Aging with intellectual disability: perception of professionals at the Association of Parents and Friends of People with Disabilities

Envelhecer com deficiência intelectual: percepção dos profissionais da Associação de Pais e Amigos dos Excepcionais

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Objective: To understand the aging of people with intellectual disability from the perspective of education professionals at the Association of Parents and Friends of People with Disabilities (Associação de Pais e Amigos dos Excepcionais [APAE]).

Methods: This is an exploratory, descriptive study with a qualitative approach; data were collected in November 2020 from 17 education professionals working at APAE by using a structured online questionnaire via the Google Forms platform. Data were transcribed and organized in a Microsoft Excel spreadsheet and a Microsoft Word text file, and data analysis followed the discourse of the collective subject methodology.

Results: Six central ideas emerged from the results: the aging of people with intellectual disability is expected, but premature; understanding the aging process of people with intellectual disability: a deficit of understanding or non-existence; stereotypes, prejudice, and stigma linked to older adults with intellectual disability; cognitive impairment when aging with intellectual disability: skills, functioning, autonomy, and independence; limitations and disabilities of older adults with intellectual disability require care and support; and communication difficulties of older adults with intellectual disability: welcoming, stimulating, and raising awareness.

Conclusions: Aging with intellectual disability involves dismissing infantilization and stereotypes, providing opportunities for activities of daily living and social experiences, prolonging independence and autonomy, and improving the process of aging with dignity, care and support.

Keywords: aged; aging; intellectual disability; education, special; nursing.

Abstract

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Resumo

Objetivo: Compreender o envelhecimento da pessoa com deficiência intelectual na perspectiva dos profissionais da educação da Associação de Pais e Amigos dos Excepcionais (Apea).

Metodologia: Estudo exploratório, descritivo, com abordagem qualitativa, cujos dados foram coletados em novembro de 2020, com 17 profissionais de educação que atuam na Apea, com questionário estruturado on-line via Google Forms. Os dados foram transcritos e organizados em planilha do Microsoft Excel e arquivo de texto do Microsoft Word, e a análise dos dados seguiu a metodologia do discurso do sujeito coletivo.

Resultados: Emergiram seis ideias centrais: envelhecimento da pessoa com deficiência intelectual é esperado, porém precoces; compreensão do processo de envelhecimento da pessoa com deficiência intelectual: déficit de entendimento ou inexistência; estereótipos, preconceitos e estigmas vinculados ao idoso com deficiência intelectual; comprometimento das funções cognitivas no envelhecimento com deficiência intelectual: habilidades, funcionalidade, autonomia e independência; limitações e incapacidades dos idosos com deficiência intelectual exigem cuidado e apoio; e dificuldades na comunicação dos idosos com deficiência intelectual: acolhimento, estimulação e sensibilização.

Conclusões: Envelhecer com deficiência intelectual envolve desmistificar a infantilização e estereótipos, oportunizando atividades de vida diária e vivências sociais, prolongando a independência e autonomia, qualificando o processo de envelhecer com dignidade, cuidado e apoio.

Palavras-chave: idoso; envelhecimento; deficiência intelectual; educação especial; enfermagem.
INTRODUCTION

Intellectual disability is characterized by significant limitations in intellectual functioning and adaptive behavior, influencing everyday social and practical skills.\(^1\) Although the aging process is experienced by all human beings, this phenomenon is accelerated in people with intellectual disability (ID), being considered atypical and premature, with limitations in intellectual functioning and adaptive skills. Moreover, these individuals have a lower life expectancy.\(^2\)

The progression of accelerated aging brings out the need for considering multidimensional aspects that are specific to the evaluation of people with disabilities, considering not only chronological age but also aspects of the life trajectory, comorbidities, and functioning.

Considering the legal scenario in Brazil, Law No. 1118 of 2011 adds a sole paragraph to section 1 of law No. 10 741 of October 1, 2003 (Statute of the Elderly), establishing that people with disabilities should be considered of old age when aged 45 years or more. This addition corroborates the accelerated aging process and especially the lower life expectancy of people with disabilities, mainly of the intellectual type. In this study, we conceptually endorse the premise of accelerated aging, considering as older adults those with ID who were aged 45 years or older.\(^3\)

During senescence, the effects in performance are noticed in attention, working memory, and processing speed.\(^4\) Older adults with ID face limitations in intellectual and adaptive functioning, especially in conceptual, social, and everyday practical skills.\(^5\)

Based on this context, it is important to promote reflections on this matter, considering the need for including people with ID and fostering their relationships, care, and social participation, in addition to promoting advances in the medical sciences and the implementation of public policies specifically aimed at this section of the population.\(^6\)

The longevity of people with ID has prompted multifaceted discussions both in the health care domain and in education, owing to the need for multidisciplinary interventions that being quality to the aging process, respecting individuality.

In the Brazilian environment, we highlight the scarcity of specialized public services aimed at providing educational assistance to older adults with ID, leading to vulnerability and caregiver burden for families. Unfortunately, these services are rare and usually organized by the civil society, such as institutions that specialize in special education.\(^6\) Therefore, achieving deeper information and knowledge on this theme is relevant and timely for promoting human dignity, providing quality to actions for older adults with ID.

Our objective was to understand the aging of people with ID from the perspective of education professionals at the Association of Parents and Friends of People with Disabilities (Associação de Pais e Amigos dos Excepcionais [APAE]).

METHODS

This is a qualitative study with an exploratory descriptive design\(^7\) that followed the Consolidated Criteria for Reporting Qualitative Research (COREQ)\(^7\) and which was registered according to the directives and standards of Resolution 466/2012 of the National Health Council,\(^8\) being approved by the Human Research Ethics Committee under Consolidated Opinion No. 4 388 328 of November 9, 2020.

This work was performed by a group of researchers with PhD, masters, and specialist degrees, along with undergraduate students, with multidisciplinary education (pedagogy and nursing) and experience with gerontology. The researchers are part of a research group linked to Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq), a national and internationally recognized institution.

The researchers received training prior to the study, with a theoretical and scientific framework on the methodological aspects and theory used in the research.

Participants were recruited in November 2020. Seventeen education professionals from an APAE special education institution participated in this study; they were invited by previous contact with a detailed explanation of the study and all participants signed the informed consent form (ICF). Participant anonymity was ensured by the attribution of an identification code with the letter P (as in Professional) and a number ranging from 1 to 17. There was no refusal to participate or patient dropout.

We used a structured questionnaire with closed and open questions for data collection. The structured instrument was tested with 3 professionals, with no need for adaptation; these answers were excluded from our results. For registering answers, an electronic address with the questionnaire was sent to the participants using the Google Forms tool.

Participants were inquired regarding their education, time working in the educational sector, time working in special education, time for filling out the form, and perceptions regarding the aging of people with ID. The participants took around 25–30 minutes to fill out the online questionnaire.
The obtained data were organized in a Microsoft Excel spreadsheet and a Microsoft Word text file. After transcribing data, 3 researchers performed coding line by line.

The researchers discussed the interpretations of each questionnaire and defined the coding consistently (central ideas and key expressions). The central ideas and their corresponding key expressions were grouped according to their similarities, comprising first-person synthesis discourses.9

Collective subjects were then grouped within the pre-existent comprehensive themes according to the discourse of the collective subject (DCS), processing the answers and collecting collective discourses (contents with similar meanings), composed in a single first-person format. This is a synthesis discourse constructed with parts of discourses of similar meaning through systematic and standardized procedures, derived from real testimonies.9 Collective discourses, representative of the reality they aim to analyze, were able to condense effective ideas and propositions regarding the perception of the theme of this study.

The structure was applied to 4 members of the research team for ensuring its correct application (applying the analytical structure). The researchers constructed a coding tree according to the central ideas and key expressions grouped by similarity, constituting the synthesis discourses, and presented it to the participants for approval. Theoretical saturation was observed for the data, with feedback of the DCS for approval by the participants; the DCS were approved with no changes.

Data verification was included in order to confirm the researchers’ interpretation with the participants.9 COREQ recognizes member checking as a method of rigor, guaranteeing that the participants’ own meanings and perspectives are represented and not restricted by the researchers’ own agenda and knowledge.7 By respecting scientific rigor, researchers familiarize themselves with the data by reading transcriptions line by line, in addition to a 1–2 page summary of the key expressions and central ideas. Summaries were sent to each participant of the study, who validated the content by revising the interpretation and verifying its suitability.10

For condensing findings, we selected 6 central ideas based on the DCS,9 writing a 1–2 page memorandum summarizing each central idea and including the main key expressions and most important findings. We employed narrative language, allowing the contemplation of matters beyond qualitative measurement, such as the inexplicable or abstract, for the concrete. We provided feedback to the participants regarding our findings, validating information provided in the questionnaire and confirming the presented DCS; this showed the relevance of this theme, aligned to the theoretical and scientific framework.

The citations of education professionals participating in this study are presented in our results for illustrating our findings in a DCS format, condensing ideas and effective propositions regarding a pedagogical intervention that focused on the (re)habilitation of older adults with ID.

RESULTS

The characteristics of the 17 special education professionals participating in this study are presented in Chart 1.

The results are presented according to the methodological guidelines of the DCS, including a detailed description of the central ideas and collective discourses. We illustrate the citations of family members in a collective manner, representing the perception along with the condensed central ideas, as follows:

- The aging of people with ID is expected, but premature. This central idea highlights the chronological relationship with the early changes expected for the aging of people with ID;
- Understanding the aging process of people with ID: a deficit of understanding or non-existence. This central idea points out the atypical characteristics of people who age with ID, leading to difficulties in understanding everyday situations;
- Stereotypes, prejudice, and stigma linked to older adults with ID. In this central idea, aspects of ageism added to prejudice toward ID are emphasized;
- Cognitive impairment when aging with ID: skills, functioning, autonomy, and independence. This central idea directs the cognitive alterations existing in the atypical aging process of older people with ID, leading to infantilizing and pejorative behaviors on the part of society;
- Limitations and disabilities of older adults with ID require care and support. This central idea condenses aspects of the independence and autonomy of older adults.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%) or mean ± SD</th>
</tr>
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<tbody>
<tr>
<td>Sex (female)</td>
<td>17 (100%)</td>
</tr>
<tr>
<td>Age</td>
<td>38 (13.50) years</td>
</tr>
<tr>
<td>Professional experience in education</td>
<td>12 (8.35) months</td>
</tr>
<tr>
<td>Professional experience in special education</td>
<td>4 (2.82) months</td>
</tr>
</tbody>
</table>

Source: authors’ own; 2021.
people with ID, fostered and enhanced by family members and the support network;

• Communication difficulties of older adults with ID: welcoming, stimulating, and raising awareness. This central idea reinforces the need to offer services with orderly, qualified and respectful access and reception for older people with ID, as well as the need for qualified health professionals, family members and the community in order to welcome, stimulate and raise awareness of the challenges of aging with ID.

The results highlighted the understanding of professionals regarding the aging of people with ID, notably in the temporal domain; it is important to understand the aging process, as participants have a knowledge deficit on this theme, in addition to a discourse of prejudice, stereotyping, and infantilization of the older adult.

The main statements approached changes due to the aging of older adults with ID regarding cognitive and functional impairment, autonomy, and independence, even mentioning aphasia; welcoming the older adult and stimulating the communication process would thus be timely.

Special education professionals highlighted their concern regarding the needs arising from limitations and disabilities, reinforcing aspects of care and support, as well as their knowledge deficit on the aging process, notably that of older adults with ID.

**DISCUSSION**

The central ideas and DCS arising from the data analysis allowed us to emphasize the relevance of the care and support of older adults with ID; the participation of a multidisciplinary team is thus paramount in the aging process. Considering special education, a specialized gerontology viewpoint is required, promoting respectful care to the peculiarities of this aging process with quality and in a healthy manner. For this, the nurse should act together with education professionals.

The aging process of people with ID happens in an atypical and premature manner, with impairments to their cognitive, sensory, adaptive, emotional, and social skills; it can hamper their autonomy and independence. Its prematurity may be linked to the fact that people with ID use specific long-term medications for many years, in addition to the biophysiological aspects involved in their bodies.

Aging is a heterogeneous and individual experience; it primarily depends on how the person experiences this process, grounded in historical, cultural, and economic circumstances and in the comorbidities faced during the aging process.

In face of this premature and sharp aging process, it is important to know favorable factors, encouraging people with ID to participate in family and/or social life and in activities that promote healthy aging, preventing functional and cognitive decline, stimulating the maintenance of acquired skills, and improving quality of life and wellbeing. This way, participation and autonomy are promoted.

We highlight the need for more detailed studies on life and health conditions during the aging of people with ID, as well as family relationships and needs. Most of these people were not able to achieve higher social or economic status, restricting their life at old age to socially determined standards and causing double vulnerability: being of old age and having an ID.

To consider the social and economic construction of older people with ID involves wishes and interests that are usually ignored. Infantilization and thingification in the care of older adults deprive them of autonomy stimulation. Acting respectfully with older adults with ID involves understanding by family members and caregivers of the shared needs and decisions, so that older adults can have their rights respected.

The infantilization and underestimation of older adults with ID can be the main barriers to their inclusion. By doing it, one does not only deny their legitimate and ensured rights such as the access to education, but also deprives them of opportunities for transformation and expanding their horizons, as well as of possibilities to develop their intellectual capacity.

Infantilizing is not the same as demonstrating affection. Using diminutive terms or making decisions without consulting the patient on a daily basis, although tangentially related with protection, care, or empathy, restricts the autonomy and independence of older adults with ID. In order to delay the loss of skills and competencies, it is important to maintain older adults with disabilities active in a multidimensional manner. Therefore, including them in the development of social, economic, health care, environmental, and spiritual activities is crucial, maintaining and stimulating their autonomy and independence; this has repercussions for their daily activities and quality of life.

Functional dependency for activities of daily living contributes to strengthening the infantilization to which older adults with ID are usually subjected. Not being able to perform these activities makes them more dependent on caregivers and family members, in addition to hindering their development and skills. The assistance provided to people with ID, in most
cases, continues for life. The family is the protagonist of this assistance (especially mothers), in a long-term perspective of dedication. Permanent and prolonged care become harder to provide as the years go by, because caregivers also grow older. Therefore, it is important to promote the autonomy and independence of older adults for as long as possible.

Population aging highlighted a common reality in many homes, with older adults providing care to other older adults and generating circumstances of multiple vulnerability. The process of aging with ID is marked by communication difficulties as it is directly influenced by the physiological process of aging, especially when associated with neurological diseases, which are frequent in this population. The caregiver has a relevant impact in the motivation and stimulation of the remaining skills of the person with disability.

Identifying and understanding the aging of people with ID from the viewpoint of education professionals that routinely work with this population contributed to our reflections on this theme, which still carries prejudice and judgements that are inherent to the social and cultural imaginary. It serves as encouragement for understanding the essentiality of a multidisciplinary approach in gerontology, acting in favor of an aging process with quality and dignity that transversally penetrates the educational and health care domains.

The care of older adults with ID requires services whose access and reception are ordered, of high quality, respecting limitations, ensuring constitutional and legal guarantees, and avoiding prejudice, discrimination, and social invisibility. It is paramount to reject the obstacles of discrimination regarding older adults with ID; this is a challenge for society.

Specifically in the population of older adults with ID, there is a misunderstanding between aging, old age, and ID, and actions considering the vulnerability and potentiality of these individuals are required. Understanding the reality surrounding the experience of older adults with ID enables us to direct planned actions centered on their needs and difficulties.

In this sense, although this research reached its goal, a limitation consists in the fact that it happened in a single moment and place. This way, we do not plan to generalize our results, which is essentially suitable for the qualitative approach chosen for this research. We also highlight the possible influence of a limitation in the education of these professionals, since contents regarding older adults with ID are not included in undergraduate curriculums.

Professional training for working with people with ID is essential because their needs are prolonged throughout life and are especially fulfilled by the parents, in a long-term perspective of dedication. Therefore, education in this context involves the older adult with ID, family members, and caregivers, also extending to all society.

The contribution of education is thus directed at the need for strengthening and discussing this matter, primarily approaching the quality of life of people with ID. Educational actions developed by trained professionals, with proposals that are personalized to the individuals’ demands, favor the development of everyday skills and stimulate collective living, in line with the fundamental right to human dignity.

CONCLUSION

The aging process is part of the life of people with ID, occurring in an atypical and premature manner. Therefore, it should be of better quality. Studies that help understanding the needs of this section of society, which still remains in invisibility, are timely.

Understanding the perceptions of professionals who work with people aging with ID is essential, since it fosters reflections on educational actions and interventions that promote quality of life and dismiss infantilization. It is necessary to provide opportunities for everyday activities, social experiences, and joined moments between family members, caregivers, and professionals, aiming to benefit the person with ID in the acquisition of new skills or maintenance or the remaining ones.

The more active is the older person with ID, the higher are the chances of prolonging his or her independence and autonomy, adding quality to the aging process and providing dignity to the individual. Even when constant support is required (with the presence of a caregiver), it is important to value the human person receiving care, and not his or her disabilities or difficulties.

Actions aimed at the older adult with ID are intertwined with respect, protection, and stimulation, not being limited to the basic care regarding locomotion, hygiene, eating, and communication. This way, educational interventions are paramount to the development of everyday skills.

This research acknowledges its limitations but validates its contribution to improving the understanding of aging with ID, considering the interface of care and support allied to the educational relevance and influence in this process.

Conflicts of Interest

The authors declare no conflicts of interest.
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Authors’ Contributions
LCSB: Project administration, writing – original draft, writing – review & editing, investigation, methodology, validation. KSAH: Project administration, writing – original draft, writing – review & editing, investigation, methodology, validation. JBRG: Conceptualization, writing – review & editing, validation. ASP: Conceptualization, writing – review & editing, validation. NPAF: Conceptualization, writing – review & editing, validation.

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