Ageing with cerebral palsy: psychosocial issues

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Abstract

Background: although much has been written about biomedical concerns in adults ageing with cerebral palsy (CP), few studies or reviews have addressed psychosocial aspects.

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Objective: The purpose of this narrative review is to critically examine studies that have addressed needs for social support, as well as issues affecting morale, self-efficacy, health attitudes, employment and sense of coherence (SOC) in adults ageing with CP.

Design: A systematic and detailed search of the literature was conducted.

Methods: Searches of CINAHL (1982–present), ERIC, PubMed (1950–present), MEDLINE (Ovid) and Web of Science databases, as well as the American Academy of Cerebral Palsy and Developmental Medicine website, were conducted. Key search terms included ‘cerebral palsy and ageing’, ‘adults with cerebral palsy’, ‘secondary conditions’, ‘functional loss’, ‘health’ and ‘psychosocial’. Nine studies were recovered that described psychosocial consequences of living with a lifespan disability. We used McMaster University’s Guidelines for Critical Review Form — Quantitative and Qualitative Studies to evaluate the studies.

Results: Psychosocial issues of concern to adults ageing with CP include the need for social support, self-acceptance and acceptance by others; the need for accommodations in the workplace and the environment; and SOC of adults ageing with CP.

Conclusions: Several studies concluded that adults with CP need greater knowledge and understanding to enhance decision-making processes about their health. The studies reviewed also provide knowledge for healthcare and social service providers who care for adults with CP to better understand how psychosocial health can be preserved during the ageing process.

Keywords: Cerebral palsy, ageing, psychosocial, elderly

Introduction

Although much has been written about biomedical concerns in adults ageing with cerebral palsy (CP) [1–7], few studies or reviews have addressed psychosocial aspects. In the social model of disability, disability is viewed not as ‘an attribute of an individual but rather a complex collection of conditions, activities and relationships, many of which are created by the social environment’ [8, p 1173]. The purpose of this narrative literature review is to critically examine studies that have addressed needs for social support, as well as issues affecting morale, self-efficacy, health attitudes, employment and sense of coherence (SOC) in adults ageing with CP.

Search strategies, study selection and guidelines for critical review

Searches of CINAHL (1982–present), ERIC, PubMed (1950–present), MEDLINE (Ovid) and Web of Science databases, as well as the American Academy of Cerebral Palsy and Developmental Medicine website, were conducted. Key search terms used were ‘cerebral palsy and ageing’, ‘adults with cerebral palsy’, ‘secondary conditions’, ‘functional loss’, ‘health’ and ‘psychosocial’.

Studies included identified age-related changes or secondary conditions affecting functional loss in adults with CP, as well as studies focusing on some of the psychosocial aspects of ageing with CP. Initially, 80 articles were identified that referred to the ageing process in adults with CP. We excluded review articles and other papers that did not constitute original research, as well as studies stating that the individuals participating had intellectual disabilities, and studies that did not focus on the impact of age-related secondary conditions and changes occurring in adults with CP. Some studies included individuals with other disabilities as well as those with CP.

Eighteen studies were identified that addressed biomedical concerns, i.e. secondary physical conditions related to ageing with CP, whereas only nine were recovered that described psychosocial consequences of living with a lifespan disability. We used McMaster University’s Guidelines for Critical Review Form — Quantitative and Qualitative Studies [9] to evaluate the studies.

Results of the literature review

In a qualitative study, King and colleagues [10] examined the desires and life goals of older adolescents with CP during the transition between high school and further education or entering the job world. The study involved seven female and three male adolescents aged 18–20 years. Five were nearing the end of high school, two had recently graduated and three had just started college or university. They were asked what success in life meant to them and what factors helped or hindered them in being successful. The theme that emerged was that ‘success means being happy’; the three factors related to that success were (i) being believed in by others, (ii) believing in yourself and (iii) being accepted by others. This study’s findings suggest the need for health service providers to focus on outcomes related to social support, self-acceptance and acceptance by others [10].

In another qualitative study [11], King and colleagues interviewed 15 adults with chronic disabilities (CP, spinal bifida or attention deficit disorder) at turning points in life to find out the nature and meaning of their social support systems. The study revealed that social supports played a significant role in adaptation of individuals with disabilities to challenging events and experiences and described three types of support: (i) emotional support (making people feel better about themselves), (ii) instrumental support (tools and strategies to address their issues) and (iii) cognitive support (being understood helped them to feel not alone
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in facing situations and experiences) [11]. The small samples and qualitative nature of both of King and colleagues’ studies limit the generalisability of their results. Nonetheless, each study provides insights into the social needs of adults with CP.

The subjective well-being of 81 adults with CP (age range 26–51 years; mode of locomotion: 39 with independent gait, 20 used crutches for gait and 22 used a wheelchair) was evaluated using the Philadelphia Geriatric Center Morale Scale (PGC Morale Scale) in a 2001 study by Furukawa and colleagues [12]. Questionnaires were mailed to former patients of the Philadelphia Geriatric Center with a 47.3% response rate. Results were: (i) former patients with CP who were dependent (requiring help in daily life) scored lower (51 vs 64%, \( P < 0.05 \)) on the PGC Morale Scale than those who were independent; (ii) former patients whose physical health was deteriorating due to senile weakness (estimated by rate of appearance of falling stamina or the ability to sustain falling), pain and gait disorders, scored lower than those without these symptoms; and (iii) the convenience of social environment (\( P < 0.05 \)) and opportunity to go out (\( P < 0.01 \)) positively influenced the subjective well-being of the former patients being studied.

The authors reported that patients scored significantly lower on the PGC Morale Scale with the appearance of senile weakness than those without senile weakness: falling stamina (52 vs 70%, \( P < 0.01 \)), pain (52 vs 76%, \( P < 0.01 \)) and gait disorder (58 vs 64%, \( P < 0.05 \)). Results suggest that the patients with CP were upset when their physical conditions led to limitations of activities and participation restrictions affecting their lifestyle [12]. The fact that all the participants were recruited from only one centre and represented only two types of CP (spastic and athetoid) is a potential study limitation.

Further insights into understanding the experience of ageing with a disability were reported in a 2004 study of women with physical disabilities by Goodwin and Compton [13]. In a hermeneutic phenomenological study of six women’s experiences of physical activity and ageing with a disability, the disabilities included CP (\( n = 2 \)), acquired brain injury (\( n = 1 \)) and spinal cord injury (\( n = 3 \)), with ages ranging from 22 to 37 years. Three themes emerged from the data analysis: (i) experiencing something normal, (ii) loss of physical freedom and (iii) maintaining function through physical activity. Ageing was expressed as something the women recognised as a normal process. Loss of function, fear of the unknown and fear of secondary disabilities were perceived threats to their physical freedom. The women revealed how important independence was to their quality of life [13], expressing how their ‘sense of happiness, freedom and autonomy’ were linked to using their bodies in ways that contributed to their sense of self; learning, mastering and maintaining independence in their lives was of primary concern [13, p 131]. Physical activities were reported as important for maintaining hard-earned lifestyles and levels of physical functioning [13], corresponding with findings of other studies [14–16].

Whiteneck and colleagues noted that people with spinal cord injury commonly experience problems associated with ageing 10–20 years earlier than persons without disabilities, i.e. unexpected changes in functional ability occur between ages 30 and 50 in people with disabilities [17]. Similarly, in Sweden, Sandström examined how adults with CP experience living with a disability and how they manage everyday life [18]. The sample included 22 community-living adults ranging from age 35 to 68 years. Two main themes were reported: (i) perceptions of living with a disability that included perceptions of a ‘dys-appearing’ body, perceptions of a not-appearing body, perceptions of difference, perceptions of being in-between, perceptions of normality, perceptions of restricted autonomy and perceptions of autonomy; and (ii) strategies that included strategies to fight one’s way, strategies to plan, strategies to get used to it, strategies to hide and strategies to give one’s all [18].

Data collected in Sandström’s study [18] support some findings in Goodwin and Compton’s study [13], i.e. perceptions of living with a disability were similar across participants in both studies. However the findings of Sandström’s study [18] may be more generalisable to adults with CP than those from Goodwin and Compton [13] because Sandström’s sample included only adults with CP (22 adults) whereas Goodwin and Compton’s sample had just two women with CP [13].

In 1995, Becker and Schaller reported a study of 28 adults with CP (aged 18–49 years) who were living in the community [19]. To examine differences in perceptions of self-efficacy and health attitudes, this group was compared to two other groups: (i) people attending a health fair and (ii) people from a statewide disability advocacy group. Perceived self-efficacy ratings for the adults with CP were most strongly related (\( P < 0.05 \)) to the nutrition (\( r = 0.68 \)) and health responsibility (\( r = 0.64 \)) subscales of the Self-Rated Abilities Scale for Health Practices [20], followed by the exercise (\( r = 0.50 \)) and psychological well-being (\( r = 0.46 \)) subscales [19]. Interestingly, those who most frequently needed mechanical assistance had significantly higher (\( P < 0.05 \)) self-efficacy perceptions than those who needed personal assistance (\( r = 0.45 \) vs \( r = 0.03 \)). In fact, the two sets of ratings were at opposite ends of the scale, suggesting that the group who needed mechanical assistance perceived themselves as more independent because they were able to operate their own assistive devices whereas the other group perceived themselves as more dependent because of their reliance on other people for assistance [19].

Becker and Schaller’s findings [19] showed also that adults with CP scored lower on the Self-Rated Abilities for Health Practices, especially in the areas of exercise and nutrition, than the two comparison groups. The Self-Rated Abilities Scale measured the respondents’ abilities to perform health behaviours that promote health. The mean exercise score for the group with CP was 12.36 compared to 19.88 for the health fair group and 16.68 for the disability advocacy group. In the area of nutrition, the group with CP also scored lower (mean = 16.14) than the health fair (mean = 22.15) and disability ad-
vocacy groups (mean = 20.59). On the Perceived Health Status Scale, 75% of the group with CP rated their health as good or excellent, which corresponds with findings by Turk et al. [21], suggesting that adults with CP perceive themselves as healthy despite their physical impairments. In other words, the CP group perceived their health as separate from their physical impairments.

On the Perceived General Self-Efficacy Scale (measuring beliefs regarding personal abilities to affect outcomes), the average rating of the CP group’s perceived ability to perform exercises was much lower than their perceived ability to carry out other health promoting behaviours (i.e. health responsibility, nutrition and psychological well-being). These ratings may suggest a need for rehabilitation professionals to facilitate feasible ways for adults with CP to exercise. Other comments by the participants with CP indicated that there are many barriers (e.g. lack of wheelchair accessibility, lack of dentists that specialise in treating persons with CP) that individuals with severe disabilities encounter when attempting to take care of their health.

It is difficult to generalise these results due to the small convenience sample drawn from one geographic area. Another potential limitation was the fact that a number of the questionnaires were completed by someone other than the individual with the disability. Nevertheless, the results provide knowledge of the perceptions that adults with CP have of their health and their abilities to take care of their health. These results provide insight also into the needs of adults with CP and may be beneficial to rehabilitation professionals working with these adults in advising them how to take care of their health as they age.

In a 2006 study, Mitchell and colleagues used a cross-sectional design to investigate the role of both ageing and disability on lifespan employment status [22]. Current employment rates were compared between 262 people with disabilities and 115 people without disabilities. The group with disabilities included five different impairment groups: polio (n = 60), CP (n = 60), spinal cord injury (n = 59), rheumatoid arthritis (n = 32), stroke (n = 20) and an ‘other’ group (n = 20), i.e. musculoskeletal system, peripheral nervous system and central nervous system disorders. Mean ages for those with and without disabilities were 48.9 years (SD = 10.7) and 45.8 years (SD = 11.7) and mean educational levels were 14.2 years (SD = 3.4) and 15.9 years (SD = 2.5) respectively. The group with disabilities consisted of 61% women versus 75% in the group without disabilities.

Using chi-square analyses, there was a significant difference in employment rates for the group with disabilities in relation to having some college education versus those with high school education or less (P ≤ 0.001). However for the group without disabilities, college education versus high school education made little difference in employment rates (P = 0.29) [22]. Within the group with disabilities, those who had some college education reported a 49% employment rate versus 23% for those with high school or less. There was no significant difference in relation to education and employment rates in the group without disabilities. Within the group with disabilities, employment rate changed significantly over time for the college-educated group (P ≤ 0.01) but not for the non-college-educated group (P = 0.425). The group with disabilities reported faster and earlier declines in employment than those without disabilities. By their 60s, the group with disabilities reported 50% reduction in employment versus 35% in the group without disabilities. The decline began around the 40s age decade in the group of people with disabilities versus the 50s and 60s age decades in those without disabilities.

These results suggest the need for adjustments in the workplace to accommodate for changes experienced by adults with CP during their 40s and later. Workplace accommodations may help to offset early employment loss in people with disabilities. The study also suggested the need for professionals involved in vocational rehabilitation to plan the employment needs and accommodations of individuals with disabilities throughout their lifespan [22]. These results concur with the findings of Ando and Ueda [1] that suggested the need to look at workplace conditions that may contribute to functional changes and early employment loss.

A limitation of Mitchell et al’s study [22] was the failure to include other age-related variables (i.e. age of onset of impairment, duration of impairment and cohort effect) in the analysis. Another limitation is the heterogeneity of impairments in the sample with disabilities. Even though the group with disabilities included people with impairments other than CP (in addition to those with CP), the data provide information that may be valuable for adults with CP in maintaining long-term employment.

In a 2002 Norwegian study [23], Jahnsen et al. used the same sample as in their study of fatigue [2]. In this more recent study, SOC in adults with CP was compared to SOC in the general population. Because no normative Norwegian data on SOC were available, normative data from a Swedish study on SOC were used. A multidimensional questionnaire was sent to a representative sample of adults with CP. The survey results were compared with results from a reference group of Swedish people within the general population [24].

Participants included persons over age 18 years with CP, but without intellectual disabilities. The response rate was as expected, considering the functional status of the CP population; 406 of 766 eligible persons responded (53%). The gender distribution was 48.5% female and 51.5% male; age range = 18–72 years (mean = 34 years). Nearly half the respondents needed help completing the questionnaire, which took from 15 min to 8 h.

Jahnsen and colleagues’ results [23] showed that Norwegian adults with CP had a lower SOC than that in the general Swedish population [24] in all three domains: manageability (36 vs 36.6%), meaningfulness (52 vs 60.5%) and especially in comprehensibility (43.9 vs 71.5%). In determining factors that might relate to SOC, socio-demographic and diagnostic variables (i.e. education, marital status, deterioration of functional skills, pain, fatigue, grade of disability and life satisfaction) were investigated as well as gender, age and employment. Based on univariate and multiple logistic regression analysis, results
showed that the most important predictive factors of low SOC were educational level ($P < 0.001$), marital status ($P = 0.01$), life satisfaction ($P < 0.001$) and fatigue ($P < 0.001$), whereas gender, age, employment, pain and grade of disability were less important [23]. The variable ‘SOC’ differed with age but the difference was not statistically significant.

One potential bias in this study was that nearly half the respondents needed help in completing the questionnaire and the time to complete was extremely long for some. However the data showing that adults with CP experience life as less manageable, less meaningful and especially unpredictable and incomprehensible suggest the need for adult rehabilitation or social programmes that include essential aspects of SOC in the socialisation process in order to enhance their coping potential [23].

Limitations

The main limitations of the studies cited in this review were that most involved small samples, selection was not random and the cohorts not homogeneous. Even though most of the study samples were small and not representative of the population of adults with CP as a whole, they provide some insights into the health and rehabilitation needs of this population. These findings may, in the future, advance some theories in approaching the needs of adults ageing with CP.

Future research suggestions

Because qualitative research can be used to generate hypotheses for later quantitative research [25], findings from qualitative studies with small samples — such as those by King and colleagues [10, 11] — could be used to generate hypotheses for quantitative studies, such as surveys to further explore the meanings of success and social support systems to much larger groups of adults ageing with CP.

A common theme identified across several studies was the negative influence of biomedical impairments on some of the psychosocial aspects of ageing with CP [12, 13, 19], e.g. the fact that secondary physical impairments associated with ageing led to activity and participation restrictions. Because study participants viewed exercise and physical activity as potentially beneficial in enhancing their overall function [13] and well-being [12] and because adults with CP scored especially low in their self-rated ability to perform exercise [19], future studies are needed to examine the benefits of physical activity, e.g. structured exercise programmes, on enhancement of participation in activities of daily living, community engagement and subjective well-being.

Another focus of future research would be to examine the effects of workplace modifications (aimed at minimising the deleterious influence of secondary physical impairments) on sustaining the employability of middle-aged adults with CP. Because fatigue (another secondary physical impairment common in adults with CP) significantly influenced SOC in adults with CP [23], studies aimed at examining lifestyle modifications that could minimise fatigue, e.g. workplace modifications, using powered mobility, are needed.

Conclusions

The foregoing studies, involving participants from five different countries, have reported some of the psychosocial issues of concern to adults ageing with CP. These include the need for social support, self-acceptance and acceptance by others; concerns of adults with CP about physical deterioration that may lead to limitations in their activities and participation restrictions affecting their lifestyles; the need for accommodations in the workplace and the environment; and the SOC of adults ageing with CP.

Several studies in this review concluded that adults with CP need greater knowledge and understanding to enhance their decision-making processes about their health [13, 19, 23]. The information obtained may also provide knowledge for healthcare and social service providers who care for adults with CP so that they better understand how psychosocial health can be preserved during the ageing process.

Key points

- Adults with CP experience psychosocial issues, as well as secondary biomedical concerns, related to their disability.
- Psychosocial issues associated with ageing with CP include the need for social support, self-acceptance and acceptance by others.
- Workplace accommodations may be needed to enhance continued employment for adults ageing with CP.
- Adult rehabilitation and/or social programmes that include essential aspects of SOC as part of the socialisation process could enhance the coping potential of adults ageing with CP.

Conflicts of interest

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References

Types of infectious outbreaks and their impact in elderly care facilities: a review of the literature

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Abstract

Background: infectious outbreaks in long-term care facilities (LTCFs) tend to have a significant impact on infection rates and mortality rates of the residents.