Original Article

TEXTO & CONTEXTO ENFERMAGEM

TEXT & CONTEXT NURSING TEXTO & CONTEXTO ENFERMERÍA

PEOPLE WITH ACQUIRED PHYSICAL DISABILITIES: FROM ACTIVITIES OF LIVING TO REHABILITATION NURSING CARE

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ABSTRACT

Objective: to describe the experiences of people with acquired physical disabilities regarding Activities of Living and to investigate the areas of attention in rehabilitation nursing care.
Method: qualitative research, based on descriptive phenomenology, which explored the experiences of 27 people with acquired physical disabilities in Portugal, through snowball sampling. Data analysis was conducted using the ATLAS.ti 9 software, following the coding process of Strauss and Corbin, using the theoretical nursing framework of the Roper-Logan-Tierney Model of Nursing Based on Activities of Living.
Results: Activities of Living emerged as a central theme, revealing challenges faced by people with acquired physical disabilities. According to the theoretical model, all Activities of Living were identified in the participants' experiences, except for the Breathing activity. Accessibility challenges in public spaces were highlighted, with sanitary facilities inadequately prepared to meet people' needs in workplaces and leisure venues, as well as in the healthcare services and in relation to their diagnostic equipment. This results in the loss of independence, autonomy, and restriction of fundamental rights. Additionally, challenges in communication and experiencing the adaptation process to disability as a period of mourning and rebirth were noted, characterized by different emotional phases.
Conclusion: The experiences of people with acquired physical disabilities and their individual needs regarding Activities of Living should be considered to provide rehabilitation nursing care that promotes quality of life and well-being.

DESCRIPTORS: Rehabilitation nursing. People with disabilities. Daily activities. Nursing care. Qualitative research.

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PESSOAS COM DEFICIÊNCIA FÍSICA ADQUIRIDA: DAS ATIVIDADES DE VIDA AOS CUIDADOS DE ENFERMAGEM DE REABILITAÇÃO

RESUMO

Objetivo: descrever as vivências das pessoas com deficiência física adquirida face às Atividades de Vida e indagar sobre quais as áreas de atenção de cuidados de enfermagem de reabilitação.
Método: pesquisa qualitativa, baseada na fenomenologia descritiva, que explorou as vivências de 27 pessoas com deficiência física adquirida em Portugal, através de uma amostragem em bola de neve. Para a análise de dados recorremos ao *software* ATLAS.ti 9 e seguimos o processo de codificação de Strauss e Corbin tendo como referencial teórico de enfermagem o Modelo de Atividades de Vida de Roper, Logan e Tierney.
Resultados: as atividades de vida surgiram como tema central, revelando desafios enfrentados pelas pessoas com deficiência física adquirida. De acordo com o modelo teórico, todas as atividades de vida foram identificadas nas vivências dos participantes, com exceção da atividade de vida Respirar. Destacam-se dificuldades de acessibilidade no espaço público, nas instalações sanitárias inadequadamente preparadas para atender às necessidades das pessoas, nos locais de trabalho e lazer, bem como nos serviços de saúde e seus equipamentos de diagnóstico. Isto resulta na perda de independência, de autonomia e na restrição de direitos fundamentais. Acrescem os desafios na comunicação e na vivência do processo de adaptação à deficiência como um período de luto e renascimento, caracterizado por diferentes fases emocionais.
Conclusão: As vivências das pessoas com deficiência física adquirida e as suas necessidades individuais relativas às atividades de vida devem ser consideradas para fornecer cuidados de enfermagem de reabilitação que promovam a qualidade de vida e o bem viver.

DESCRITORES: Enfermagem em reabilitação. Pessoas com deficiência. Atividades cotidianas. Cuidados de enfermagem. Pesquisa qualitativa.

PERSONAS CON DISCAPACIDAD FÍSICA ADQUIRIDA: DE LAS ACTIVIDADES DE LA VIDA A LOS CUIDADOS DE ENFERMERÍA DE REHABILITACIÓN

RESUMEN

Objetivo: Describir las experiencias de las personas con discapacidad física adquirida enfrentando las Actividades de la Vida y explorar cuáles son las áreas de atención de los cuidados de enfermería de rehabilitación.
Método: Investigación cualitativa, basada en la fenomenología descriptiva, que exploró las experiencias de 27 personas con discapacidad física adquirida en Portugal, a través de un muestreo tipo bola de nieve. Para el análisis de datos, se utilizó el software ATLAS.ti 9 y se siguió el proceso de codificación de Strauss y Corbin, con el Modelo de Actividades de la Vida de Roper, Logan y Tierney como marco teórico de enfermería.
Resultados: Las actividades de vida surgieron como tema central, revelando los desafíos enfrentados por las personas con discapacidad física adquirida. De acuerdo con el modelo teórico, todas las actividades de vida fueron identificadas en las experiencias de los participantes, excepto la actividad de vida de Respirar. Se destacan las dificultades de accesibilidad en el espacio público, en las instalaciones sanitarias inadecuadamente preparadas para satisfacer las necesidades de las personas, en los lugares de trabajo y ocio, así como en los servicios de salud y en sus equipos de diagnóstico. Esto resulta en la pérdida de independencia, de autonomía y la restricción de derechos fundamentales. Se suman los desafíos en la comunicación y en la experiencia del proceso de adaptación a la discapacidad como un período de duelo y renacimiento, caracterizado por diferentes fases emocionales.
Conclusión: Las experiencias de las personas con discapacidad física adquirida y sus necesidades individuales, en relación con las actividades de vida, deben ser consideradas para proporcionar cuidados de enfermería de rehabilitación que promuevan la calidad de vida y el bienestar.

DESCRIPTORES: Enfermería en rehabilitación. Personas con discapacidad. Actividades cotidianas. Cuidados de enfermería. Investigación cualitativa.

INTRODUCTION

The acquisition of a physical disability arises in the life of the individual and their family as a disruptive event that brings about changes in functionality, with repercussions in their Activities of Living (AL), impacting the quality of life. The causes for acquired physical disabilities include accidents (road, work-related, during sports or leisure activities, firearm incidents), the increased incidence of chronic diseases related to modifiable risk factors such as hypertension, diabetes, or obesity, natural disasters, conflicts, and the aging of the population[1]. Therefore, throughout the life stages, people experience events leading to the acquisition of a physical disability, altering the way they perform AL[2–3].

Activities of living, according to the Roper-Logan-Tierney Model, encompass all activities, tasks, and functions contributing to the complex life process. The mentioned model includes 12 AL: Maintaining a Safe Environment; Communicating; Breathing; Eating Food and Drinking Fluids; Eliminating; Personal Cleansing and Dressing; Controlling Body Temperature; Mobilizing; Working and Playing; Expressing Sexuality; Sleeping; and Dying. Over the life cycle, people oscillate between dependence and independence in each of these AL, influenced by various factors[2]. Dependency arises due to the need for support from others to perform AL.

The rehabilitation process of people with acquired physical disabilities (PwAPD) is influenced by multiple factors, centered on the individual or the environment, which can exert either positive or negative influence when planning the functional recovery of these people[4–5].

Therefore, the Activities of Living Model is essential in guiding the professional practice of rehabilitation nurses, offering a holistic approach centered on the individual as a whole. This model allows nurses to assess compromised AL and the various factors influencing them, enabling personalized care provision. By identifying specific areas of intervention based on a comprehensive understanding of the problem, we recognize that it extends beyond the individual dimension and should include family, community, and society. Additionally, the model understands that an individual's needs and capacities may change over the life cycle, with the ultimate goal of enabling the individual to live as independently as possible[2].

Rehabilitation nurses, by optimizing functionality and capacity for AL of people with functional dependence, promote the social participation and exercise of citizenship, as well as the quality of life, of these individuals and their families, consequently stimulating their well-being[6–7]. As such, it is consensus that the recovery of functional capacity poses a significant challenge to the individual, their family, and the rehabilitation nurse.

The assessment of functionality for AL is of particular importance so that the rehabilitation nurse can diagnose changes that determine limitations in the individual's activity. Accordingly, the nurse can devise individualized intervention plans, with the purpose of promoting adaptive capacities, aiming for self-control of health/disease and/or disability transition processes. This professional can, therefore, implement and evaluate planned interventions with the aim of optimizing and/or re-educating functions/actions in the motor, sensory, and cognitive domains.

This study aimed to provide valuable insights that can inform and guide the practice of rehabilitation nursing care, based on the experiences of PwAPD, aiming to improve their quality of life and promote social participation through the recognition of the individual, respect for their rights, love, and solidarity[7].

Consequently, the following research question was formulated: How do PwAPD experience their AL that have implications for rehabilitation nursing care? The objectives of this study were defined as follows: to describe the experiences of PwAPD regarding their AL and to investigate the areas of attention for rehabilitation nursing care.

METHOD

The research presented in these pages is a descriptive phenomenological study with a qualitative paradigm, as we aimed to explore, analyze, and describe a phenomenon according to the perspective and experience of the individual[8]. For the realization of this study, semi-structured interviews were conducted with 27 PwAPD living in various regions of Portugal. The participants were selected using the snowball sampling technique. For this, contact with the participants was made through the Salvador Association and the Observatory of Disability and Human Rights, which, through their contact networks, promoted the dissemination of this study. Consequently, people who expressed interest in participating were contacted by email by the principal investigator.

Regarding the inclusion criteria for participants, the following were selected: people with physical disabilities acquired at least one year ago, living at home, at least 18 years of age, and with access to a mobile phone and internet. The exclusion criteria were as follows: people with cognitive impairment and/or institutionalized. Participants were recruited until theoretical saturation was expressed in their discourses, as no relevant information was identified[9].

Continuing with the study, data collection was carried out between January and November 2020. Initially, face-to-face interviews were conducted after previous contact via phone or email. However, due to confinement as a result of the SARS-CoV-2 pandemic, interviews were conducted online, via video conference. In both strategies, if the individual wished, the presence of non-participants, such as family members, was allowed. At the end of each interview, we asked the participant to indicate other PwAPD and so on until the sample was constituted.

For the interview, a guide was constructed by the researchers based on the assumptions of the literature, containing the following questions: how have you experienced being a PwAPD? What positive and negative aspects have occurred in your life? How do you manage/organize your daily life? What special conditions does your home have to live there? Did you make changes after your disability? What changes? After this group of questions, a set of sociodemographic questions followed. It is important to emphasize that the effectiveness of the guide was previously evaluated through the implementation of a pilot test, to ensure that the questions were understood by the participants, with no changes to this data collection instrument resulting from this prior test.

After obtaining consent and authorization for audio recording, the verbatim transcription of the interviews was performed, with their content being confirmed by the participants. The interviews lasted approximately 30 minutes.

The next phase, regarding data analysis, was carried out with the support of the qualitative data analysis software ATLAS.ti 9. For this process, two of the researchers analyzed the transcriptions according to the three stages of the coding process: open coding, axial coding, and selective coding[10].

The coding process was dynamic and fluid. Thus, in the open coding phase, the aim was to identify standard concepts and ideas, so the data were separated into distinct parts and rigorously examined through comparison, seeking similarities and differences between them. Axial coding, through inductive-deductive thinking, was carried out based on the data identified previously, which were regrouped into emerging categories to explain the phenomenon under study. For example, the open codes “Rebirth” and “Memories of before and after” gave way to the AL “Dying”; the code “Third-party dependence” to the AL “Mobilizing” and “Personal cleansing and dressing.”

Selective coding followed axial coding. In this stage, the identified categories were refined, using the Activities of Living Model[2] as support, which allowed the main category to be identified: the concept “Activities of Living,” which was considered the main theme of the study[9]. Accordingly, the code “Activities of Living,” being too broad, was subdivided to give way to each of the daily life activities mentioned by the participants. Furthermore, the code “Support Products” was integrated into the AL for which it was intended. After the analysis of all the transcriptions, several important thematic areas emerged. However, as mentioned earlier, we selected the theme “Activities of Living” for this article.

Regarding the rigor of the study, this was achieved through: the credibility criteria inherent in the accuracy in describing the phenomenon experienced by the participants – the AL; investigator triangulation; reliability in integrating the different perspectives expressed by the participants, as well as through the involvement of two researchers in the analysis and coding process, and transferability by detailing the methodology. The credibility criteria described allowed applicability to other contexts and populations, as well as the maintenance of data objectivity, reflecting the participants’ experience and not the researchers’ view[8].

Finally, it is important to emphasize that written consent was obtained from all study participants, with guaranteed anonymity and data confidentiality. To ensure the anonymity of the participants, they were identified in the study by the letter “E” (*entrevista* – interview) followed by the Arabic number assigned to them. To ensure the quality of the report presented, we followed the items of the Consolidated Criteria for Reporting Qualitative Research[11]. The study obtained authorization from the Ethics Committee and followed the principles of the Helsinki Declaration.

RESULTS

The sample consisted of 27 PwAPD, of whom 14 were male and 13 female, with ages ranging from 17 to 71 years (=40.89; =13.43). The subjects were mostly single (48.1%) and married (40.8%), with the remaining being divorced (11.1%). The main source of household income varied in the sample, with 11 participants (40.8%) having a household member as the source of income; 10 participants (37%) being themselves, and 6 participants indicated other sources of income. Regarding education, 13 participants had higher education qualifications, 7 had completed secondary education, and 7 had education levels less than the previously mentioned. Also, concerning the sample, it was possible to ascertain that most of the participants lived in urban areas. The main cause for disability acquisition was spinal cord injury (63%), with 70.4% using manual wheelchairs.

From the expression of experiences from the perspective of PwAPD, it was possible to describe their experiences regarding AL. Therefore, in accordance with the Activities of Living Model[2], through discourse analysis, the following 11 categories were identified: Maintaining a safe environment, Communicating, Eating food and drinking liquids, Eliminating, Personal cleansing and dressing, Controlling body temperature, Mobilizing, Working and playing, Expressing sexuality, Sleeping, and Dying, which will be presented in the following section of the text. It should also be highlighted that the Breathing AL did not appear in the participants’ discourse.

Maintaining a safe environment

According to the Maintaining a Safe Environment category, participants expressed their experiences regarding the accessibility and safety of the environment, highlighting the lack of adaptation of public spaces, which makes them dangerous and inaccessible, as can be observed from the transcriptions of parts of their responses: [...] *I may need help in public spaces because... they’re not adapted at all, and often dangerous* (E14); [...] *if they put me on the street I stay in the same place, how can I go on the road where a car comes and takes me? I can’t even leave the house!* (E22).

More concretely, participants identified problems such as slippery pavements and tree roots damaging sidewalks, contributing to a sense of insecurity: [...] *there are trees planted on the sidewalk and their roots have ruined the sidewalk* (E18); [...] *the chair passes with difficulty... there are sidewalks that I can't even pass because the trees don't fit* (E22); [...] *the floor is very slippery... with rain, the wet floor... tree leaves are dangerous* (E22); [...] *this history of creating sidewalks, it is very dangerous!* (E27); [...] *the sidewalk is uneven, the cobblestones are not straight, I have to drive carefully* (E25).

Falling was a common event among participants, who shared some of their falling experiences, both at home and in public spaces. For this reason, participants highlighted the need for accessible ramps to be built: [...] *I sat on the ground thinking now how am I going to get up, alone at home?* (E27); [...] *less pavement on the streets, I've fallen several times* (E8); [...] *ramps with a much steeper incline than allowed* (E18), and [...] *at the classic art museum, there's a very dangerous ramp... the staff themselves admitted that several people have fallen there* (E24).

Communicating

In this category, participants described how they faced communication challenges due to paternalistic attitudes and pitying looks from society, as reported in the following excerpts: [...] *many people look with paternalism* (E24), reinforced by [...] *the looks on the street and the typical comments "poor thing"* (E17). In light of this, participants revealed that they adopted different strategies to deal with these constraints, from drawing attention to their needs to avoiding confrontations due to shame: [...] *"I'm here!" ... they start to understand the difficulties and start to stop thinking only about themselves* (E24); [...] *I'm one of those people who feel ashamed... I won't get upset* (E22).

From the participants' experiences, online service providers were highlighted as facilitators of communication with various services [...] *with online services, there are few situations where I need face-to-face service* (E26). In one participant's particular experience, the use of technological resources that respond to voice commands was advantageous: [...] *"OK Google, set the bedroom temperature to 24 degrees." "Sure, adjusting the bedroom to 24 degrees." "Ok Google, set the living room temperature to 23 degrees." "No problem, adjusting the living room to 23 degrees"* (E18).

Eating and drinking

Regarding eating, participants shared their strategies to ensure their independence, including meal preparation, the use of equipment and adaptive strategies, as well as the challenges faced due to muscle weakness, as can be seen in the following statements: [...] *if I have dinner in the microwave, I can do it perfectly [alone]* (E24); [...] *If they put cut food on the table and it's not a very heavy glass, and it's full of water, so I don't need to fill it, I can eat alone* (E18); [...] *they taught me to eat with an adaptation where I inserted the fork, nowadays I simply interlace the fork with my fingers* (E24); [...] *when eating soup, my arm starts to tremble... because the muscles start to weaken* (E25).

Eliminating

Difficulties related to elimination were experienced by participants, including issues of incontinence and the need to adopt different strategies: [...] *the "extras" of the disability, namely incontinence* (E9); [...] *I have a urinary collector* (E18); [...] *if I stay out for a long time I use a catheter* (E22); [...] *with help, I can transfer to the toilet, at night I use a urinal* (E25).

More specifically, participants shared their experience regarding bowel elimination: [...] *I have to take medication, sometimes it doesn't work for two weeks!* (E22); [...] *the assistant comes twice a week, at night for bowel training and bathing* (E24).

The experience of two participants indicates that adapted bathrooms do not serve their purpose according to the needs of each person. According to them, [...] *it's impossible to change a diaper anywhere! Even in an adapted bathroom... because I needed to lie down* (E22); [...] *I have to use a mirror... as I don't have sensitivity... I have to have a place to put my legs to understand where to put the catheter. A small bathroom with bars on the toilet is not enough for me* (E27).

Personal cleansing and dressing

Regarding personal cleansing and dressing, participants discussed their experiences related to the strategies adopted and the dependence on others: [...] *I have a bed bath, occasionally, I go to the bathroom. My mother doesn't have the strength she used to have to take me to the bathroom every day* (E22); [...] *my wife undresses and puts me to bed. To avoid getting a marked body, I sleep naked* (E18); [...] *I dress on the bed* (E27); [...] *I'm always dependent... if I want to take a shower, I have to depend, if I want to wash my hair... I'm dependent on everything* (E22).

On the other hand, some revealed that they could perform some activities without help: [...] *I can shave even though it's difficult* (E25). However, one of the participants mentioned that: [...] *we're talking about routines, I never take less than 1 hour and 30 minutes to get ready in the morning to leave the house* (E27).

Another strategy adopted and shared by participants based on their experiences is the need to adapt the environment, such as bathrooms, to maximize their independence: [...] *to make this roll-in shower, with an adapted chair and, widen it a bit* (E18); [...] *we had to widen the bathroom* (E9); [...] *yes, I had work done in the bathroom by installing a shower, but the bathroom is very small, I don't have enough space to move freely* (E5).

Controlling body temperature

Participants also expressed their experiences regarding body temperature control, highlighting the challenges they face due to inadequate temperature regulation and the necessary strategies to ensure their comfort and well-being: [...] *a person with a spinal cord injury regulates temperature poorly and there needs to be greater care regarding temperature differences* (E24); [...] *thermal changes in the environment also hinder my CNS communication ability* (E7); [...] *the electric blanket... I don't use it when I'm sleeping, but it warms up the bed before I go to bed* (E18).

Mobilizing

The experience of mobility alteration was expressed as a significant concern by participants, who highlighted, on the one hand, the difficulties faced due to the loss of independence and autonomy and, on the other hand, the need to request help in the external environment to the home: [...] *using a cane, then crutches, now a wheelchair has been an accumulation of my limitations, I'm dependent on others* (E7); [...] *the right arm is still the one with the most mobility, but it no longer stretches, there are exercises that I can no longer do* (E25); [...] *at home, I rarely need help, outside I depend on people's goodwill* (E3); [...] *one of my big limitations is needing someone to put me in and out of the car, it greatly limits my daily life* (E24); [...] *I always go accompanied, I never go alone... if there are steps... people have to go with me!* (E22); [...] *I didn't have a car and couldn't leave the house. I could only leave if someone took me... it wasn't so much the fact that I couldn't walk, it was the loss of autonomy, of independence, which I regained when I got a car again* (E27).

Participants also spoke about their experiences with the use of support products and emphasized their importance in promoting independence and mobility: [...] *transfer board, adjustable bed* (E24); [...] *pressure relief cushions* (E4); [...] *I chose the best wheelchair for me, comfort, stability, safety, and the right measurements to fit in the elevator because it's small* (E10); [...] *the motor, to attach to the wheelchair, I've had it for a short time* (E26); [...] *I have support products that allow me to compensate for this loss of autonomy* (E27).

Due to the change in mobility, participants highlighted some additional care they took to prevent the development of pressure ulcers or worsening existing ones: [...] *sometimes I stay in bed... I have wounds and need to let them rest* (E22); *[...] I need to be turned twice during the night* (E18).

Working and playing

Participants also shared their experiences regarding the challenges faced due to the lack of accessibility and the need to adapt the work environment, which is not always ensured: [...] *I used to work as a kitchen assistant on cruises, but now it's difficult to work* (E10); [...] *I stopped working as a practicing nurse* (E6); [...] *I'm a family nurse... I do everything... I just don't do home visits* (E26); [...] *they adapted a workstation for me at the training center* (E6); [...] *the employer simply ignores it, doesn't provide me with a workstation* (E5); [...] *I adapted myself to the space, the space was not adapted to me, the only thing they gave me was a parking space* (E26).

Due to the acquisition of disability, participants mentioned that, in their experience, they had to stop doing sports and leisure activities due to the lack of adapted sports and accessibility conditions: [...] *I stopped hunting, playing soccer, and fishing* (E3*); I've always liked nature, camping, rappelling, hiking, driving, doing those activities that I can't do anymore* (E10); [...] *in my area there are no adapted sports* (E2); [...] *yes, I had to stop participating in activities due to the lack of accessibility* (E16); [...] *when we went to book, everything was already sold out... there are few places for people with restricted mobility* (E22).

From the data collected, it was also possible to understand that online resources were an option to minimize the impact of accessibility to spaces for physical activity: [...] *I have online gym classes, I have weights here, a pedal exerciser* (E24).

Participants then shared some leisure activities they engaged in. Nonetheless, they mention isolation as one of the challenges they face: [...] *we've been to different places for vacations* (E26); [...] *I still read and write...* (E25); [...] *the auditorium where I usually go... has a cinema and shows... going by the river* (E26); [...] *I spend my days in bed* (E1); [...] *being locked at home, losing certain things I used to enjoy... I'm at home on the computer* (E10).

Expressing sexuality

One participant reported their experience with body image changes and the difficulties faced due to lack of accessibility to sexual and reproductive health services: [...] *the issue of sexuality in women... It's a double discrimination... it's very much based on physical accessibility* (E27); [...] *for me to have a mammogram is a horror movie, for me to have access to reproductive and sexual health is a nightmare. I had to choose a gynecologist – private! – who had a table I could transfer to... I don't have the same rights to have a mammogram. I end up managing to get one because my chair goes up and down* (E27); [...] *I used to do sports, and I was very thin, it may seem trivial, but it's very complicated. I look in the mirror and that body isn't mine* (E27).

Sleeping

Participants expressed their experience regarding sleeping and sleep, highlighting the challenges and strategies found to promote their comfort during sleep due to the lack of adaptation in the sleeping environment: [...] *I'm sleeping in the living room because it's easier* (E12); [...] *I stopped sleeping, I got post-traumatic stress disorder* (E27); [...] *at night I can turn over by myself with the support of the triangle, I sleep prone. I have a very soft mattress and I never had major bedsores* (E24); [...] *I have an articulated electric bed* (E18).

Dying

Regarding the "Dying" AL, participants described their experience of acquiring and adapting to physical disability as a process of mourning and rebirth. Additionally, they reported their experiences, the challenges they faced during this process, the different stages of mourning experienced, and highlighted the importance of acceptance during this transition process: [...] *the moment of the accident is a death... I died and was reborn in that accident* (E27); [...] *it's almost like being born again* (E24); [...] *it's exactly the same process as when someone dies. It's the 5 stages of mourning until you reach the acceptance phase. There's a whole mourning process there* (E27); [...] *there's always a before and an after, I died. The person I knew as myself died and another person was born. A lot changed in me... my way of being, the music I listened to, my way of dressing changed!* (E27); [...] *you have to relearn how to dress, how to feed yourself, how to take care of yourself, how to interpret the signs of the body, it's a process of rebirth* (E24).

Some participants reported that the emotions experienced in this process were different from those previously described: [...] *I wasn't depressed, I didn't go through that mourning process* (E18). Another participant also emphasized that [...] *the person has to rebel, has to cry, has to go into depression... if they don't do it at that time, they'll do it later* (E27).

Considering the experiences shared by the PwAPD, the various relationships between the categories that emerged were identified. As indicated in Figure 1, it was found that the ability to perform the activity "Mobilizing" is fundamental for PwAPD, as it influences the performance of other activities.

Furthermore, "Maintaining a Safe Environment" will influence, due to the lack of accessibility conditions, the performance of the activities "Eliminating," "Personal Cleansing," "Working and Playing," and "Mobilizing," often representing a risk to the safety of PwAPD. The performance of personal cleansing and dressing, being able to rely on adaptive strategies and equipment, as well as a personal assistant, influences the performance of work or leisure activities. These are also influenced by the activity "Eliminating," as it requires PwAPD to adopt different strategies to fulfill those activities.

To address the second objective, for each of the AL that emerged from the participants' discourse, a proposal on areas of attention for rehabilitation nursing care was presented (Figure 2), considering the experiences of the PwAPD and based on the Activities of Living Model[2].

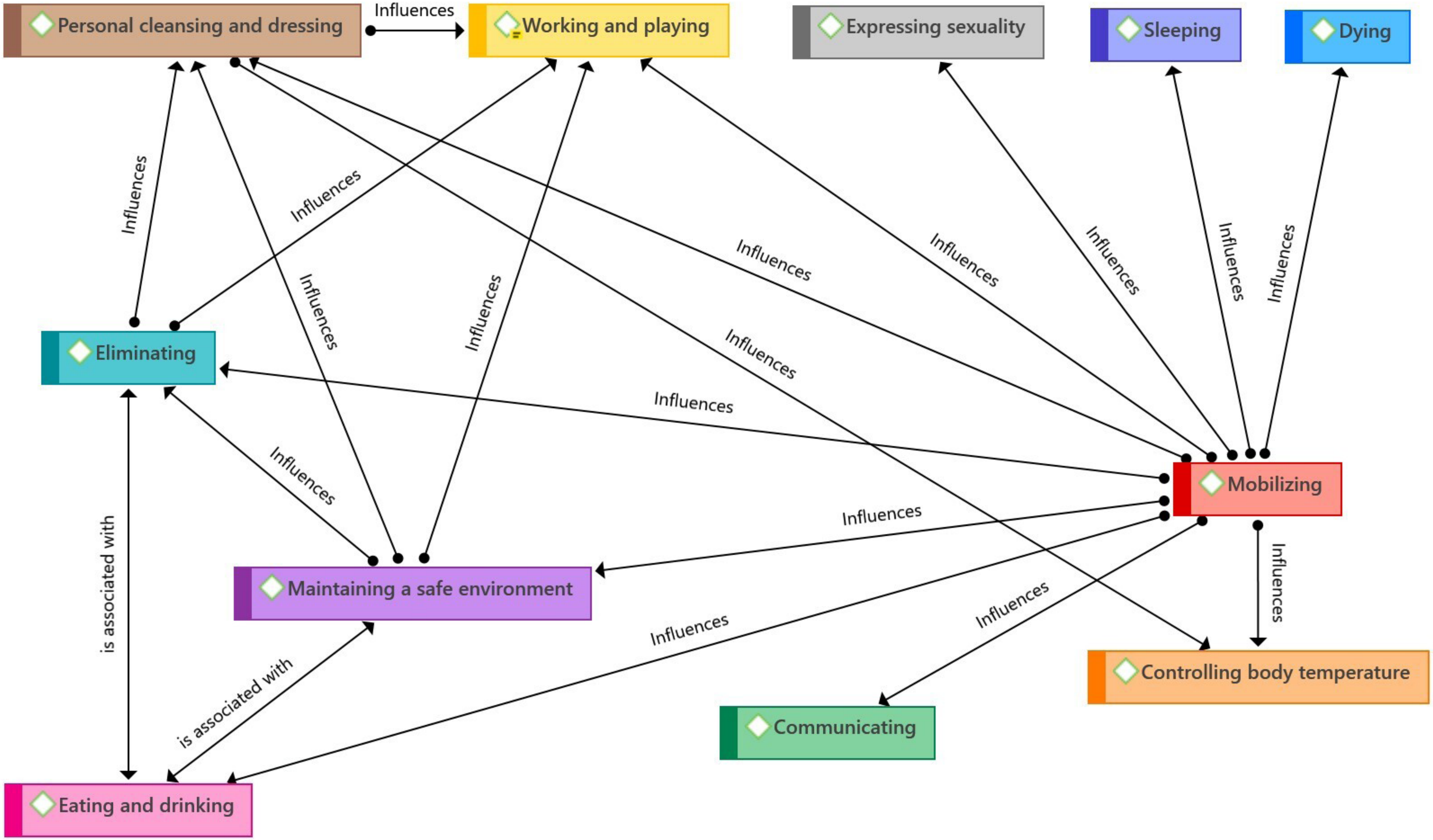

Figure 1 – Activities of Living Network with its categories and relationships.

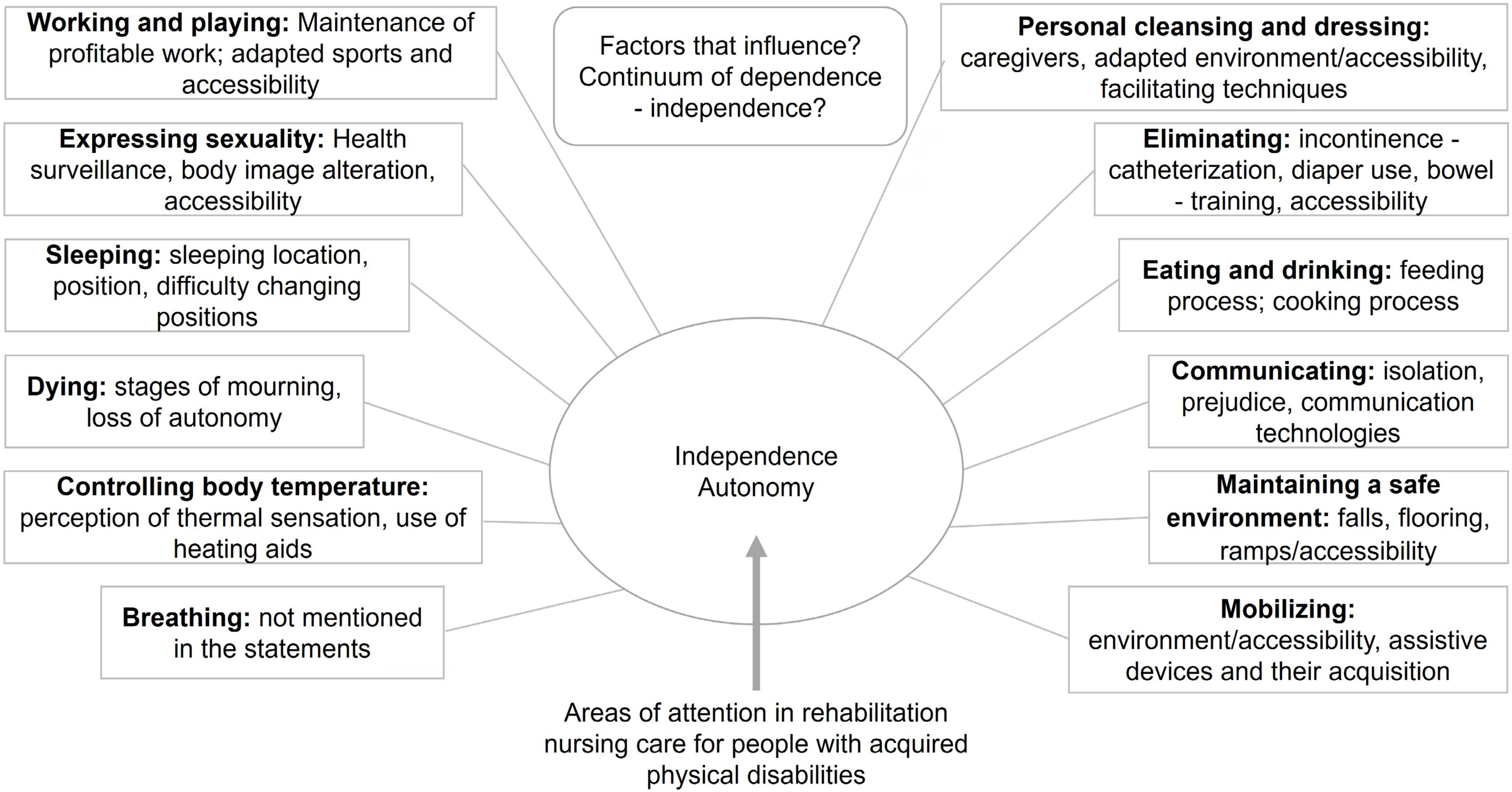

Figure 2 – Proposal of areas of attention for rehabilitation nursing care for Activities of Living.

DISCUSSION

The present study provides an in-depth insight into the experiences of PwAPD regarding AL. As we have seen, all AL were mentioned, except for Breathing, which was not reported by any of the participants. The lack of accessibility conditions, such as inclined ramps, steps, and other obstacles in the public environment, conditions the ability to maintain a safe environment, with falling being a frequent event reported by the participants and corroborated by previous research[12–17].

Communicational and attitudinal barriers arise in the experiences of PwAPD and hinder their social participation, as well as their emancipation process. Therefore, the importance of visibility and presence of PwAPD in the public space is highlighted as a strategy for raising awareness in society, as supported by various studies[14–15,18].

Through this study, it was possible to perceive that the use of technology, such as the use of voice commands through mobile phones, which allow automation and remote control of household devices, fostered the independence and participation of PwAPD, as evidenced by the literature[19]. On the other hand, challenges faced regarding urinary incontinence were evident in the participants' experiences. The subjects specified that certain sanitary facilities, even if considered accessible and compliant with legal provisions, did not meet all the needs of PwAPD. This finding echoes discoveries from other studies that pointed out the lack of appropriate structures to enable transfer for diaper changing and self-catheterization, especially among women[20–21].

The loss of independence and autonomy hinders Mobility, a situation aggravated in the environment outside the home. Most participants use a wheelchair for their mobility, and architectural barriers limit their independence. However, in accessible environments, some participants are independent in AL[3,13,22–23]. Independence in AL inside the home comes from renovations aimed at eliminating architectural barriers, especially in areas such as the kitchen and bathroom, which is consistent with previous research[24].

The PwAPD also face significant challenges in seeking and maintaining employment, as mirrored in the experiences of the participants of this study. This data is particularly relevant, as the right to work is enshrined in the Constitution, and through it, it is possible to reduce the risk of poverty associated with disability, allowing for social inclusion[1,25].

As widely experienced by the participants, the transition to a life with a disability often forced them to give up sports and leisure activities. This renunciation reflects changes that occur at the level of functionality of PwAPD but is also exacerbated by the lack of accessibility to spaces and the scarcity of suitable facilities for adapted sports practice, as corroborated by previous studies[22,26]. The lack of accessibility also arises at the level of medical equipment used for diagnostic tests, such as mammography and cervical cytology[21]. As reported, negative and discriminatory situations are experienced in seeking healthcare, especially related to sexual and reproductive health, which are experienced by women with disabilities.

The acquisition of a disability is a complex process and encompasses different experiences and dimensions. For example, the change in body image requires an adjustment in which the person needs to recognize and reconnect with the body they see. This is a theme also described in other studies[27,28]. The acquisition of a disability is described as a journey of mourning and personal reconstruction, in which the need to recognize and experience all phases of this process for rehabilitation and adaptation to the new reality is reiterated, as demonstrated by previous studies[23,29].

Support products were described by the participants as valuable resources that promote their independence and autonomy in performing AL, in accordance with what is described in previous studies[30]. The various relationships suggested reflect the complex interconnection between the AL of PwAPD, reinforcing how one AL can affect others and how different activities are interconnected. In the experiences of PwAPD, it is evident that accessibility plays a fundamental role in the performance of many of the mentioned AL, so this should also be an area of intervention for rehabilitation nurses.

Although nursing care needs are individualized, which implies differentiated care, nurses need to specifically master what care is necessary related to AL, based on the experiences of PwAPD. While the study has provided valuable insights, it is important to emphasize that it is based on snowball sampling, which may have resulted in the inclusion of participants with more established social ties. This fact may influence the shared experiences, constituting a limitation of the study.

CONCLUSION

Based on the limitations of the study, the importance of interpreting the results as a reflection of the specific experience of these participants is emphasized, not being generalizable to the entire population. Future research should be conducted using diversified sampling methods that allow for a comprehensive and representative understanding of the people's experiences. The relevance of the results presented for the practice of rehabilitation nursing care and the use of the Activities of Living Model should be highlighted. This model allowed the identification of the main changes in the daily lives of PwAPD, providing important clues for appropriate care approaches for each reality.

Understanding the impact of AL, based on the experiences of PwAPD, opens up the possibility of creating organized strategies for rehabilitation care, where it is essential to understand which factors influence them and also the continuum of dependence-independence. This finding points to the importance of future research that further explores this process of dependence-independence and identifies effective strategies to promote the maximum possible independence of PwAPD. Rehabilitation care, as was demonstrated, needs to be rethought, considering the importance that the performance of AL has for PwAPD to live well and have quality of life.

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NOTES

ORIGIN OF THE ARTICLE

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CONTRIBUTION OF AUTHORITY

Study design: Pereira RSS, Martins MM, Machado WCA, Lourenço MCG.
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Data analysis and interpretation: Pereira RSS, Martins MM.
Discussion of the results: Pereira RSS, Martins MM.
Writing and/or critical review of the content: Pereira RSS, Martins MM, Machado WCA, Lourenço MCG, Schoeller SD.
Review and approval of the final version: Pereira RSS, Martins MM, Machado WCA, Lourenço MCG, Cruz VV, Schoeller SD.

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CONFLICT OF INTEREST

There is no conflict of interest.

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