

Active aging: What supports do older people with Cerebral Palsy need?

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Abstract

Advances in medical care have greatly helped increase the life expectancy of people with cerebral palsy (CP). A focus group and an open-ended questionnaire were applied to identify the changes associated with aging in CP and explore the most appropriate support services to promote active aging from the perspective of sociosanitary professionals. Five themes emerged from thematic analysis: aging peculiarities, support needs, autonomy, services, and contextual factors. The results have showed that professionals recognized an accelerated aging process associated with CP. They described as key aspects of active aging perceiving physical and emotional well-being, having a life project, participating, enjoying autonomy, and being self-determined. In addition, they suggested the desirability of developing person-centered interventions throughout the life cycle. The findings associated with the aging process are considered strategic for designing procedures to provide opportunities for older people with CP to enjoy an active and healthy life.

Keywords

Cerebral palsy; aging; active aging; health; support services; qualitative research.

Introduction

Older adults are a growing age group worldwide. According to recent figures from the World Bank (Social & Affairs, 2020), almost 10% of the world's population is 65 years old or older, the fastest-growing age group. Likewise, the population pyramid in Spain continues its evolution with an increase in the average age and the proportion of older people. As of January 1, 2021, Spain has 9.310.828 older people, 19.65% of the total population (Pérez Díaz et al., 2022). Regarding the population of people with disabilities, according to estimates from the Survey on Disability, Personal Autonomy and Dependency Situations ((INE), 2022), a total of 4.38 million people in Spain have some disability, and the set of people with disabilities older than 64 adds up to more than 2.6 million people.

There is now a consensus to consider cerebral palsy (CP) as a “group of permanent developmental disorders of movement and posture, causing limitations in activity, which are attributed to non-progressive alterations in fetal or infant brain development. Motor disorders of cerebral palsy are often accompanied by disturbances in sensation, perception, cognition, communication, behavior, epilepsy, and secondary musculoskeletal problems (Rosenbaum et al., 2007). According to recent studies, the incidence of CP has declined dramatically in the last decade, with the prevalence of CP in high-income countries being 1.6 per 1000 live births (Larsen et al., 2022; McIntyre et al., 2022; Perra et al., 2021). However, in Spain, there are no recent publications on epidemiological studies of the population with CP (Avellanet et al., 2018). Consequently, we have no estimates on the prevalence of older adults with CP.

Currently, the presence of older people with CP is becoming more common as their life expectancy increases (Jones et al., 2015; Mahmoudi et al., 2022; Peterson & Hurvitz, 2021). For 22% of individuals with CP with mild impairment, survival duration

is similar to that of the general population, and those with severe impairments, currently the majority, reach adulthood (Blair et al., 2019). This increased longevity means that the prevalence of CP is higher, so these individuals are more likely to acquire deficiencies and diseases associated with aging (Mudge et al., 2016; van Heijningen et al., 2021). Several studies have shown that changes in functional skills and age-related physiological changes occur earlier in adults with CP, increasing the prevalence of secondary conditions such as pain, osteoporosis, fatigue, sarcopenia, musculoskeletal problems, and loss of mobility (Dogruoz Karatekin et al., 2022; Jonsson et al., 2021; Noten et al., 2022; Ryan et al., 2023; Thorpe et al., 2021; van der Slot et al., 2021). In addition, concerning emotional changes, several studies have found an increased risk of anxiety and depression, especially in people with no associated intellectual disability (Noten et al., 2022; Peterson et al., 2021; Pizzighello et al., 2022; Smith et al., 2019; Van Der Slot et al., 2012). Furthermore, a recent study showed that people with CP are more vulnerable to developing Alzheimer's and related dementia, although we need studies to replicate these findings (Engelborghs, 2022; Mahmoudi et al., 2022).

Fortunately, we can currently refer to aging in people with CP while recognizing the need to provide adequate support services to meet their demands (Carroll et al., 2021; Hurvitz et al., 2021; Manikandan et al., 2022; van Loon et al., 2013). Thus, a better outlook of life expectancy in people with CP leads to the implementation of strategies to promote "Active Aging", defined by the World Health Organization as the "process of optimizing opportunities of health, participation, and safety to improve the quality of life as people age" (World et al., 2002). Likewise, *The Global Report on Aging and Health* (World Health Organization, 2015) presents an action framework to promote healthy aging using a model of comprehensive care focused on older people. More recently, the World Health Organization has declared the decade of *Healthy Aging*

2020-2030, whose purpose is to improve the quality of life of older people (Organization, 2019), including older people with disabilities, which requires adopting measures aimed at preventing diseases, promoting health, and maintaining functional capacity.

Although there has been further progress in the study of chronic conditions among older people with CP in the last decade, there is still a lack of information about the indicators of premature aging, intervention strategies for active aging promotion, and the organization and planning of comprehensive support services. Therefore, this study's purpose was to provide direct-care professionals with the opportunity to describe their experiences with aging in people with CP and comment on strategies to improve active aging. More specifically, the objectives were as follows: (1) to identify the physical, emotional, and social changes of aging in CP; (2) to explore the experiences of the care procedures carried out and to consider how services for active and quality aging throughout old age could be improved.

Data and methods

Study design

A descriptive, qualitative methodology and thematic analysis methods were used to identify, analyze, and report patterns within the data (Braun & Clarke, 2006). This method for the treatment of information allows identifying, organizing, analyzing in detail, and reporting patterns or topics from a careful reading and re-reading of the information collected and inferring results that promote the proper understanding/interpretation of the phenomenon under study. Identifying, establishing, and reporting themes and structures reveal the subjects' experiences, meanings, and realities, and examine the circumstances in which these experiences, meanings, realities, and events are the effects of society's discourses (Braun & Clarke, 2006). To ensure the

study's quality, we completed the checklist parameters by the Consolidated Criteria for Reporting Qualitative research (COREQ) for performing focus groups, analyzing data, and reporting results (Tong et al., 2007).

Setting and participants

A total of 19 professionals from entities providing services and supports to adults with CP, dependent on the Castile and León Federation (Spain) Associations for the Care for People with Cerebral Palsy and Related Disabilities (ASPACE), were invited to participate in the study. This organization aims to improve the quality of life of people with PC and their families and promote the defense of their rights and social inclusion. It currently offers direct care services to more than 700 people with PC, with about 400 professionals working in different centers.

The participants were 14 females and 5 males, aged between 28 and 60, with professional experience between 1 and 33 years. Regarding the professions, 8 were social workers, 6 were psychologists, 3 were pedagogues, and 2 were nurses. Five of the participants who answered an open-ended questionnaire three were females, and two were males between 36-60 years old and with more than 10 years of professional experience. The focus group (N = 14) comprised eleven females and three males aged 28-47, with a professional background of 1-20 years (Table 1).

[Insert Table 1 about here]

Data collection

Two sources were used for the qualitative analysis: an open-ended questionnaire and a focus group. In two face-to-face sessions, the research team (YG, RA, and MB) prepared the questions for the open-ended questionnaire focused on the purpose and objectives of the study, which was subsequently used to guide the questions for the focus group. Then, one researcher (RA), managing director of ASPACE, established our

contact with 5 participants from different centers by email. This email described the purpose of the study, including an open-ended questionnaire about the aging process in people with CP and a set of sociodemographic questions, which the participants completed and returned. The focus group was conducted according to the methods established by Krueger (Krueger, 1988) in a room of ASPACE, a place with optimal conditions for this purpose. It lasted approximately 75 minutes. The research team consisted of three people; two held an academic post (YG and MB), the other served as manager (RA). RA was the moderator in the focus group, and YG was a relator. Both the moderator and the relator, with experience in qualitative research, received training and support to carry out the focus group.

The moderator led the focus group and coordinated all the logistics for its execution, while the relator acted as an assistant. We informed the participants and requested their permission to record the focus group to facilitate the preparation and analysis of the data. Following the requirements for the performance of a focus group, guidance questions on the subject of study were used (Krueger, 1988). The participants described their experiences as direct caring professionals working with aging people with CP in 3 domains: (1) physical, emotional, and social changes in the aging of people with CP; (2) active and healthy aging in people with CP; (3) services offered by entities to support active aging. Participants were asked to assess the signs of aging, the needs and demands of older people with CP, their perceptions of the model of care provided, the attitudinal experiences towards that collective, and the role of the family.

Data analysis

The focus group and the open-ended questionnaires were audio-recorded and transcribed literally. Subsequently, the data were organized into a hermeneutic unit, encoded, and systematically analyzed through the qualitative analysis program

MAXQDA (version 20). This program analyzes the thematic content of the focus group collected through an inductive method of reading and coding, generating an explanatory framework about the objective of the research (Costa & Amado, 2018). Once all the contents of the focus group and the open-ended questionnaires had been extracted, MB proceeded to determine the significant units through an initial reading of the data to identify the key themes or contents. For this purpose, frequent words were searched to determine the most repeated terms in the textual body (Costa & Amado, 2018). Subsequently, the significant units were labeled, and a list of codes was generated that was discussed and agreed on with YG. Next, MB coded the transcription line-by-line, highlighting the important passages of the text and writing memos. These memos helped to deepen the meaning of the data, generating categories and subcategories. This first coding was performed by compiling all the passages of the text belonging to each of the main categories. Subsequently, subcategories were made inductively based on the analyzed data. In order to ensure trustworthiness, we used as a triangulation strategy with two researchers from the team to help with the coding and identify convergences and divergences, and make decisions (Korstjens & Moser, 2018). The data of YG were checked to confirm the categories and subcategories obtained. Next, differences in interpretation were resolved by discussion between researchers MB and YG. Table 2 describes the five main categories identified and thirteen subcategories with the corresponding explanations of each one and the key findings.

[Insert Table 2 about here]

Ethical considerations

The institutional board of Federation ASPACE approved the study, and all individuals provided written informed consent.

Findings

Five categories reported by professionals regarding the aging process in CP emerged from the analysis of the data: (1) peculiarities of aging; (2) support needs; (3) autonomy; (4) services; and (5) contextual factors. The first category comprises the subcategories: life project, tools for detecting early symptoms of aging, and indicators of active aging. The second one includes personal needs, individualized supports, and intervention proposals. The third category consists of the subcategories: self-determination and promotion of personal autonomy. The fourth category contains: support resources and changing to the person-centered paradigm. And finally, the fifth category joins the subcategories: family, care environments, and structural changes.

Below are the research results, organized into the five categories of analysis.

Peculiarities of aging

The professionals stated that older people with CP who experience physical and emotional changes perceive their difficulties in identifying early signs of pathological aging, the importance of taking into account a person's life project at different stages of the life cycle, and establishing formulas for healthy and active aging.

The professionals explicitly acknowledged that aging impacts motor skills, sometimes in an accelerated way, and has negative consequences for daily life activities.

One of the things we are encountering is that people with CP, who, until recently, were completely autonomous, suddenly lose autonomy overnight. [Peter]

Participants discussed the effects of the aging process on emotional aspects, emphasizing the presence of sadness in many of the users of their centers.

A feature we observe in aging people is an increase in mental illness, which often stems from a process of sadness that has not been managed or dealt with. In the end, well, we find much more complex symptoms to treat, such as depression. [John]

A common thread is the need to pay greater attention to the early signs of aging in center users to take preventive measures. They highlight the importance of detecting

whether changes in functional abilities are simply due to age or whether they occur earlier in older adults with CP and the factors to which these changes should be attributed.

As I'm a nurse, in the end, I consider the health level more, and I think it's essential to keep an eye on the symptoms of aging. We often assume that it is a normal aspect of their pathology because they have some physical deficiency, when it may be a clear sign of aging. [Sue]

Participants described the need for assessment tools for detecting changes in physical capacities associated with aging, as well as intervention protocols. They also noted the importance of having tools to identify the emotional changes that are so prevalent in aging people with CP.

First, for everyone, we should know what to look for when we refer to aging in any of our users; what factors should we consider to realize that the person is in that process; we need some tool or some homogeneous ideas to understand that any user may already be in that process. [Sally]

Professionals reported that few experiences of active and healthy aging were developed in their centers, and they did not show comprehensive and informed knowledge about the meaning of active and healthy aging. In addition, they stated that there is often a dissonance between the interests of the older person with CP and those of the professional. However, throughout the discourse, concepts associated with active aging emerged, such as "the person's satisfaction," "aspects that the person considers important," "accompaniment for satisfactory aging," "positive and healthy aging," and "empowerment."

In particular, we have doubts rather than a definition. One of them, we consider that, ultimately, active aging is about the person's satisfaction, and understanding those aspects that they consider important. The issue is that older people sometimes identify these important aspects for them, but sometimes, the activity to develop those aspects is conflictive because their satisfaction may consist of doing nothing. [Peter]

The participants' statements reveal the existence of a consensus that active aging should not begin to be applied when the person with CP is already old. On the contrary, for the person to exercise their rights and own their own lives, intervention processes are necessary from the early stages of the life cycle, oriented towards the acquisition of competences and skills of self-determined behavior as a strategy to defend their rights as full citizens.

But it is true that sometimes—I commented on it a little—to see the evolution of needs in each of the phases, it seems that at early ages, we are focused on therapeutic care; and then, we start on the work issue. But we have to generate—I don't know—a more global view of everything that is a life cycle—because a person without a disability, a priori, already has more or less organized their life, but not in the case of a person with a disability. That global view of their life cycle or where to go are unclear. [Peter]

Support needs

Several needs emerged from participants' discourse for measures to help promote active and healthy aging. Identifying the new demands of the aging process in CP is a way to ensure that these older people receive adequate quality care. These needs come from different sources, such as the people themselves, support resources, intervention procedures, assisted living modalities, and the family of origin.

Often, the needs of people with CP differ from those expressed by the professionals and the family. For example, professionals focus on individual treatments, whereas users do not perceive that need. On the contrary, professionals need to consider their desires and that they are the protagonists of their own life projects. Likewise, professionals express the importance of generating needs in the people themselves because other people have always done everything for them. Needs have also arisen about promoting a healthy lifestyle and preventing premature aging, especially the emotional needs of aging people with CP. The need to address aspects related to the grieving process is mentioned in the context of emotional aspects.

How to approach the loss of a family member? For me, the users have given me the answers; they've been telling me: "Of course, you experience it like this; but when you get home, you have someone's support; but I live here, I am living in the residence, and I have no support from my parents...; if your father were missing, your mother is at home, but I am here, going through my bereavement". So they have created a natural self-help group in many cases. [Cathy]

Professionals think that the current needs must be met, and appropriate support systems must be offered to each person with CP during their aging process so that they can lead a full life. Providing individualized supports implies the need for the figure of the personal assistant to address support systems throughout the life cycle and to provide residential service support based on each person's needs.

Tackling the issue of aging means that I realize that the supports to be given are not limited to having a good care ratio, and that's it; we cure ourselves in health. A caregiver for three or four users, that's not bad, is it? You have to realize the flexibility it takes to care for these people. It is also necessary to be aware of the individualized systems this entails. [Charles]

In general, our study participants think that the intervention procedures carried out so far with older people with CP show signs of exhaustion. New needs are emerging that require new responses. In this sense, the need to plan interventions to meet the short-term needs that these people will require is expressed.

I think it's like, when that day comes, what will we do? Because right now, you know, they have their parents in their little house at a specific time or even all day, but tomorrow? [Luci]

The need for supported residential service resources for the near future, expressed by professionals, opens the door to the approach of modalities of services to meet the new demands posed by the aging of people with CP.

We do not have a residential center; then, the unknown is: When those families, which are the ones who are currently supporting them [people with CP], get older, what part of the problem will we focus on? [Rachael]

Autonomy

Participants identified autonomy, understood as the decision-making ability of people approaching an older-person status, as a vital aspect of the aging process in people with CP to plan their future life, including identifying their desires and preferences.

The comments about autonomy go beyond the idea of a person's ability to perform daily activities independently and the power to make decisions. Throughout the discourse, self-determination, conceived as a set of activities and skills necessary to act as the causal agent or the protagonist of one's actions, appears as a critical concept (Wehmeyer, 2005).

Some people can make decisions and express their interests. But then, we have a lot of people who have never made any decisions in their entire life, nor do they have the option or ability to make a decision. [Cathy]

Some participants identified the efforts required to achieve satisfactory personal autonomy. From the professionals' perspective, promoting personal autonomy is one of the challenges, valuing any minimum gain as a success.

We have people with great difficulties with autonomy, and in the process of aging, we are attaching a lot of value to the autonomy that is being lost. It's like a two-train crash. We professionals grant a lot of importance to autonomy; we think we must gain and achieve as much autonomy as possible, but, of course, there comes a time in life when autonomy...; we have to find a balance between what we can do, what we can gain, and what we are going to lose at a certain point in our lives to seek that adaptation. For me, it's one of the biggest challenges we see regarding aging. [Peter]

Services

The professionals emphasize the relevance of resources and strategies that support the development of healthy, active aging according to the person's interests, enhancing their well-being, improving their functioning, and collaborating so they will be

considered citizens with full rights. They also comment on the emergence of changes in models of care services based on this group's demands and needs.

The professionals express the need for services and programs providing opportunities for active aging. In this regard, they prioritize establishing individualized care models that promote community participation and provide opportunities for people with CP to share activities and experiences with other groups. They also agree that service models facilitating individualized interventions should be used for the aging person with CP to achieve the desired well-being in different life areas.

Changing our contexts, that is, moving from residential macro-centers to residential models with personalized supports that allow fulfilling one's wishes... [John]

However, the professionals express their concerns about the model of services, either assisted living or occupational services, which are provided to older people with CP, as they are predominantly assistential and overprotective.

It's just that we've been working for many years using a model, and this carries a lot of weight for us. So, I think we must understand that we must drop that model, where professionals decide everything. They decide everything for the center, everything for the families, and everything for the user. And the thing is, even if you've been working like this for 30 years, you have to drop it, right? But it is essential to work with a model focused on the person, on the family. [Cathy]

This assistential predominance is reflected through comments on certain activities performed by adults with CP in the entities where the study participants practice their profession.

The problem is that activities are often not oriented to different ages in occupational centers. For instance, singing carols, doing crafts...; perhaps we should stress that at different ages, people want to do various types of activities, and other activities are not suitable; we sometimes treat them like children. [Sue]

Together, the professionals describe as a priority objective at this time the need to offer personalized supports based on the wishes and preferences of people with CP. In

this sense, they recognize the emerging paradigm, the person-centered approach, as a valuable strategy to guide the transformation of services. They are aware that the prevailing model is markedly rehabilitative/assistential.

Residential services with personalized supports can make it easier to fulfill wishes, such as, “I want you to give me a shower in the afternoon...” I think that, unless they have desires, our adults can’t participate in their life project. [John]

Through the participants' discourse, valuable initiatives are emerging oriented towards applying the new paradigm of person-centered care and changing the terminology used, whose contents have a less rehabilitative/assistential connotation and a greater psychosocial perspective.

In our experience in aging—because we have an occupational center that is moderately adapted to people in the process of aging—the activity level has been reduced, and they have more freedom in the center... They have their workshop, so to speak, where they can come or go as they please; if they want to go out, they go to the bar, and they drink their wine. [John]

Context

Study participants relevantly illustrate the role of context in addressing the structural changes necessary to meet the new demands of aging people with CP. The International Classification of Functioning, Disability, and Health (ICF) (World Health Organization., 2001), based on a social model of disability, includes in the contextual component the environmental factors, which constitute the physical, social, and attitudinal environment in which people live, and which can facilitate or impede their participation. Environmental factors include (1) products and technology; (2) the natural environment and changes in the environment arising from human activity; (3) supports and relationships; (4) attitudes; (5) services, systems, and policies. In addition, environmental factors are organized into two levels: (a) personal (family, work, neighborhood, etc.) and (b) social (organizations and services related to the work environment, community activities, communication, transport services, social networks,

etc.). A high percentage of the participants' discourse precisely referred to the family as the nearest social environment and to residential environments as environmental factors that affect change processes.

In their comments, the professionals reflect that the family has been and continues to be an important pillar of support for the person with CP and frequently adopts an overprotective attitude towards their son or daughter.

Overprotection also affects the users; maybe they want to do something and can't; they can say it once: "I want to do this"; but, as people always put things off, like my mother or father do to me, well, I...; they adapt. [Louise]

Similarly, they comment that families have considerable difficulties accepting their children's aging and recognizing their own limitations in their caregiver roles, experiencing this situation with anguish and fears about their near future as a family.

Then there comes a time when they can't [manage]. It's horrible for them to see that they are getting older and can't take care of their daughter or son. It turns out they've been taking care of their mother-in-law and their mother all their lives, and now, when they have to take care of their daughter, they can't. [Cathy]

They also express aspects about the aging of the parents themselves: how they age with their children and the professionals' difficulties in supporting them in their care roles. The participants point out how little interest families have in participating in training courses, which would make it much easier for them to manage their children, for example, in terms of mobility and food.

But most of the time, we have a lot of relatives who are pensioners; that is, their mornings and afternoons are free, or they may have gaps, but they do not go to the courses... I want to say that I think it's a great idea to do a program for families, but they're reluctant to come. [Cathy]

However, at the same time, they point out that the paradigm shift would facilitate an approach to the family, as interventions would be based on the specific needs of each family and each person with CP.

From my experience, the solution is individualized care and personalized attention to the individual case; and I am not referring to a training action for everyone, but instead, I come to your home, and we talk about your son and what's going on, and we talk about... That's what's working. [Peter]

One of the professionals' appraisals is that the parents do not consider their child an independent person with their own life, desires, and preferences. The professionals emphasize the need to work together with the family from the early stages of the life cycle so that the person with CP has their own life project. In this sense, participants say that experiences of early care, based on the family-centered model, lead to the transformation of services oriented to individual-centered planning.

And we can't forget that the families will decide for the people with significant support needs. It is true that there are some changes, and that they are making it easier for us because young parents are beginning to think that their child can live in a flat in the future, even if he is a child with great support needs. [Sally]

Most of the feedback related to the necessary changes adapted to the current paradigm revolves around the fact that the prevalent model of services does not adequately meet older people's demands and needs. Person-centered services are based on respect for the whole family and the person with CP. The professional does not play the role of expert but of collaborator, identified as a facilitator of the structural changes essential to meet the new demands of people with CP in the process of aging and those of their families.

The context conditions us so that people's desires occur in that context. And it is our job to fulfill these wishes; life without desires is meaningless. We need adults to express their wishes and dream and be self-determined. Let's change our contexts... Residential services with personalized supports that allow all those wishes to come true. [John]

Discussion

This study aimed to explore the perceptions of health professionals and social services professionals concerning the experiences of aging people with CP, their

opinion of the types of interventions carried out so far, and to offer information on intervention strategies for active and healthy aging. To a large extent, the participants acknowledged an accelerated aging process associated with CP, a result consistent with previous studies documenting age-related changes (Dogruoz Karatekin et al., 2022; Jonsson et al., 2021; Noten et al., 2022; Ryan et al., 2023; Thorpe et al., 2021; van der Slot et al., 2021). They also referred to the need for a tool to guide them, from a multidisciplinary, person-centered perspective, in the early detection of the biopsychosocial manifestations of deterioration in functioning. In this sense, González-Alonso et al. (2017) claim that it is necessary to detect the physical and psychological changes experienced by people with CP early in this stage of the life cycle to fulfill the needs that these changes entail. A good tool is the *NICE Guide “Adult Cerebral Palsy,”* based on recommendations of scientific evidence, which aims to improve health and well-being, promote access to services, and support the participation and independent living of people with CP. Its guidelines include recommendations on access to services, support systems (e.g., communication, independent living, technical aids, physical activity, etc.), spasticity management, and evaluation procedures (e.g., mental health problems, eating, pain, etc.) (National et al., January 2019).

As in other studies, the professionals emphasize that active aging is still a challenge, and they express a lack of guidance to design interventions that so older people with CP can enjoy a healthy life (Haak et al., 2009; Hurvitz et al., 2021; Llewellyn et al., 2004; Santos et al., 2022). Although they comment on the difficulties of implementing interventions for active aging, they also identify the concepts involved, such as well-being, social participation, active support, or personal autonomy. **In this way, interventions tailored for older people with CP such as creative arts and animal-assisted programs (Hodgson et al., 2022) or the application the Plan-Do-Study-Act Cycle can be**

initiatives to enhance active aging (Wongsala et al., 2023). The participants also clearly describe the desirability of developing life cycle interventions to prepare the person with CP for adult life and optimal healthy aging, as pointed out in previous studies (Carroll et al., 2021; Colver, 2016; Haak et al., 2009; Santos et al., 2022; Törnbohm et al., 2013).

Many participants agreed about older people's difficulties in expressing their needs because, throughout their lives, someone else has done everything for them. Motor difficulties and the absence of controlled movements can lead an adult with CP from early childhood to problems contacting with reality, dependence on another person, and a mismatch between what they want and what they can do, all this causing lack of interest in the environment, passivity, and dependence. At the same time, the person's expressive difficulties, often associated with CP, limit their communication possibilities, and lead them to consider that their repertoires are useless. This perception of inefficiency can have negative motivational and emotional consequences, leading to a lack of motivation, interest, and passivity (Badia Corbella, 1997). That is, when the person is subjected to chronic frustration because their behavior is not rewarded adequately and in a timely way, they "learn" to remain helpless (Seligman, 1975). These functioning restrictions of old people with CP require a holistic approximation that considers biological, psychological, and social factors as a framework for a healthy and successful aging; as well as interventions that focus on the factors that should be modified taking into account the needs and skills of each individual (Gonot-Schoupinsky et al., 2022).

Approaching the emotional aspects of healthy aging in people with CP is a need explicitly expressed by the participants. This result coincides with previous studies indicating the high prevalence of negative emotional signs frequently associated with comprehension problems, difficulty discussing their symptoms, and seeking help or

advice, which can lead to a delay in diagnosis and treatment (Noten et al., 2022; Peterson et al., 2021; Pizzighello et al., 2022; Smith et al., 2019; Van Der Slot et al., 2012). In this sense, the professionals also affirm the need to pay greater attention to the emotional difficulties that the person with CP can present at every stage of the life cycle, from childhood to maturity, which can interfere with the process of their socio-emotional development. Therefore, it is imperative to promote techniques and strategies that facilitate socio-emotional development in each life stage and, at the same time, are considered as a part of more comprehensive programs (Badia Corbella, 1997; Weber et al., 2016). Another explicit aspect concerning the emotional aspects reported by the professionals is detecting the needs of people with CP during the grieving process and the urgent need for an intervention protocol. Some studies have shown that bereavement and loss produce an increase in symptoms such as depression, anxiety, and behavioral disturbances (Dodd et al., 2005) and that the implementation of good practices through prevention and intervention programs to facilitate understanding of loss would help to express feelings and emotions individually (Muñiz Fernández et al., 2017).

The professionals also note the need to offer personalized supports to achieve active and healthy aging. In this regard, they highlight the importance of the figure of the personal assistant as a support resource to enhance self-determination and independent living (López Pérez & Ruiz Seisdedos, 2018; Pallisera Díaz et al., 2018). In this sense, Levasseur et al. (2023) point out the importance of this figure because it offers opportunities for older people to satisfy their needs and improve their social life and inclusion in the community

In general, the participants underline the relevance of promoting self-determination in this group. Although little is known about self-determination in older people with CP, some studies indicate that healthy aging is shaped by supports and environments

providing self-determination opportunities (Heller, 2013; Heller et al., 2011). Navas et al. (2014) point out that person-centered planning, vocational training, and environmental modifications and interventions promote self-determined behavior. This way, programs tailored for old people with CP that support and offer opportunities to control their own lifestyles, are good strategies to achieve and active and good-quality aging (Larsson Ranada & Österholm, 2022; Wongsala et al., 2023).

The professionals generally state that the guiding principles for a model of care that promotes active aging should include, but not be limited to, person-centered planning, promotion of autonomy and self-determination, independent living, social participation, well-being, and privacy. These comments made by the participants on the model largely coincide with the priorities set out in the *Active Aging White Paper* ((IMSERSO), 2011), which envisages the design of health promotion programs for individuals aimed at reducing secondary health conditions, promoting personal development, providing leisure opportunities and enjoying leisure time, and promoting the development of alternative residential centers.

An important finding of our study is that the professionals express the need to offer individualized supports based on the needs of the person with CP. From this perspective, person-centered planning, which aims to reduce the mismatch between the person's capabilities and their environment's demands to improve their functioning, becomes worthwhile (Noten et al., 2022; Thompson et al., 2009). This result reflects this need for a change of model perceived by the participants, which aligns with professional practices focused on functional skills and contextual factors (Verdugo Alonso, 2018). For example, a program focalized on using strategies to keep the mind alert, about what should the person do to maintain their well-being, and to establish

social relationships have long-term positive cognitive, physical, and social impacts (Timmermans et al., 2022).

The professionals reveal that environmental factors—the physical, social, and attitudinal environment in which people live and carry out their activities—influence the active and healthy aging process in people with CP (Noten et al., 2022). The family represents the fundamental environment of the person with disabilities, and the parents are considered the central contextual factor in their children's lives (Rosenbaum & Gorter, 2012). Throughout the discourse, professionals refer to the parents' excessive overprotection toward their children, negatively influencing their autonomy and self-determination. This result is consistent with previous studies indicating that overprotective parents may involve adverse experiences, with negative consequences such as their children's lack of control over their life, feelings of lack of autonomy, and emotional disturbances (Hemm et al., 2018; Holmbeck et al., 2002; Pallisera Díaz et al., 2018). Professionals also express the need for a change in professional family care services, oriented towards a family-centered approach, a model based on respecting and recognizing each family's strengths and prioritizing their needs and concerns. Rosembaum and Gorter (2012) point out that a family-centered service is a good tool for managing each family's problems, finding that parents report better mental health and satisfaction and less stress in their interaction with the professionals. In this sense, the study participants perceive the family-centered approach as an appropriate strategy to work in a professional-family collaborative environment so that persons with CP can develop their own life project. This result is confirmed by Pallisera Díaz et al. (2018), who affirm the professionals' expressed need to work with families for people with intellectual disabilities to achieve an independent life.

Within the framework of environmental factors, the professionals of this study emphasize that certain environmental factors negatively influence establishing a service model that promotes active and healthy aging. In this sense, the participants refer to how the social environment is a barrier to the necessary paradigm shift. Currently, some legal frameworks and documents guarantee, in principle, the right to an active and healthy life of persons with disabilities: the *Convention on the Rights of Persons with Disabilities* (United, 2006), the *World Report on Aging and Health* (World Health Organization, 2015), the *I National Plan for the Healthy Well-being of People with a Disability* (2030., 2023), etc. However, while this regulatory framework offers access to support resources that improve the care for the person with disabilities and their quality of life, their implementation and development are far from reality. In this sense, the results of this study agree with those finding that the lack of funding and staff training and the professionals' work overload, among other factors, act as obstacles to the implementation of individual support services aligned with the needs of people with disabilities in the process of aging (Schepens et al., 2019).

Limitations

Although the study, based on the professionals' perspective, has provided relevant information on the active and healthy aging of people with CP, it has some limitations. First, it had only one focus group of health and social service professionals. The second limitation is that it included exclusively questions about active and healthy aging, limiting information on the theoretical model on which intervention strategies are based. The third, given the heterogeneity of this disability, is the possible bias of the results, as needs during the aging process can be very different depending on whether or not people with CP have significant needs for support. Finally, it should be borne in mind that this study was conducted in a region of Spain. Although the services that provide

care for people with CP in the aging process are similar in the rest of the regions, this could reduce generalization to other areas of Spain or other countries.

Future research aims to better understand the active aging of people with CP from the experiences of individuals, their families, and other direct care professionals. However, to date, we have no holistic approach that considers the biological, psychological, social, economic, and environmental factors that impact healthy and successful aging (Gonot-Schoupinsky et al., 2022). In this direction, González-Alonso et al. (2017) propose the new needs linked to the changes caused by aging should be identified from the dimensions and indicators of the quality of life model proposed by Schalock and Verdugo (2002) to carry out the changes required to promote active and healthy aging. Finally, research should be done on aging in people with CP with significant and multiple disabilities, with the greatest and most complex needs of supports to meet this group's needs and offer quality services.

Conclusions

Summing up, in this study, we attempted to explore the current situation of older people with CP to detect physical and emotional changes and identify their needs for support services for healthy and active aging. The results show signs of early aging associated with the comorbidities accompanying CP. The professionals' discourse reveals the demand for a change of model in the services context, already manifesting through some initiatives carried out in the professionals' organizations. Nevertheless, the professionals consider that the current services do not meet the individual needs of older people with CP and are still based on a medical/assistential model dedicated to the care and provision of primary services (e.g., food, medication, hygiene, mobilization, falls, continence, etc.) to the person and their basic functional needs (Basic Activities of Daily Living - Instrumental Activities).

In this regard, the professionals made the following proposals for the improvement of support services: (1) to develop a tool for the early detection and prevention of alterations associated with the aging process; (2) to adapt the supports to the particular needs of each person, taking into account the principles of person-centered planning; (3) to promote autonomy and self-determination at this stage of the life cycle; (4) to include the figure of the personal assistant in a crucial role for person-centered planning; (5) to prepare the person with CP for situations of loss of a loved one; (6) to promote vocational training initiatives in line with the principles of the person-centered paradigm and active aging; (7) to organize training actions aimed at family-centered intervention; and (8) to coordinate active aging initiatives that are being carried out in different organizations to design a strategic plan to guide professional practices.

Conflicts of interest

The authors have no conflicts of interest to declare, and the research has not been previously published.

Funding

This study was partly supported by the Institute on Community Integration (INICO), University of Salamanca, Spain.

Data availability

The data that support the findings of this study are available from the corresponding author, MB, upon reasonable request.

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