomfort. The localized pressure on the skin tends to compromise the circulatory system in the affected body region and, when combined with factors such as humidity, heat and friction, it can result in a pressure injury in a short period of time. The National Pressure Ulcer Advisory Panel (NPUAP) defines pressure ulcers as localized damage to the underlying skin and/or soft tissues. It usually occurs on a bony prominences or related to the use of a medical device or other artifact. The lesion can appear on intact skin or as an open ulcer and can be painful [6]. Users who have no preserved and/or altered sensitivity have no perception of pain or awareness of the deterioration of their skin.

In order to contextualize the severity and impairment of pressure ulcers in the health and social life of wheelchair users, Candido [7] comments that depending on the degree of the skin lesion, the healing time may be high, in some cases reaching up to 20 years with an open ulcer. During the healing period, pressure at the site should be restricted, and the user should avoid sitting. Pressure ulcers are listed as a direct cause of death in 7-8% of all patients with paraplegia in the United States [8]. Prevention is the best treatment as pressure ulcers can significantly affect the quality of life of users and delay the rehabilitation process, thus leading to social and economic commitments from their families.

When discussing the severity of pressure ulcers, it is essential to mention that pressure ulcers tend to be the predominant factor for the condition of social exclusion, as well as causing a recurrent and constant

fear of death. It is important to emphasize that there are exclusionary social processes, but there are no consummated, definitive and irremediable exclusions. Exclusion is a sociological category, not the way of referring to someone, as it is the phenomenon that is excluding and not the subject that is excluded.

From this context, the general objective of this study was to analyze the representation of pressure ulcers in the perception of life/death of wheelchair users.

2. Material and Method

From the point of view of its nature, this research is an applied research. In regard to its objectives, it is a descriptive research, and considering its procedures, it is a field and participatory research. The problem is approached through the qualitative paradigm [9].

The sample was constituted in a non-probabilistic way for convenience. The collections were carried out at the Association of Spinal Cord Injuries in Rio Grande do Sul (LEME), in the city of Novo Hamburgo, Brazil. LEME is a philanthropic civil association that provides assistance to people with spinal and physical disabilities.

All participants signed an informed consent form (ICF) prior to being interviewed, so that they were aware of their contribution in the study and granted permission for the use of the information collected. Authorization was also requested so that the interviews could be recorded. During the interviews, seven participants exposed their experiences, opinions and fears about the appearance of pressure ulcers after spinal cord injury.

As for the data collection instruments, participant observation was carried out from the weekly contact for two years with the LEME members, in addition to the observations recorded in the field diary. According to Minayo [10], participant observation is essential in a qualitative research, as researchers place themselves in direct relationship with interlocutors, participating in social life to obtain data and understand the research context. The analysis was carried out by using data categorization and triangulation as suggested by Minayo [10].

3. Results

Table 1 presents the data of the general profile of the participants in this research. Pressure ulcers had already affected 5 out of the 7 participants, and the healing time of the injuries ranged from 2 months to 4 years. The type of motor deficit of all employees is paraplegia. Except for participant 3, the others acquired spinal cord injury due to an accident, which ended up compromising motor control and sensitivity in the lower limbs. It is important to highlight that the lack of sensitivity combined with reduced mobility increases the risk of developing pressure ulcers.

Table 1. Characteristics of study participants

Collaborator	Gender	Age (years)	Time wheelchair (years)	Reason	Pressure injury	Injury location
1	Male	28	16	Car accident	Yes	Buttocks
2	Female	62	12	Falling window	Yes	Buttocks and feet
3	Female	35	08	Virus in the marrow	No	-
4	Male	62	23	Falling Tree	Yes	Buttocks
5	Male	27	04	Car accident	No	-
6	Male	43	08	Fire gun	Yes	Buttocks and toe
7	Male	33	06	Motorcycle accident	Yes	Feet and heels

Based on the analysis of the interviews, the results were grouped into two categories according to the classification and the grouping of elements in common, which are: a) fear of the appearance of pressure ulcers; b) fear of death. The triangulation was then carried out, based on three aspects that led to the analysis: the empirical data collected in the research, the dialogue with the authors who study the issue and the analysis of the situation [11].

3.1 Fear of the Appearance of Injuries

The interviews revealed that the participants are very afraid of the appearance of pressure ulcers, including the two individuals who have never had, and those who have already had the injuries. Participant 1, who has already suffered a pressure injury, refers to his fear as follows: "It is a villain, I don't like it. I am not afraid of the dark, I am not afraid of lightning, but I am afraid of it. I run away from it. It is to stop life". This report is extremely relevant in the sense of the representation of pressure ulcers as limiting in all senses, causing fear. According to Bauman [12], the feeling of helplessness is the most frightening impact of fear, and "fear" is the name we give to our uncertainty, to our *ignorance* of what the threat is and our incapacity to determine what can and can not be *done* to counter it, if ceasing it is beyond our reach" (p. 5).

In the daily lives of the participants, the fear of being affected by the injury and the feeling of helplessness in the face of their involvement is constantly manifested. This situation appears in the speech of collaborator 1 when he mentions that he is not afraid of many situations (which are usually fearful for some people), but that he is afraid of injuries and that he runs away from them, so that they do not "stop his life".

Participant 2 reports her experience in the period when she had the open wound and in the process of healing:

I am very afraid, the way I got, I do not wish for anyone, it is very sad. I had to stand sideways, it leaked and leaked. I have never seen anything like that. It's awful. When they removed all those spoiled meats, then I would not sit for days, and it would bleed, horrible.

This narrative, in which participant 2 comments on the “spoiled meats” that doctors had to remove from her body, reports the loss of parts of her body that no longer serve. It is important to note that the fact of presenting an open and exposed wound on the body is extremely dangerous, as it is a gateway for bacteria. According to Linder-Ganz et al. [13], about 80% of wheelchair users have already had injuries, usually in the coccyx region and ischial tuberosities, and 8% of these have developed *sepsis* (infection by bacteria). In this sense, participant 3, who never had pressure ulcers, exposed the following:

Imagine you having that in your body, wow, I can't imagine it, I can't imagine the discomfort it must be. [...] you have to be very careful, the bacteria, anything that goes in there, must be terrible, I can't even imagine. And if you are not sensitive, you will always hurt, and it will hurt, hurt, and it will open more, it will open more. You can't do anything, it interrupts you, it disrupts everything.

The last sentence of this narrative is quite significant, as the participant considers the pressure ulcer as an affection that tends to interrupt life, changing not only the health aspect, but alternating the flow and sequence of life. It is noteworthy the fact that the employee has never been affected by pressure ulcers, however, the feeling of apprehension when she says that “it must be terrible, I can't even imagine it”, expresses the fear and understanding of the danger and consequences that an injury can result. In this sense, Bauman [12] says that the dangers that cause fear fall into three categories. Some threaten the body and property. Others are of a more general nature, threatening the durability of the social order and the reliability in it, on which the security of livelihood depends on income and/or employment, or even survival in the case of disability (or old age). Then, the dangers that threaten the people's place in the world surface, namely, the position in the social hierarchy, identity and, more generally, immunity from degradation and social exclusion.

The presence of pressure ulcers affects, in a certain way, the three types of dangers and fears mentioned by Bauman [12]. The injury directly threatens the body of the affected subjects. It interferes with the security of sustenance, because with the injuries on their body, individuals are temporarily or indefinitely away from work and social space - when they are no longer away from work due to disability due to spinal cord injury. Consequently, the injury threatens the individuals' place in the world when it puts their social inclusion at risk.

Still on fear and its effects and influences on daily life, Bauman [12] states that:

The opportunities to be afraid are among the few things that are not lacking in our age, which is highly lacking in matters of certainty, security and protection. Fears are many and varied. People of different social, age and gender categories are plagued by their own fears; there are also those we all share - whatever part of the planet we may have been born in or have chosen (or been forced to choose) to live in (p. 23).

The fear reported not only by employees who have already had injuries, but also by those who have

never had injuries, clearly demonstrates the feeling of being susceptible to danger and the feeling of insecurity and vulnerability that the 'derived fear' implies. The author explains that this derived fear is a constant mental system that can be described as the feeling of being susceptible to danger; a sense of insecurity (since the world is full of dangers that can collapse on us at any second with some or no warning) and vulnerability (if the danger materializes, there will be little or no chance of escape and/or defense successfully). Still, a person who has repressed and internalized “a worldview that includes insecurity and vulnerability will routinely resort, even in the absence of a genuine threat, to appropriate reactions to an immediate encounter with danger; “derived fear” acquires the capacity for self-propulsion” (p. 6) [12].

When discussing the fear of being affected by injuries, it becomes relevant to contextualize the relationship between fear and the interference factors in the occurrence of the injury and the reasons that make it so feared. In this sense, one of the biggest problems that are limiting in terms of health and quality of life is the prolonged period of treatment for the healing of injuries, which leads to the removal of the individual from living in society. In addition to the fact that they are dependent on the help of other people, reducing their autonomy and the freedom to come and go. Costa et al. [14] state that in addition to the time for healing of the wounds, conservative treatment tends to be long (including periods of morbidity due to mild trauma with skin breakdown). In contrast, the time to develop an injury can vary between 24 hours up to 5 days. Therefore, it is extremely important that wheelchair users have access to information regarding preventive approaches to pressure ulcers.

When it comes to approaches and care for bedridden people with reduced mobility, which is the case for wheelchair users, most caregivers and people affected, are aware that the development of pressure ulcers is a consequence that must be avoided. Ota [8] states that approaches focused on prevention can be less costly than approaches focused on treatment, and prevention can decrease the incidence by at least 50%, which makes the situation less difficult, both economically and in relation to the suffering caused. As a means of prevention, the author suggests repositioning the individual every 30 minutes to alternate the distribution of body weight. Pressure redistribution, especially on bony prominences, is a major concern when it comes to prevention. Every effort should be made to redistribute pressure on the skin by repositioning it every two hours and using pressure redistribution surfaces [15].

In the interviewees' narratives, few statements refer to preventive strategies. However, based on the perceptions transcribed in the field diary and participant observation, it is evident that preventive actions occur. The movement of suspension of the body from the wheelchairs is frequently observed. This movement represents a quick and small pressure relief, as the wheelchair user suspends the body with the strength of their arms for a few seconds, relieving the discomfort of the pressure (although they have little sensitivity or almost none). The purpose of suspension and/or repositioning is to redistribute, alternate and relieve pressure on susceptible areas, and consequently, maintain circulation in areas of the body at risk of developing injury. In the case of bedridden or wheelchair users, pillows and cushions are easily available materials that can be used to assist in redistributing pressure. When used properly, they can expand the surface that supports body weight. Generally, the skin of spinal cord injured persons at risk for pressure injury breaks easily during repositioning. Therefore, care should be taken with friction during this procedure [15]. The NPUAP also suggests additional prevention alternatives, such as humidity control, maintenance of the user with dry and hydrated skin. Moist skin is more vulnerable, facilitates the

development of skin lesions, and tends to break more easily. The skin must be clean, whenever it is dirty and at regular intervals [6].

Rabeh, Caliri and Haas [16] emphasize that the frequency of the development of injuries interferes with physical, psychological and social conditions, causing a negative impact on the quality of life of users. When it comes to quality of life, the minimum and universal material level to discuss about, refers to the most basic needs of human life, and among them is health, leisure, education, work, food, in addition to relative notions of comfort, well-being, personal and collective fulfillment [17]. In addition, the WHO [18] also mentions the physical and psychological state, level of independence, social relationships, and the individuals' relationship with the environment. With pressure ulcers, all aspects mentioned related to quality of life are affected, and, consequently, have a negative impact on the social inclusion of wheelchair users.

3.2 Fear of Death

The speech of most participants was related to the awareness of the risk of death due to pressure ulcers. In this sense, participant 4 explains that: "In life, it is a crucial problem. It has to be treated as a priority, it can lead to death". Rodrigues [19] comments that the awareness of death is a mark of humanity, because humanity is the only species to be truly aware of its own finitude, and this awareness "opens a passage through which remarkable forces will pass that will transform the human way of seeing life, death, the world" (p. 19).

Participant 5 report: "You don't die from a gunshot, you don't die from an accident, but you die from the wound". This statement is very significant and is in line with the reports of all employees, who are aware of the possibility of death due to injuries. That is, the primary cause of spinal cord injury tends not to be the predictive factor for death, but rather, the resulting factors and associated comorbidities, in this case, pressure injury. We can relate this narrative of participant 5 with the "death-events" that Rodrigues [19] presents, in which death-events mean different things according to the themes they occupy and according to the particular condition of death to which they belong.

Rodrigues [19] states that all cultures in principle insert death into a system of classifications to understand death-events, to dialogue with them and to attribute some meaning to them. He cites examples in Brazil, in which a person can die of natural causes, or of old age, or of external sources, and still of violent death, each of which causes a particular emotional reaction in the surviving people.

Dying of natural causes' means that it is not necessary to look for a culprit and that the individual has reached the end of biological existence for reasons linked to the very functioning of the organism, without a particular disease being held responsible. In this case, if the cause exists, it is always pointed out: 'died of a heart attack', 'knot-in-the-guts', 'weakness', 'heartbreak'. Dying of 'old age' is perhaps the most typical occurrence of 'natural cause death'. It is the death of the elder, who slowly approaches the end - because all terrestrial existence is finite - without involving accidents, aggressions or other changes in the normal process of life. Death 'by natural causes' and of 'old age' perhaps confirms what traditional Brazilian culture calls 'natural death' [...]. At the other extreme, we find the 'external sources' death, a category that includes all death events for which a responsible person could be pointed out: by accident, murder, suicide [...]. For a Brazilian, this system of

classification of death-event is fundamental: when faced with the news that someone has died, people will ask immediately, without much thought – died of what? (p. 26) [19].

Unfortunately, in the universe of wheelchair users and/or spinal cord injured people, dying of “death by wound” (a term that is often used by them to designate pressure ulcers) is an imminent reality, because the cause of death is constantly due to some complication of direct or indirect reason to pressure ulcers. This fact is known to participants, because through the narratives it is clearly noted that they address the risk of infection by bacteria as a factor that may lead them to death because of the injury, as previously mentioned. Participant 6 reports:

It is a disease that ends up killing you, it kills and it doesn't kill lightly, it kills you little by little, because it will eat you from inside out. The wound corrodes and corrodes all the person's flesh. It stays there, the skull. You stink, it's cruel. You don't want to eat, you don't want to drink water, nothing, because of that carrion, the guy feels it. You move a little and you already feel that stench”.

Participant 6 relates this stench to the scent of carrion, including reporting a feeling of shame due to the odor exhaled by his body. For this reason, he often ends up not leaving his home and avoids moving his body too much so as not to smell it. The relationship that this employee makes of the body that corrodes inside, which gradually deteriorates and spoils with the wounds, is very sad, and can be directly related to the slow death of parts of his body. This leads us to infer, from these narratives, that these wounds are the representation of the death of the perfect body and the birth of a vulnerable and deteriorating body. Vicensi [20] states that “the terminality of life is a fact, and the process of dying, especially when it happens due to illness, accident or any situation that causes physical pain and suffering, requires that all involved people have awareness and wisdom to face it” (p. 71).

When we go back in time and study ancient cultures and peoples, we have the impression that man has always abhorred death and will probably always repel it. From a psychiatric point of view, this is quite understandable and perhaps best explained by the basic notion that, in our unconscious, death is never possible when it comes to ourselves. It is inconceivable for the unconscious to imagine a real end to our life on earth and, if life has an end, it will always be attributed to an evil intervention beyond our reach [...]. Therefore, death itself is linked to a bad action, a ghastly event. (p.14) [21].

Vicensi [20] states that death and the process of dying is part of the phenomenon of life, “although it arouses fear in human beings, justified by the difficulty in dealing with their own finitude. It can be characterized as an event inherent to life, because, in a way, one is gradually dying at all times” (p. 65). The fear of dying due to pressure ulcers reported by most participants may be related to the fact that, in surviving, they had “a second chance”. In the interviews, many mention God as a superior force, including thanking Him for being alive and giving them a second chance.

Bauman [12] states that fear is inherent in every living creature and links this experience of fear

that human beings feel with the fear that animals feel, in which reactions to the immediate presence of a threat that puts their lives at risk (both of animals and humans), oscillate between attempts to escape and aggression. However, human beings know something more than that, which would be, according to the author, a “secondary fear”, which can be present both in a situation of immediate threat or not. And this fear “can be seen as a trace of a past experience of facing the direct threat - a remnant that survives the encounter and becomes an important factor in shaping human conduct even though there is no longer a direct threat to life or integrity ” (p. 5) [12]. It is believed that there is a double fear of death in which, in addition to being close to death at the time of the accident, wheelchair users end up again facing the risk of dying due to pressure ulcers.

In the fact of the death of some known person or the death of some unknown person, Rodrigues [19] report the idea that the death of the other “is the announcement and the prefiguration of death in 'itself'” is emphasized. It mutilates a community, breaks the normal course of things, questions the moral foundations of society, threatens the cohesion and solidarity of a group that is wounded in its integrity” (p. 82). Participant 7 comments: “I already lost a friend of mine because of these ulcers, he died due to the wound”. It is noteworthy that during the period of insertion in the field of study for data collection, many participants reported knowing someone who died due to pressure ulcers, including mentioning two LEME users who died close to the period of completion of the study. Rodrigues [19] states that death is not just the destruction of a physical and biological state from a human point of view. It is also the death of a person who is social, of a person who interacts. And the emptiness of death is felt first as an interactional emptiness that affects not only close people, “but the whole of the social scope in its very principle, the image of society printed on a corporeality whose action - dancing, walking, laughing, crying, speak ... - does nothing more than expressing itself” (p. 20). One would hardly find any wheelchair user and/or spinal cord injured person who does not know or has heard of someone who died as a result of pressure ulcers.

Regarding human finitude, Rodrigues [20] claims that physical death is not enough to achieve death in consciousness. For the memories of a person who died recently, remain a way of their presence in the world. And this presence is slowly succumbing through a series of lacerations by the survivors who remain here. Death is the only absolute certainty in charge of life, it is a final event, the fact of which cannot be denied. And the death of the other will always evoke one’s ‘own death’, it will force you to think about your own limits and will confirm the fragility of the human being in the face of life.

4. Conclusion

Based on the results of this research, it was possible to verify the negative impact of pressure ulcers on health and on the social inclusion of wheelchair users. The constant presence of the fear of being affected by pressure ulcers and the possibility of death overlaps with any other situation that may result from their condition as wheelchair users.

Users are aware that the incidence of pressure ulcers associated with a bacterial infection could lead to death. The malaise felt by the need for care and dressings and exposure of the body that is mentioned as “fetid” turns out to be an important limiter of social life. In addition, pressure ulcers are addictive, delay the rehabilitation process of the primary injury, and lead to impairments in social and family life and

relationships and living with people.

Finally, the importance of preventing pressure ulcers is emphasized as a way to promote and maintain social inclusion and the physical and emotional well being of those who are conditioned to live in a wheelchair. In this case, may the coexistence be as harmonious as possible.

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