Mexican Bioethics Review ICSa

Biannual Publication, Vol. 8, No. 15 (2026) 7-11

Mexican Bioethics Review ICSA

ISSN: 2683-2062

The impact of support networks on the quality of life of a 47-year-old woman with Down syndrome during her aging process in Pachuca de Soto, Hidalgo

El impacto de las redes de apoyo en la calidad de vida de una mujer de 47 años con síndrome de Down durante su proceso de envejecimiento en Pachuca de Soto, Hidalgo

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Abstract:

This study aims to evaluate the influence of support networks on the quality of life of a 47-year-old woman with Down syndrome during her aging process, highlighting the gap in approaches to healthy aging for this population group. A qualitative and interpretive study was conducted. The most relevant results indicate that the participant has strong family support from those who live with her, which contributes positively to her quality of life. However, a notable lack of connection with other family members who are not present in her daily life is also noted. Therefore, it is important to promote an environment where enriching and supportive relationships not only improve individual quality of life but also foster a collective sense of community and support. Future projections suggest that strengthening these networks could be key to improving the overall well-being of people with similar conditions as they age.

Keywords:

Down syndrome, Aging, Quality of life, Support networks, Family, Environment, Independence, Autonomy, Functionali

Resumen:

El presente estudio busca evaluar la influencia de las redes de apoyo en la calidad de vida de una mujer de 47 años con síndrome de Down durante su proceso de envejecimiento, como evidencia del vacío en abordaje del envejecimiento saludable de este grupo poblacional. mediante un estudio cualitativo e interpretativo. Donde, los resultados más relevantes indican que la participante cuenta con un sólido apoyo familiar de quienes conviven con ella, lo cual contribuye positivamente a su calidad de vida. Sin embargo, se destaca una notable falta de conexión con otros familiares que no están presentes en su vida diaria. Con ello es importante promover un entorno donde las relaciones sean enriquecedoras y de apoyo, ya que no solo mejoran la calidad de vida individual, sino que también fomenta un sentido colectivo de comunidad y apoyo. Las proyecciones futuras sugieren que fortalecer estas redes podrían ser clave para mejorar el bienestar general de las personas con afecciones similares a medida que envejecen.

***Palabras Clave**:*

Síndrome de Down, Envejecimiento, Calidad de vida, Redes de apoyo, Familia, Entorno, Independencia, Autonomía, Funcionalidad

INTRODUCTION

There are different approaches to aging individuals, however, the current predominant construct is healthy aging. Based on which, according to the World Health Organization, it is sought that people maintain their integral well-being and functional capacity; that is, that they are capable of both carrying out the activities and performing the roles that are important to them, based on the combination of the characteristics of the environment and the components of intrinsic capacity (World Health Organization [WHO], 2015).

Where, among the components of the environment are social ties, on the one hand, and on the other, intrinsic capacity is constituted by both personal and health characteristics.

Among the components of the environment is social support, where support networks are structures that are formed by relationships between people, groups or entities, which develop in a context of reciprocal interaction and have a direct impact on the behavior and experiences of the individuals who compose them (Sluzki, 1999).

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Received: 06/03/2026, Accepted: 28/04/2026, Published: 05/07/2026

DOI: https://doi.org/10.29057/mbr.v8i15.17126

Therefore, they have an impact within areas of life such as employment, health, emotional support, etc. (Action Against Hunger, 2021).

Thus, the social support networks that an older person has can be formal in nature, or secondary, when they are associated with the institutional; while informal networks, known as primary, are made up of family, neighbors, and friends, which are of vital importance as part of the functional, affective, and social structure (Botero et al., 2007)

These networks are an essential part of a person's well-being and quality of life, understanding quality of life as "the individual's perception of his or her position in life within the cultural context and value system in which he or she lives and with respect to his or her goals, expectations, norms and concerns", according to the World Health Organization (WHO, 1998,
Schwartzmann, 2003).

However, the main intervention programs, both social and health, focus on strengthening the
well-being of the population, without emphasizing the characteristics of each individual; in particular, the perspective of the aging process of people with specific intrinsic characteristics such as individuals with Down syndrome must be considered; who show different capacities in the functioning of Activities of Daily Living (ADL) and whose support networks of people with syndrome encounter some emotional and economic challenges during their aging process, which deteriorates their quality of life.

Thus, the influence of support networks on the quality of life of people with Down syndrome during their aging process is increasingly relevant, especially considering the increase in their life expectancy, as well as premature aging due to the syndrome (Cano et al., 2022). This, added to unhealthy lifestyles, contributes to the appearance of neurodegenerative and metabolic disorders in middle adulthood, between 40 and 50 years of age. However, despite a dominant discourse of old age, the approach to ageing seems to have omitted the characteristics of vulnerable populations, such as people with Down syndrome.

Thus, according to the WHO (networked), in one out of every 1000 births the infant has Down syndrome, worldwide, with a life expectancy of more than 50 years, in 80% of cases. Meanwhile, in Mexico the proportion rises to 1 in every 650 births. This poses challenges and opportunities to understand how the support networks formed by family, friends and caregivers impact the well-being and development of these people in old age, which seem to have be en omitted in care systems; even more so the need for support from the community and institutions.

There are currently numerous studies that address and explore the relationship between support networks, quality of life, education, health, autonomy, etc. A research study by Morales (2019) highlighted the importance of continuity of care and family support to promote quality of life in old age; where categories such as family care, nursing competencies and active aging were identified as key factors in this process.

Likewise, studies such as that of Skotko et al. (2020) underline the relevance of these networks in the old age of people with Down syndrome, especially in the prevention of unwanted loneliness and in the maintenance of mental health; highlighting that an active and socially integrated life can protect against cognitive decline in old age.

In this way, each of these areas has focused mostly on childhood and adolescence, leaving a gap in the study of ageing in this population group. Where, as Signo, S, et al. (2016) refers, prevention and intervention adjusted to the needs of each person is necessary, since adults with Down syndrome present neuropsychological changes associated with age in specific cognitive domains, whose monitoring in the aging process favors the early detection and prevention of cognitive decline. thus promoting active and healthy aging.

Social support is essential for the adaptation and well-being of people with intellectual disabilities, both in their ageing process and in their quality of life, which makes it necessary to investigate how these networks adapt to the challenges of ageing; in order to provide evidence of the prevailing need for intervention and strengthening of both immediate social ties and the support of the community and institutional programs.

People with Down syndrome have the right to be part of social networks that promote their integration and participation in the community. These networks, which include family, friends, health professionals and specialized organizations, provide emotional, social and practical support, contributing to the autonomy and well-being of the person.

Participation in recreational and social activities, along with access to quality health services and inclusive educational programs, are essential to prevent isolation and promote active and healthy aging. In addition, planning for the transition to adult life must consider individual needs, encouraging integration and full participation in the community. (McGuire et al, 2024).

Therefore, the purpose of this study was to analyze how support networks influence the quality of life of a 47-year-old woman with Down syndrome during her aging process in the city of Pachuca de Soto, Hidalgo, as evidence of the gap in addressing the healthy aging of this population group; both in immediate networks, such as family, friends and community and institutional support.

It is based on two key theories: Cohen and Wills' 1985 Social Support Theory, which highlights the importance of social support for physical and emotional well-being, and the World Health Organization's 2002 Active Aging Theory, which highlights the importance of maintaining active participation in society during old age. Both theories provide a conceptual framework to understand how social networks can be vital to improve the quality of life of older people, in this case, those who age with an innate condition that conditions a greater degree of vulnerability.

METHODOLOGY

Objective

To evaluate the influence of support networks on quality of life in the aging process in a 47-year-old female with Down Syndrome.

Unit of analysis

The study subject is a 47-year-old adult woman with Down syndrome, resident in Pachuca de Soto. Instead of randomly selecting, an intentional choice based on specific criteria was chosen and selected due to the closeness, autonomy and independence of the participant.

Inclusion criteria were established for the selection of the participant: being female, having a diagnosis of Down syndrome, and being in an adult age range. As exclusion criteria, those people who could not participate in interviews due to communication limitations or health conditions that prevented their participation were considered.

Type of study

The present study is considered qualitative and interpretive.

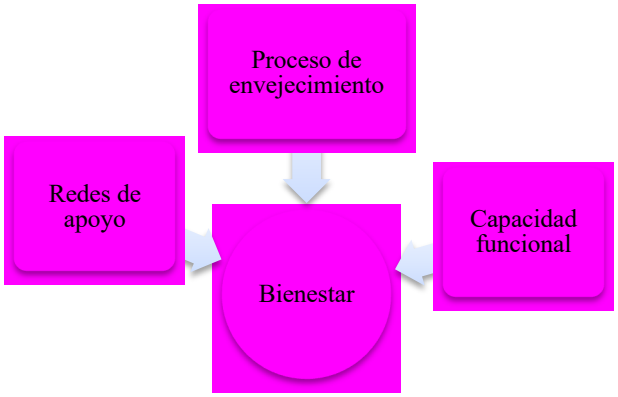
Instruments

The evaluation of the participant was carried out through a semi-structured interview based on three axes of analysis: impact of the networks on the physical and emotional well-being of the individual; aging process; and functional capacity, contemplating the plausibility of the participant performing the roles that are important to her, as well as the independence to carry out the activities relevant to her.

Likewise, the medical history was carried out, which is a document that compiles the information derived from the clinical practice related to a patient, in which all the procedures to which he or she has been subjected are detailed (Castillo, 2024).

The data were collected in the participant's home, providing a familiar and comfortable context that favored openness during the interviews.

The following categorization was used for analysis of the information (Figure 1):



Source. Own Authorship

Figure 1
Axes of discourse analysis.

Ethical considerations

Regarding ethical aspects, approval to conduct the study was obtained through informed consent addressed to her legal guardian, ensuring that the participant understood the purpose of the study and her right to confidentiality and withdrawal at any time without repercussions. Measures were taken to ensure the respect and dignity of the participant throughout the process.

RESULTS

Support networks

According to the interviews conducted with the participant and her family, it is crucial to highlight that the support networks for the participant's physical and emotional well-being are limited exclusively to the people with whom she lives. This means that they do not have a wider support network, made up of friends, siblings, acquaintances or neighbours. Although the participant expresses feeling comfortable with her family nucleus, her family considers it essential to have another type of external support, both for herself and for themselves. There are difficult times that require greater assistance, and this situation can be worrying, since support networks are essential in the emotional development and mental health, not only of an individual, but also of the family as a whole. A lack of external connections can limit access to additional resources and diverse perspectives, which is vital in times of need.

Aging process

The participant does not have an ongoing participation in society, as her family mentions that she feels exposed to being judged for her condition. She is often perceived as an "abnormal" person, which causes her to be treated with pity or in a way that is not very empathetic. In addition, his health condition has a significant influence on his social life, as he fatigues quickly, which further limits his interactions. The family also tends to be overprotective, which can restrict their autonomy and personal development.

It is important to note that the family has little information about Down syndrome and the effects of aging on people who suffer from it. This knowledge is essential to understand the changes that the aging process can cause in individuals with Down syndrome, since a better understanding could allow them to provide more appropriate support adapted to their needs.

Functional capacity

The interviews revealed that the participant is completely independent, although she leads a somewhat sedentary lifestyle, since she does not perform physical exercise or cognitive activities. However, she engages in various activities that bring her personal satisfaction, such as playing games on her tablet, drawing, painting, taking photos, and making jewelry. His health is complex, as he faces multiple diseases (pulmonary hypertension, strabismus, visual impairment, hypothyroidism and Hodgkin's lymphoma) that limit his ability to lead a full life outside the home. This forces her to need company whenever she goes for a walk, since she faces a high

risk of falls, dyspnea, discrimination and disorientation.

Despite these difficulties, it is important to mention that the participant emphasizes her happiness and enjoys living with the people around her. However, she expresses her desire for other members of her family to visit more frequently, as they currently only do so every two to three years.

Bottom line in wellness

Despite her multiple illnesses, the participant is happy and enjoys her personal activities, wishing for more family visits and recreational activities that make her a little distracted. However, the participant depends exclusively on her family nucleus for physical and emotional support, lacking a broader network that includes friends or acquaintances, even solid community and institutional support.

Although she feels comfortable with her family, they recognize the need for external assistance, since their state of health and social perception limit their participation in the community, generating overprotection from their family, due to the lack of integration and programs focused on their active participation. In addition, they have little information about Down syndrome and its aging, which is crucial to understanding their needs

CONCLUSIONS

Based on the findings of this study, the important role of social support networks in the well-being, both physical and emotional, of the participant is highlighted, with special emphasis on the support of her family nucleus.

In situations where there are few support networks, the individual's access to external resources is limited; which could enrich her life and provide different perspectives, or life alternatives, to the participant, as well as have an impact in difficult moments that she faces in her family nucleus. Therefore, the lack of social interaction and the stigma associated with Down Syndrome generate family overprotection, with the intention of care, which somewhat restricts their autonomy and personal development, restricting the possibility of autonomy and, therefore, their healthy aging, in terms of the ability to choose to carry out the activities and roles that are of interest to them. while strengthening her intrinsic capacity to achieve the goals that she sets for herself, both in old age and at previous ages.
This shows a gap in the approach to healthy aging, from the perspective of old age, in the face of the heterogeneity of aging; especially with population groups in vulnerable conditions, such as Down syndrome. It is essential in intervention programs to include awareness and training of social support networks, especially immediate ones, such as the family, to strengthen the aging of all individuals, but with emphasis on those who are in a situation of vulnerability.

In the same way, there is evidence of a lack of understanding of Down syndrome and its aging process by the family, which is essential to offer more adequate support to the participant. Despite facing multiple health challenges, she shows a positive approach to life and enjoys activities that bring her personal satisfaction. However, she longs for more family or social interaction where she can have recreational opportunities that allow her to improve her quality of life. It is essential to foster broader support networks and provide adequate information to improve the participant's holistic well-being

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