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PSYCHO-EDUCATIONAL PROGRAMS FOR ADULTS WITH AUTISM: A MINI-REVIEW

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ABSTRACT

Autism Spectrum Disorder (ASD) is characterized by patterns of delay and deviance in the development of social, communicative, cognitive skills, and the presence of repetitive and stereotyped behaviors as well as restricted interests. Psycho-educational programs are interventions on the nature of the illness, including causes, progressions, and treatments. Some clinical guidelines recommend psycho-education as the first step in treatment immediately after diagnosis. There are several psycho-educational programs for children, while for adults, they are lacking and burdened by results that are at times unpromising. Further development of psycho-educational programs aimed at adults with autism is necessary to achieve the most independent life possible and the best possible quality of life.

INTRODUCTION

In the literature, numerous definitions of Psycho-Education (PE) are present. Indeed, since 1971, with the definition of PE by Guerney et al. [1], numerous descriptions of different but complementary aspects of PE have followed [2,3,4] (see Table 1). The World Health Organization (WHO) defines PE as "the process of teaching people with Mental, Neurological and Substance use disorders and their carers/family members about the nature of the illness, including its likely causes, progression, consequences, prognosis, treatment and alternatives" [5]. PE combines the elements of cognitive-behavior therapy, group therapy, and education. Over the years, starting from the person-centered concept of knowledge of the characteristics of a pathological condition, we have gradually moved on to incorporating family members, coping strategies, and the concepts of quality of life and healthy aging into these approaches.

Table 1. Psycho-education Definitions

Authors	Definitions
Guerney et al. 1971 [1]	Teaching skills and personal and interpersonal behavioral modalities that an individual can apply to resolve psychological problems and improve their life satisfaction.
Ivey 1977 [2]	The psycho-education model is committed to providing people with the abilities required to manage their own lives in their own way.
Barker 2003 [3]	Process of teaching clients with mental illness and their family members about the nature of the illness, including its etiology, progression, consequences, prognosis, treatment, and alternatives
Kumar et al. 2015 [4]	PE is a widespread and structured systematic form of information and education for patients, with the aim of informing patients and their families about the etiology of a condition or disease, triggers, management of the condition and treatment options.
WHO 2016 [6]	The process of teaching people with Mental, Neurological and Substance use disorders and their carers/family members about the nature of the illness, including its likely causes, progression, consequences, prognosis, treatment and alternatives.

The Autism Spectrum Disorder (ASD) includes a group of developmental disorders characterized by core symptoms that include social communication issues, the presence of restricted interests as well as repetitive behaviors that impact on quality of life of patients and their caregivers [6,7]. There are numerous medical and psychiatric comorbidities that can aggravate the core symptoms of autism [8,9].

Some clinical guidelines for autism [10,11,12,13] recommend PE as the first step in treatment (before starting personalized treatments), immediately after diagnosis. Moreover, some authors already consider assessment to be the initial phase of PE [14]. They also recommend involving family, friends, or loved ones in the PE program [15]. Despite these recommendations, internationally, access to PE for adults and older adults (>65 years) with a recent diagnosis of autism appears severely hampered and limited, both due to barriers to access to care and to a lack of training among health workers [16,17,18,19]. Indeed, in a survey conducted among autistic adults, caregivers, and professionals in 11 European countries, less than 35% of adults and caregivers had used each of the post-diagnostic services/supports recommended in the national guidelines [20,21].

PE interventions vary depending on the age of the individual, with notable differences between developmental, adolescent and adults with autism. Therefore, with young children, the priorities should be speech therapy, special education, and parent coaching. With adolescents, the focus should be on social skills development groups, behavioural problems that interfere with learning, occupational therapy, problem-solving, and sexual issues. In adults with medium and high cognitive levels, the focus should be on self-determination, empowerment, sexuality, housing, employment, medical and psychiatric comorbidities management, well-being, and quality of life [22,23]. Precisely to work on well-being and quality of life, the laboratory offers psychoeducational paths based on the area in which one wishes to focus. Interventions that can be carried out are represented by PE to monitor health conditions, psychosocial in small groups [24], social skill training [25,26], cognitive behavioural therapy [27], mindfulness-based stress reduction [28], and sexual health education [29]. In adults with low and very low cognitive levels, PE interventions are carried out with family members, while with the person with autism, behavioural paths are carried out to teach new skills and make the person as independent as possible. Behavioral interventions directed at the person are classified into comprehensive treatment models and focused interventions [30]. The former consists of a set of focused interventions organized around a common conceptual framework [31], while the latter includes cognitive-behavioral techniques specific to target goals [32].

MATERIALS AND METHODS

A literature search was conducted on major databases to find useful studies for the purposes of this paper.

DISCUSSION

In the literature, there are few empirical data on the effectiveness of PE for adults and older adults with an autism diagnosis. In 2008, Kan and colleagues' study [33], conducted on adults with autism and their partners, found that PE significantly increased knowledge about autism in both autistic adults and their relatives. In 2014, Spek and Boxhoorn [34] conducted an online survey of 130 autistic participants aged 18 to 60. Nineteen percent of women and 24% of men believed PE helped them accept the diagnosis. Furthermore, interaction and discussion with other people with autism were very helpful in accepting the diagnosis. In 2017, Boland and colleagues [35] conducted a qualitative interview and found that older autistic participants who received PE reported positive changes in reconfiguration of their self-image and a better appreciation of their individual needs. The study by Ouwens et al. in 2022 entitled "Living together according to one's strengths" [36], found that partners reported increases in knowledge about autism, recognition of autism in their partner, and in self-esteem, and a decrease in psychological distress.

As previously stated, PE programs vary depending on the age of the person. PE programs for children with autism are represented by "I am special", "PEGASUS", "Brain blocks", "Give me Five", and "Working Together" programs [37,38,39,40]. On the other hand, such programs for adults with autism are very few and burdened by less than promising efficacy results. To the best of our knowledge, in the scientific literature, three PE programs for adults are present (see Table 2) [41,42,43].

DaWalt et al. [41] used a randomized waitlist control design and evaluated the effectiveness of a multifamily group psychoeducational intervention, called Working Together, for adults with autism spectrum disorder without intellectual disability. The results indicated medium-to-large effects associated with the Working Together intervention on key outcomes (engagement in work, engagement in meaningful non-work activities, behavior problems) and reductions in internalizing problems. However, the results were not statistically significant, but clinically evident. Of note was the maintenance of the treatment effect up to 6 months after treatment for the intervention group.

Groenendijk et al. [42] explored the effects of a co-designed PE program for older autistic adults regarding insight into autistic traits, cognitive challenges, mastery, self-esteem, quality of life, self-efficacy, self-stigmatization, hope, and future perspectives. The results showed no significant improvement, but the authors stated that, based on the positive feedback and suggestions of the study participants, developing an improved version of a specific PE program for older adults with autism is a worthwhile pursuit.

Lenders et al. [43] explored the effects of the "Me and Autism" program adapted for older adults with autism in a 6-month pretest-posttest follow-up design. The authors observed an increase in knowledge and acceptance of the diagnosis, with a strong and positive correlation between patients and proxies for knowledge. On the other hand, ambiguous results were observed on coping with the diagnosis, and no positive effects on psychological distress were found.

These programs are burdened by some limitations, such as the low sample size, self-reported questionnaires, and in some cases, scales that are not fully validated (for knowledge, coping, and acceptance). One study (Me and Autism) has no control group.

On the other hand, the PE programs presented have some strengths and future potential. In fact, few studies take into consideration autism in adulthood, often considered chronic or residual schizophrenics. Furthermore, the co-designed interventions represent a change of direction in the conceptualization of autism, no longer based on deficit constructs, but on the concept of neurodiversity. This concept appears fundamental to restoring dignity to the person with autism, in an attempt to accept and see the person's needs and talents and not, necessarily, the limitations of the disease.

Table 2. Psycho-educational Programs for Adults with Autism

Authors	PE programs	Main findings
Smith DaWalt et al. 2021 [41]	Working Together	- Adults experienced significant increases in meaningful activities and decreases in internalizing problems. - Although increases in work-related activities were not statistically significant. Differences from before to after the intervention indicated a clinically significant change.
Groenendijk et al. 2023 [42]	Based on Older and Wiser	- Authors observed neither intervention effects on primary outcome measures (discrepancy scores) nor the secondary outcome measures (mastery, self-efficacy, self-esteem, self-stigmatization, quality of life, and hope and future perspectives). - Despite co-designing the current intervention, the results were not promising.
Lenders et al. 2024 [43]	Me and autism	- An increase in knowledge and acceptance of the diagnosis was observed. - Ambiguous results were observed on coping with the diagnosis and no positive effects on psychological distress were found. - The feedback of participants and proxies about the psychoeducation program was largely positive.

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CONCLUSIONS

There are numerous definitions of psychoeducation in the literature, and they all have in common concepts of knowledge of the pathology, resilience, and quality of life. Psycho-educational interventions in autism depend on the age of the person and on the level of functioning. Psycho-educational programs for adults with autism are represented by "working together", "older and wiser", and "me and autism". Such programs are few and burdened by less-than-promising efficacy results. Future research with larger group samples and larger time scales is necessary to gain more insight into the effectiveness of the Psycho-educational program. These findings highlight the need for more research on adult intervention services, and particularly the need for family-focused supports.

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