

A Scoping Review of Education and Training Interventions in Autism Spectrum Disorder

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Conflicts of interest

None.

Funding: This work is part of a commission from the Interministerial Delegation for the National Autism Strategy within the broader landscape of neurodevelopmental disorders and the Directorate-General of Health / Sub-Directorate for Population Health and Chronic Disease Prevention (Paris, France), to write a report and recommendations on the integration of education on ASD for people living with ASD and their caregivers.

Abbreviations

ASD: Autism Spectrum Disorder

TPE: Therapeutic Patient Education

Keywords: Autism Spectrum Disorder, Patient Education as Topic, Empowerment, Counseling, Needs Assessment

Abstract

Objective: Autism Spectrum Disorder (ASD) is a chronic neurodevelopmental disorder. Living with ASD requires that individuals and parents develop skills in order to cope with daily life. Education interventions are recommended to support them. **This study aims to get an overview of education and training interventions in ASD.**

Methods: A scoping review of international literature was conducted.

Results: 43 articles were analyzed. Four main types of intervention stand out: support groups, parental training; psychoeducation; therapeutic patient education. However, the majority of publications is focused on the parents rather than on individuals living with ASD, and the needs assessments identified focused on general needs rather than educational needs.

Conclusion: While educational interventions for parents and individuals with ASD are now encouraged, considerable heterogeneity is observed. But this variety is not based on a reasoned approach to matching supply and needs. Future studies could focus more on the educational needs of individuals with ASD.

Practice Implications: Overview of education and training interventions in ASD help health care providers to better understand the strengths and limitations of their interventions.

1. Introduction

Autism Spectrum Disorder (ASD) affects 1% to 2.5% of children. It is a chronic neurodevelopmental disorder, whose prevalence has been steadily increasing over the past 30 years [1,2] and which is characterized by the combination of impairments in communication and social interactions, and the presence of restrictive, repetitive patterns of behavior and interests [3]. ASD can often come with other conditions, such as language impairment [4], Intellectual Development Disorder [5], epilepsy [6], psychiatric or neurodevelopmental disorders [7], involving complex care needs. Challenging behaviors are also frequently associated with ASD [8].

Parents play a central role in the care of their children with ASD, which subjects them to significant and repeated stressors related to the children's care and the difficulty to interact with them due to their disorder [9,10]. Parental stress in ASD is reportedly greater than that of parents with children with other neurodevelopmental disorders such as intellectual disabilities, Down syndrome, or language impairment [11,12]. Parents are also at greater risk of health problems such as anxiety or depression [13]. And, although everyone does not have the same capacity to face such challenges and manage life with a child with ASD, parents have to acquire complex knowledge in order to care for their children on a daily basis [9]. These difficulties can lead parents to feel that they lack educational skills and need support to develop them [14, 15].

Moreover, individuals with ASD who experience significant difficulties being autonomous (including those without intellectual disabilities) and who usually live in an environment in which decisions are made for them, may lack the skills to make choices about everyday activities such as choosing a meal or leisure activities [16]. As they grow up, children with ASD need to be supported to develop appropriate self-determination and life skills in order to live with their disorder [17].

Empowering parents and individuals with ASD is indeed one of the central objectives of education and training interventions delivered by the health care system. These interventions are designed to develop self-care and psychosocial skills in individuals and/or caregivers to enable them to best manage living with an illness or a disorder [18]. They are part of a framework to empower individuals and caregivers. Their effectiveness has been widely demonstrated in a variety of settings. They have beneficial effects on health status and the reduction of complications, and improve adherence to treatment, well-being and quality of life [19].

At present, education and training interventions in ASD include diverse and heterogeneous practices. They can be structured interventions or focused interventions, group or individual interventions, standardized or personalized, aimed at parents and/or at people with ASD, and they focus on fostering the acquisition of knowledge, various skills

and/or social skills, etc. [9,20,21]. While several studies highlight the effectiveness of education and training interventions in ASD [22,13], to our knowledge, no work classifies all types of education and training interventions available in the management of ASD by defining specific criteria, which would help determine their relevance to the needs or demands of the target audience. No work has been done to define or classify the educational needs of individuals with ASD, or of parents, that must be met to enable them to live independently with the disorder. However, the relevance of educational and training interventions depends on the extent to which they meet the beneficiaries' needs. Consequently, it also depends on the analysis of the reasoning and theoretical models that define the criteria for identifying and prioritizing these needs [23].

The aim of our study is to get an overview of the educational needs and the education and training interventions available in ASD, to classify them, define the specificities of each of the categories identified, and analyze the characteristics of the different types of interventions identified. The objective is to identify the appropriate methods available according to the needs of the individuals and their parents.

2. Method

A scoping review of international literature was conducted between February and April 2020 using the Medline, PsycINFO, and CINAHL databases with the following search terms: "*Patient education*" OR "*Self-management*" OR "*Self-Care*" OR "*Therapeutic Education*" OR "*Psychoeducation*" OR "*Health Education*" OR "*Empowerment*" OR "*Therapeutic Patient Education*" OR "*Education Needs*" (Title, abstract) AND "*Autism Spectrum Disorders*" (Title, abstract & MeSH). We also used the French translation of these terms: "*Education patient*" OR "*auto-soins*" OR "*Education thérapeutique*" OR "*Psycho-éducation*" OR "*Education santé*" OR "*Education thérapeutique du patient*" OR "*Besoins éducatifs*" (Title, abstract) AND "*Troubles du spectre de l'autisme*".

A scoping review is a type of literature search that is recommended for mapping the key concepts underpinning a research area and the main sources and types of evidence available, as well as for identifying potential gaps in the existing literature [24]. This method is advisable when the research question is related to a complex area or a topic that has not yet been studied extensively, such as in the case of the analysis of patient and/or caregiver education in ASD.

Publications were included in the analysis if they were (1) articles assessing the educational needs of people with ASD and/or their caregivers; (2) articles evaluating the process, impact, and/or effect of an educational intervention (patient education, psychoeducation, health education, empowerment, etc.) aimed at people with ASD and/or

their caregivers; (3) articles presenting an educational intervention (therapeutic patient education, psychoeducation, health education, empowerment, etc.) aimed at people with ASD and/or their caregivers; (4) or if they dated back to 2010 or more recently in order to include the most recent knowledge published on the subject.

Publications were excluded from the analysis if they were editorials or commentary articles, dealt with non-health related educational interventions or were not written in English or French.

A total of 336 articles were obtained by searching the cited databases. After reading the titles and abstracts of all these articles, 288 articles were excluded from the analysis as they did not meet the inclusion criteria mentioned above. 43 articles were deemed eligible for our study (Figure 1 - Flow chart). Four researchers (MM, CA, CR and XDLT) proceeded to read the abstracts of all articles identified and analyzed the eligible articles.

Patients' caregivers (n=2) were integrated in the steering committee (n=15) in order to validate the research plan. Patients' caregivers were members of associations of patients and caregivers in ASD. The steering committee was also composed of experts in ASD and patient education (health practitioners, psychologists, researchers and project leaders). One meeting was held before the study and another was held after the analysis of the results. The steering committee did not participate strictly in the analysis but gave its opinion on the study objectives and on the results to highlight.

3. Results

We will present the results of the study in two parts. First, the articles will be analyzed according to their characteristics (type of study, origin, etc.). Secondly, the content of the articles will be examined.

3.1. Characteristics of the studies

Eighteen papers are from North America (Canada and USA), 16 from Europe, 7 from Australia, 3 studies from Asia and 2 from South Africa. One article was written jointly by a French and a Canadian team.

We classified the articles according to the type of study, i.e., whether they are educational needs assessment studies, describe an educational intervention with individuals with ASD and/or their families, or evaluate an educational intervention with patients with ASD and/or their families (Table 1). This classification allows us to identify whether the study was done prior, during or after the educational intervention.

Among the 43 articles selected, there are:

- 33 articles evaluating educational interventions;
- 6 needs assessment articles;

- 4 articles describing educational interventions.

We also examined the type of educational interventions reported in the literature, depending on whether it was psychoeducation, therapeutic education, or another type of educational intervention. Thus, among the articles describing or evaluating interventions (37 articles in total):

- 20 publications discuss parental training or parent support interventions;
- 14 are about psychoeducation;
- 2 are about therapeutic education;
- And 1 is on both psychoeducation and parental training.

The vast majority of publications is therefore focused on the parents rather than on individuals living with ASD (39/43), as well as on the study or description of educational interventions (37/43) rather than on the analysis of the educational needs of individuals.

3.2. *Content of the articles*

Our analysis of the literature is divided into two parts: on the one hand, identifying the educational needs expressed by individuals living with ASD and/or their families and, on the other hand, identifying the structuring elements of educational interventions that have shown positive results.

3.2.1. **Educational needs**

Six publications study educational needs in ASD, five of which focus exclusively on the needs of parents and one on the needs expressed jointly by young people living with ASD and their parents (**Table 2**). The educational needs of people living with ASD are therefore poorly documented.

The five studies on parents were quantitative studies with data collected through self-administered questionnaires. The educational needs expressed are mainly related to the need for information. Accessing information on available specialized services [26,10], as well as on ASD [26] is therefore a clearly identified need. Gibson et al. [27] further highlight that the availability of information decreases as children age. In addition, the authors emphasize that parents rely heavily on local sources of information, which vary from one area to another, preferring them to nonlocal sources such as the Internet. Educational needs may also relate to decision-making. Cappé & Poirier [26] show that parents want more advice when making decisions about their children's future and want to be more involved in these decisions. Finally, educational needs may relate to the parents' ability to communicate with their children and to help them lead an appropriate social life

[28]. Casagrande and Ingersoll [29] show that, without resources, parents are often left to develop coping strategies on their own to manage living with their children's ASD, but would prefer having some support (support group, coaching program, etc.) if it existed. The authors emphasize the need for an educational relationship or partnership between parents and the health care team.

However, expressed needs may vary according to the gender of the parent (fathers are reportedly more concerned about the stigma associated with the child's disorder), the gender of the child with ASD (parents of girls are more concerned about the child's self-help skills, while parents of boys are more concerned about the child's social skills) [28], the socioeconomic status of the parents, or the geographic area where the parents live [11,28]. Cappé and Poirier [26] highlight significant disparities in the needs expressed by parents in France and Canada.

The one study conducted on the educational needs of people living with ASD themselves [16] is also the only qualitative study on educational needs that was identified in our scoping review. The results show that, in order to live independently, young people living with ASD need to be able to set concrete, everyday, short-term goals. This seems to be an essential skill for self-determination and in order to avoid living according to the objectives of third parties (family, caregivers, etc.)

3.2.2. Education and training interventions

Among all the interventions identified in our scoping review, four main types of intervention stand out: (1) support, self-help, and counseling groups, (2) parental training intervention; (3) psychoeducation; (4) therapeutic patient education (TPE).

In **Figure 2**, we mapped the key concepts of education and training interventions identified in the literature, focusing on the pedagogical differences between each other. While these different types of intervention have the same purpose (to promote autonomy through the development of self-management skills and/or improve the quality of life for people living with ASD and/or their families), they may differ in their means, methods and operational objectives.

(1) Support, self-help, and counseling groups:

Organized in group or individual sessions for parents of children living with ASD, these interventions consist of psychological and social support mainly focused on the parental experience of ASD [30]. These interventions are less structured pedagogically than the parent training interventions, psychoeducation, or therapeutic education interventions, favoring the free expression of participants without any particular objective of knowledge acquisition.

Such interventions are beneficial to enhance a sense of self-efficacy in parents of children with ASD and their coping skills [21,28].

(2) Parental training interventions:

Parenting interventions are the most common type of intervention reported in the literature. They aim to teach parents strategies for managing their children's disorders and promoting communication. These interventions are not based on a systematic assessment of the educational needs of parents or a biopsychosocial diagnosis of the children living with ASD and their families, and are therefore relatively standardized [31]. Parenting interventions are derived from behavioral approaches that focus on the acquisition of skills and are generally available for parents in the presence of their children in order that they experiment with communication strategies and techniques together [32].

Their benefits may be a decrease in parental stress levels [32–34], improved emotional regulation [34], or a reduction in challenging behaviors in children [33].

(3) Psychoeducation:

Psychoeducation can be defined as a didactic intervention that is designed to inform patients and their relatives about their disorder and aims to promote their coping abilities by providing them information, building skills, developing social support, and reducing isolation. Psychoeducational interventions are usually delivered in a group setting over several 30-minute to 1-hour sessions. They aim to provide information and knowledge to help manage life with ASD, as well as to enable a sharing of experience (between people with ASD or parents/families). A health professional usually facilitates the sessions, although other professionals (psychologists, educators, etc.) may be asked to facilitate or co-facilitate sessions [35].

Psychoeducation interventions may help decrease mothers' stress levels through the acquisition of new knowledge to help them care for their children [36,37]. A decrease in depressive symptoms as well as improved problem-solving skills are also observed in parents [37].

The results of the reviewed studies also show that psychoeducation leads to improved social functioning in adolescents [37] and children with ASD [38], improved knowledge about ASD [39] and their rights, better understanding of the children by the parents, and a better ability in the parents to promote the development and learning of their children [40].

(4) Therapeutic patient education (TPE):

Therapeutic patient education (TPE) can be defined as a process that enables people with a chronic condition and their families to acquire or retain skills they need to maintain a

healthy lifestyle, through a person-centered educational approach tailored to their unique needs [41]. Two articles [30, 42] examine a therapeutic education intervention. Both are written by the same team in France, which created a therapeutic patient education intervention focused on parents. Historically, therapeutic education is associated with the care of people living with a somatic pathology. It remains more commonly used in somatic rather than psychiatric pathologies, despite an increase in the latter field in recent years [41].

The TPE intervention developed by the French team aims to develop self-care and psychosocial skills within a framework centered on the beneficiaries' needs, structured in four phases: educational diagnosis, negotiating the educational contract, implementing educational actions, and evaluating these actions. This approach respects the structuring of therapeutic education interventions as framed in the French law about 'Hospital, Patients, Health, and Territories' ('HPST Law', article 84 of title III of act No. 2009-879), included in the French Public Health Code (art. L.1161-1 to L.1161-4). The program consists of seven group sessions that bring parents together and take place every two weeks for a total duration of three and a half months. The social validity assessment showed that the therapeutic patient education model could be transferred to supporting parents of children with ASD. TPE addresses a gap in practice for parents, that of learning how to parent a child with ASD [30].

This TPE intervention has shown positive preliminary results, including a positive impact on the quality of life and depressive symptoms in the parents participating in the intervention [42]. As indicated by the authors, these are preliminary results and should be taken with caution. However, they do support the hypothesis that offering a wide range of TPE interventions is appropriate in ASD.

The TPE intervention is only available to parents of children with ASD and does not provide direct interventions for individuals living with ASD.

4. Discussion and Conclusion

4.1. Discussion

Individuals with ASD and their families experience alterations in their daily lives that require the acquisition of many self-care and psychosocial coping skills. The lack of understanding of the disorder and cognitive functioning of individuals with ASD, the inability to find strategies to communicate with them, or the difficulties in managing any associated medical conditions can lead parents to experience very high levels of stress and prevent them from achieving a satisfactory level of development in their children, as well as impair their quality of life [11,12]. Similarly, as individuals with ASD grow up, they

need to exert autonomy in their daily lives in order to self-determine and make decisions about their own lives and futures [43]. While educational interventions for parents and individuals with ASD are now encouraged [9], considerable heterogeneity is observed in their use, and we do not know to what extent the interventions currently available meet the needs of the population.

Our scoping review shows that research on education and training interventions in ASD is predominantly parent centered. There is also a lack of information on the educational needs of people with ASD. In addition, the needs assessments identified in the literature focus on general needs (including access to care, support, etc.) and do not focus on educational needs, which are understood as needs that can be met through learning (understanding cognitive functioning related to ASD, knowing the recommended treatments, the treatments for co-occurring disorders, etc.) These studies do not allow us to draw conclusions about the specific skills that need to be developed to live well with ASD, or to parent a child with ASD.

Based on our results, it can be hypothesized that individuals with ASD and/or their parents need to be provided with more information about the resources available and need to develop the appropriate skills to maintain an acceptable social life (or that of the child), and to help develop independence skills in adulthood. However, the results are likely to remain modest in relation to the educational needs of people with ASD, who are required to adapt to challenges in every part of their lives [44]. Finally, the results obtained overwhelmingly come from quantitative studies. This means that the subjective experience of living with ASD and its associated special needs has still rarely been the subject of qualitative studies, although these help explore this aspect further and produce high-value knowledge [45].

The educational interventions available for parents include gradual interventions as part of an educational continuum: psychological support services (self-help, support, and counseling groups); parental training interventions aimed at developing complex parenting skills centered on the management of the disorder, such as managing the children's challenging behaviors, communicating with them, etc.; psychoeducational interventions aimed at providing information on the diagnosis of ASD and on existing treatments, as well as sharing experience between families; and therapeutic patient education interventions aimed at developing the appropriate skills to care for children on a daily basis according to the specific needs of each family. This wide range of support available can be understood in the light of the variety of situations experienced by each family. But this variety is not based on a reasoned approach to matching supply and needs. It depends solely on the capacity to provide support and not on an assessment of the parents' specific needs. The potential for a mismatch between the two is therefore significant [46].

Similarly, as noted by Derguy et al. [31], interventions that do not strictly belong to therapeutic education, but to psychoeducation or parent training, are not based on a systematic assessment of parents' educational needs. They are standardized and do not depend in their format or content on the audience to which they are aimed. Through this approach, this type of intervention may reduce the subject to a sick object [47] and consider that the individual holds a passive role in the care proposed [48,49], contrary to patient education, which is based on the learning process of patient autonomy, and on adapting the knowledge provided to each individual's specific needs [50]. In several French-speaking countries (France, Switzerland, etc.), such interventions are described as “therapeutic patient education”. The term “therapeutic” refers to the fact that they allow the individual to improve their confidence and self-sufficiency and to care for himself or herself and his or her family. Such interventions have multiple goals that include both supporting the patient/caregiver and providing them education or skills [51].

The analysis of health education provision addressed directly to people with ASD is still scarce in the scientific literature reviewed. One reason may be that ASD primarily affects children whose young age restricts their participation in training, or people with limited autonomy who are therefore unable to appropriate it. Yet it is recognized that people with ASD, including those with normal intelligence, suffer from a lack of autonomy in everyday decisions (choosing a meal, engaging in leisure activities, maintaining social relationships, etc.), which often leads them to be more dependent from their proxies [17]. The development of self-determination skills in youth with ASD before adulthood could improve their academic performances, employment rates, and access to independent housing [52]. The development of health skills could provide similar results for daily self-management. Understanding the learning process of autonomy for people with ASD and how the health system can support them is an important issue for future research on educational interventions in ASD. Individuals fall differently on the autism spectrum, resulting in a wide array of learning needs and abilities that are not shared by all individuals with ASD. The support of a theoretical framework that would conceptualize the necessary pedagogical adaptations would reinforce an educational approach centered on the uniqueness of each individual.

A limitation of our study is that it does not analyze gender inequalities. Indeed, training and education programs were mainly offered to mothers although they are called “parents programs”. Most of studies considered in our analysis exclude fathers or they are just shaping a small number of the sample. It could be an impeding factor in generalizing the findings. Another limitation concerns the educational intervention of the “therapeutic patient education” (TPE) type highlighted in our results, which is only developed in France where it is supported by the public authorities. We have considered TPE in this

international review because it provides a new intervention strategy that could be transferred to other countries. Finally, we didn't analyze the conformity to gold standards of the methods used in the articles. Considering that our aim was to have an overview of education interventions in ASD, we didn't analyze the study methods that would be relevant in a systematic review to evaluate the effectiveness of education interventions in ASD.

4.2. Conclusion

The educational support or intervention offered by the health care system to people with an ASD or their caregivers are very heterogeneous. They range from occasional psychological support to a structured and personalized intervention tailored to the needs of the beneficiaries. One challenge is that the educational needs of individuals with ASD and those of their caregivers are still insufficiently documented. The production of knowledge on educational needs in ASD is therefore an issue for future research and the implementation of appropriate interventions. For this purpose, research could be more centered on the actual experience of people with ASD and involve them more. Furthermore, research could include health practitioners such as healthcare providers, psychologists, and therapists in order to identify the educational needs of younger children as well as parents.

4.3. Practice Implications

Our scoping review of education and training interventions in ASD help healthcare providers to differentiate the various interventions according to their theoretical framework, to identify their strengths and weaknesses and to adapt their objectives according to the target population. Our results should facilitate the reflexive practices of healthcare professionals on their own current educational and training interventions in ASD, as well as the efficient choice of a specific approach.

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Figure 1: Prisma Flow Diagram, from Moher et al. [25]

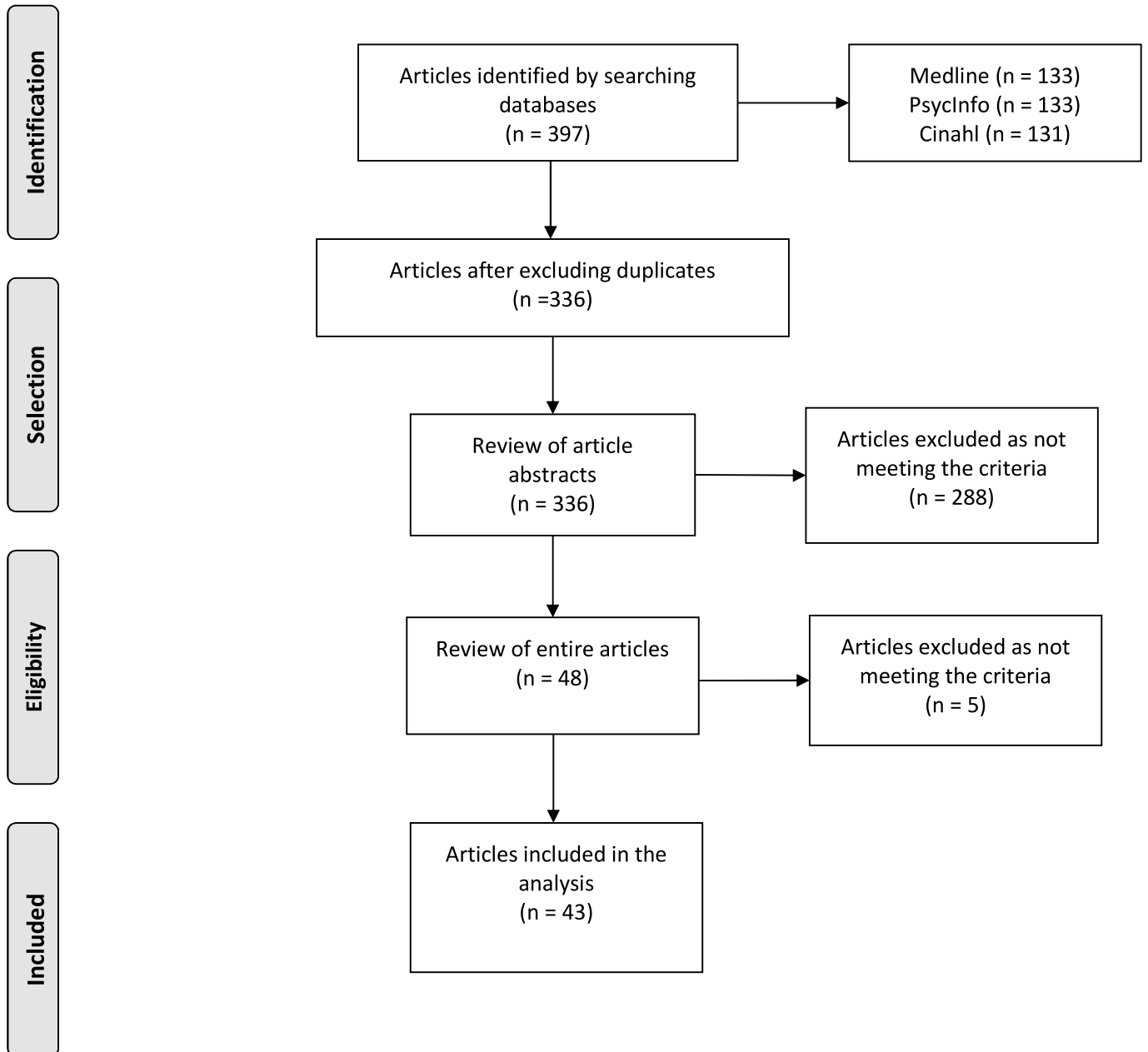


Table 1: Characteristics of included studies

Authors	Country	Type of article	Objectives of the article	Type of educational intervention
Connan, 2019 [35]	France	Description of intervention	Describe a psychoeducational program for adults with autism without intellectual impairment	Psychoeducation
Sankey et al., 2019 [53]	France	Evaluation of intervention	Evaluation of the social validity of the programs (3 programs for parents in France and/or Quebec) from the parents' perspective	Parental support / training intervention
Palmer et al., 2019 [54]	United Kingdom	Evaluation of intervention	Test: 1) the acceptability of the research procedures (recruitment, retention, suitability of measures); 2) the parental acceptability of EarlyBird (attendance, views of the program, perceived changes); and 3) the facilitators acceptability of EarlyBird (fidelity, views of the program, perceived changes)	Psychoeducation
Schrott et al., 2019 [55]	Germany	Evaluation of intervention	Explore the effectiveness of the Stepping Stones Triple P (SSTP) group parenting program as an additional intervention in the treatment of ASD	Parental support / training intervention
Zhou et al., 2019 [56]	China	Evaluation of intervention	Design, implement and evaluate family-focused psychoeducational therapy (FFPT) for autism spectrum disorder (ASD) family	Psychoeducation
Backman et al., 2018 [57]	Sweden	Evaluation of intervention	Evaluate the new Internet-delivered psychoeducation for adolescents and young adults aged 16-25 years with ASD in the normative IQ range: SCOPE (Spectrum COmputerized PsychoEducation)	Psychoeducation (digital)
Bishop, 2018 [58]	United Kingdom	Evaluation of intervention	Present the first evaluation of the Autism, Emotional Well-being and Adolescence (AEWA) psychoeducation program for families of children with autism. The program aims to develop parents' understanding of emotional well-being and how to promote it, with a particular focus on adolescence.	Psychoeducation

Connolly et al., 2018 [59]	USA	Description of intervention	Describe the development and methodology of a new psychosocial intervention for children with high functioning autism spectrum disorder.	Psychoeducation
DaWalt et al., 2018 [37]	USA	Evaluation of intervention	Provide a preliminary assessment of a multi-family group psychoeducation program for families of individuals with ASD during the transition to adulthood	Psychoeducation
Hodgetts et al., 2018 [16]	Canada	Needs assessment	Examine perceptions and barriers to autonomous goal setting as perceived by: (1) adolescents with autism spectrum disorder, (2) parents of adolescents with autism spectrum disorder, and (3) interdisciplinary professionals	Not specified
Iadarola et al. 2018 [36]	USA	Evaluation of intervention	Compare the impact of parent training <i>versus</i> psychoeducation on the following indicators: Parenting Stress Index (PSI), Parent Sense of Competence (PSOC), and Caregiver Strain Questionnaire (CGSQ).	Parental support / training intervention <i>versus</i> psychoeducation
Ilg et al., 2018 [38]	France	Evaluation of intervention	This study aims to evaluate the social validity and efficacy of a new parenting skills training program (PSTP). "ABC of children with autism spectrum disorder: Parents in action!" is a psychoeducational program of 12 two-hour sessions and 3 home visits for families of young children up to the age of 7 with autism spectrum disorder (ASD) and developmental delay.	Psychoeducation
Kuravackel et al., 2017 [33]	USA	Evaluation of intervention	Evaluate the effectiveness of COMPASS, a training and support program for parents of children with ASD. COMPASS for Hope (C-HOPE) is an 8-week parent intervention program that was developed with the option of telehealth or face-to-face delivery	Parental support / training intervention
Mazzucchelli et al., 2018 [60]	Australia	Evaluation of intervention	Examine the feasibility of Building Bridges Triple P (BBTP), an eight-week (11.5 hours) parenting program specifically targeted to the needs of parents of adolescents with a developmental disability.	Parental support / training intervention
Mukhtar et al., 2018 [61]	Indonesia	Evaluation of intervention	Measure the impact of the psychoeducation group on parenting stress levels of parents who raise a child with ASD	Psychoeducation

Zand et al., 2018 [62]	USA	Evaluation of intervention	Evaluate a pilot project of a brief positive parenting program on children newly diagnosed with autism spectrum disorder (a four-session, manualized, positive parenting program on 21 parents of newly diagnosed children aged 2-12, using a mixed methods design)	Parental support / training intervention
Casagrande and Ingersoll, 2017 [29]	USA	Needs assessment	To better understand the contributions of empowerment and parent-professional partnerships to address disparities in families of children with ASD	Parental support / training intervention
Derguy et al., 2017 [30]	France	Evaluation of intervention	Present the methodological steps to develop a TPE program for parents of children with ASD and test its social validity. (ETAP program)	Therapeutic education
Derguy et al., 2018 [42]	France	Evaluation of intervention	Test the effectiveness of the ETAP program on the quality of life, and anxiety and depression symptoms of parents of children with ASD	Therapeutic education
Gibson et al., 2017 [27]	USA	Needs assessment	Investigate the information source preferences of parents of individuals with ASD	Not specified
Hemdi et al., 2017 [63]	United Kingdom (sample study in Saudi Arabia)	Evaluation of intervention	Evaluate the effectiveness of a psychoeducation intervention developed to support mothers of children with ASD in the Kingdom of Saudi Arabia	Psychoeducation
Ilg et al., 2017 [64]	France	Evaluation of intervention	Evaluate the "ABC of children with autism spectrum disorder: Parents in action!" program to determine its effectiveness and social validity	Psychoeducation
Magaña et al. 2017 [65]	USA	Evaluation of intervention	Pilot study to examine the feasibility, acceptability and preliminary outcomes of a culturally derived intervention, Parents Taking Action, for 19 Spanish-speaking mothers of children with ASD	Psychoeducation

Cappe et Poirier, 2016 [26]	France and Canada	Needs assessment	Understand the needs of families of children with ASD	Not specified
Dababnah & Parish, 2016 [65]	USA	Evaluation of intervention	Assess the feasibility of implementing an existing empirical supported practice, The Incredible Years, tailored to parents of young children with autism spectrum disorder. (Parents raising preschoolers (ages 3-6) with autism spectrum disorder (N = 17) participated in a 15-week pilot study of the intervention)	Parental support / training intervention
Dababnah & Parish, 2016 [66]	USA	Evaluation of intervention	Report on the acceptability and outcomes of an evaluation of an empirically supported practice, The Incredible Years, tailored to parents of children with ASD	Parental support / training intervention
Rattaz et al., 2016 [32]	France	Evaluation of intervention	Evaluate the benefits of participation in a parenting group in terms of quality of life and stress in parents whose child has recently been diagnosed with ASD	Parental support / training intervention
Gordon al., 2015 [39]	United Kingdom	Evaluation of intervention	Evaluate PEGASUS (psychoeducation group for autism spectrum understanding and support), a group psychoeducational program aiming to enhance the self-awareness of young people with ASD by teaching them about their diagnosis	Psychoeducation
Al-Khalaf et al., 2014 [67]	Australia (sample study in Jordan)	Evaluation of intervention	Determine whether the implementation of an education program for mothers of children with autism spectrum disorder in Jordan increased mothers' understanding of their child's behavior, improved the mothers' coping skills, and reduced their stress levels	Parental support / training intervention
Ji et al., 2014 [68]	China	Evaluation of intervention	Determine the effectiveness of a multidisciplinary parent education program focused on improving health-related quality of life (HRQOL) for caregivers of children with ASD	Parental support / training intervention
McAleese, al., 2014 [69]	Ireland	Evaluation of intervention	Review and evaluate a three-session psychoeducational and psychotherapeutic group program for parents of children with ASD	Psychoeducation

Tellegen & Sanders, 2014 [70]	Australia	Evaluation of intervention	Evaluate the efficacy of Stepping Stones Triple P, a brief individualized parenting program, in a sample of parents of children with ASD	Parenting program
Farmer & Reupert 2013 [71]	Australia	Evaluation of intervention	Evaluate a six-session program provided to parents of children with autism in rural Australia. The program was designed to improve parents' knowledge and understanding of autism, improve their confidence in managing their child and decrease parental anxiety	Parental support / training intervention
Samadi et al., 2013 [34]	United Kingdom (sample study in Iran)	Evaluation of intervention	Evaluate an intervention for parents on emotional coping strategies and parental knowledge about ASD	Parental support / training intervention
Sénéchal, et al., 2013 [72]	Canada	Evaluation of intervention	Evaluation of a parent education program	Parental support / training intervention
Brown et al., 2012 [11]	Canada	Needs assessment	Assess the needs of parents regarding decision-making regarding the allocation of limited resources and other unmet needs	Not specified
Murray et al., 2012 [73]	Canada	Description of intervention	Describe the project planning phase, implementation phase and evaluation phase (i.e., lessons learned)	Parental support / training intervention
Banach et al., 2010 [21]	USA	Evaluation of intervention	Pilot study to measure the effects of a six-session, co-facilitated, support group on the advocacy skills and self-efficacy of parents coping with a child's diagnosis	Parental support / training intervention
Papageorgiou, & Kalyva, 2010 [28]	Greece	Needs assessment	Explore the self-reported needs and expectations that parents express according to their gender and education, and according to the age and gender of their child with ASD	Parental support / training intervention
Gutstein, 2009 [74]	USA	Description of intervention	Review Relationship Development Intervention's theoretical underpinnings, current methodology and preliminary research results	Parental support / training intervention
Whittingham et al., 2009 [75]	Australia	Evaluation of intervention	Examine the qualitative data arising from the RCT as well as the evaluation of the particular parenting strategies that the parents found helpful	Parental support / training intervention

Whittingham et al., 2009 [76]	Australia	Evaluation of intervention	Assess the role of parental attributions in predicting treatment outcome	Parental support / training intervention
Whittingham et al., 2009 [77]	Australia	Evaluation of intervention	Evaluate the Stepping Stones program with the ASD population	Parental support / training intervention

Table 2. Studies on the educational needs of persons with ASD and parents of child with ASD

Study	Data collection	Population	Educational needs identified
Hodgetts et al., 2018 [16]	Qualitative	Young people with ASD, parents and healthcare providers	- Being able to formulate goals regarding their daily lives independently
Casagrande and Ingersoll, 2017 [29]	Quantitative	Parents	- Having a partnership relation with the caregivers
Gibson et al., 2017 [27]	Quantitative	Parents	- Obtaining local information that is available and age-appropriate to their child
Cappe and Poirier, 2014 [26]	Quantitative	Parents	- Obtaining information on the specialized services available - Getting advice - Getting information about ASD - Being involved in decisions concerning their child
Brown et al., 2012 [11]	Quantitative	Parents	- Obtaining information on the specialized services available
Papageorgiou and Kalyva, 2010 [28]	Quantitative	Parents	- Being able to communicate with their child - Being able to offer a social life to their child

Figure 2: Map of Education and Training Interventions in Autism Spectrum Disorder

