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People with intellectual disability who are ageing: Perceived needs assessment



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KEYWORDS

Intellectual disabilities;
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Assessment interview;
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Instrumental study

Abstract *Background/Objective:* Ageing and progressive increase in life expectancy in people with intellectual disability present significant challenges. The present study is to examine the needs that arise in the aging process of this population. To detect these needs is fundamental to ensure personal wellbeing; almost no psychometrically sound instruments have been developed. *Method:* A structured interview was developed and evaluated by a panel of 20 experts to obtain evidence of content validity. The interview was then applied to 1,173 people with intellectual disability. The ages ranged from 35 to 80 ($M=52.27$; $SD=7.5$). *Results:* The interview consisted of 93 items evaluating four areas: perceived needs, personal problems, future perspectives, and solutions required. The results demonstrated the proximity and relationship of the various needs evaluated. In addition it was observed that those with intellectual disability who were older, male and users of residential services tended to indicate more needs, problems, and required more solutions. *Conclusions:* The instrument has adequate evidence of validity, allowing the evaluation of specific needs of people with intellectual disability. The results advocate the design of transversal intervention policies in order to effectively meet the needs and requirements of this population.

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PALABRAS CLAVE

Discapacidad intelectual; envejecimiento; entrevista de evaluación; necesidades percibidas; estudio instrumental

Personas con discapacidad intelectual que envejecen: evaluación de necesidades percibidas

Resumen *Introducción/Objetivo:* El envejecimiento y progresivo incremento de la esperanza de vida de las personas con discapacidad intelectual supone importantes retos. El presente estudio examina las necesidades relacionadas con el proceso de envejecimiento de estas personas. La detección de dichas necesidades resulta fundamental para asegurar su bienestar personal, siendo necesarios instrumentos de evaluación que muestren garantías psicométricas. *Método:* Se elaboró una entrevista estructurada valorada por un panel de 20 expertos para la obtención de evidencias de validez de contenido. La entrevista fue aplicada a 1.173 personas con discapacidad intelectual de entre 35 y 80 años ($M = 52,27$; $DT = 7,5$). *Resultados:* La entrevista consta de 93 ítems que evalúan cuatro áreas: necesidades percibidas, problemas personales, perspectivas de futuro y soluciones demandadas. Se muestra la proximidad e interacción de las diferentes necesidades evaluadas y la tendencia a que sean las personas con discapacidad intelectual de mayor edad, hombres y usuarios de servicios residenciales quienes refieran mayor número de necesidades y problemas, y demanden más soluciones. *Conclusiones:* El instrumento desarrollado muestra adecuadas evidencias de validez, permitiendo evaluar necesidades específicas de las personas con discapacidad intelectual. Los resultados abogan por el diseño de políticas de intervención transversales que permitan cubrir eficientemente las necesidades y demandas de este colectivo.

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The progressive increase in life expectancy has had an effect on people with disabilities in general and those with intellectual disabilities (ID) in particular (Ng, Sandberg, & Ahlström, 2015). We find ourselves facing a social phenomenon which poses significant, unexpected challenges, and key amongst those challenges will be the political and professional response to both the new needs these older people with ID present, and the exacerbation of already existing needs (Beadle-Brown, Bigby, & Bould, 2015; Lehmann et al., 2013; McCausland, Guerin, Tyrrell, Donohoe, O'Donoghue, & Dodd, 2010; Townsend-White, Pham, & Vassos, 2012).

Schalock and Verdugo's (2012, 2013) quality of life model, which has evolved into a validated multidimensional conceptual model composed of core domains and domain indicators (i.e., personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being and material well-being), has the same components for all people, has both subjective and objective components, is enhanced by self-determination, resources, purpose in life, and it is experienced when the person's needs are met (Schalock & Keith, 2016). This model includes among its premises meeting the needs of people with disabilities as a fundamental principle for personal wellbeing, highlighting the evaluation of those needs (Simões, Santos, & Biscaia, 2016). In old age these needs are accentuated, as the problems associated with the disability, which may involve significant limitations and adjustments, are added to by problems due to the ageing process itself. The changes and adjustments affect various areas. The physical disorders most often found in the population of older people with ID are related to problems of mobility, the senses and endocrine system along with

cardiovascular, respiratory, joint and bone issues, problems which are more pronounced and serious than in the general older population (Haveman et al., 2011; Winter, Hermans, Evenhuis, & Ehteld, 2015). Cognitive decline and mental health problems also particularly affect this group. The most commonly referred psychological problems include; the lack of ability to communicate feelings, react to stress or tolerate changes to routines, depressive feelings and the presence of dementia, especially the increased propensity to Alzheimer's in adults with Down syndrome up to 30 years earlier than in the general population (Glasson, Dye, & Bittles, 2014; Hermans & Evenhuis, 2014; McCarron et al., 2013; Winter et al., 2015). In addition, social interaction and participation decreases significantly due, amongst other things, to the difficulties of access owing to frequent existing obstacles, changes of residence, and the loss of loving ties (Judge, Walley, Anderson, & Joung, 2010). In order to properly assess and use personal outcomes, it is necessary to develop psychometrically sound measurement instruments that are based on an empirically validated quality of life model (Arias, Verdugo, Navas, & Gómez, 2013; Carbó-Carreté, Guàrdia-Olmos, & Giné, 2015).

Despite the importance of this topic, the majority of the scientific literature has centered on the group of people with ID as a whole, without dealing with the specific needs of those who are ageing (e.g., Jahoda et al., 2015). The scarce data in the published literature indicate that these older people's perceived needs are related to personal health, economic resources, health resources, social service resources, and the presence of obstacles (Aguado, Alcedo, & Fontanil, 2012; Navas, Uhlmann, & Berastegui, 2014; Ouellette-Kuntz, Martin, & McKenzie, 2015). As in the general elderly population, these needs have often been

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