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THESIS SUMMARY

ATTITUDES, KNOWLEDGE AND COMMUNICATION ABOUT SEXUAL HEALTH EDUCATION AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD)

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STRUCTURE OF THE DOCTORAL RESEARCH PROJECT

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1. CHAPTER I.: THEORETICAL FRAMEWORK

1.1 General Framework and Introduction

Sexual Health Education (SHE) is one of the most important and challenging issues in the context of disability, as it can affect the quality of life of people with special needs, their families and other members of society in terms of perceptions, attitudes and behaviours. HES is a very difficult topic worldwide in terms of education and research on various issues. Several individual and social factors should be considered when implementing a sexuality education programme for people with autism spectrum disorders. An important factor is represented by the role of parents as primary educators, their attitudes and knowledge towards sex education.

The main aim of this PhD dissertation is to identify the attitudes and needs of parents of children with clinically diagnosed autistic spectrum disorders in relation to their knowledge and attutuded toward sexual health education. Another aims are the following ones: to investigate parental attitudes and acquired knowledge about sexuality in relation to a number of psychological constructs, such as parental distress and parental self-efficacy, and to implement and test a curriculum material of an education programme on SHE for parents of children and adolescents diagnosed with ASD.

1.2 Current definition, etiology and prevalence of autism spectrum disorders

Autism Spectrum Disorder is defined as a developmental disorder of the nervous system with persistent challenges in social communication, restricted interests and repetitive behaviours (APA, 2013). According to DSM V (APA, 2013), ASD is included in the category of neurodevelopmental disorders. According to DSM V, this disorder is manifested by: persistent deficits in communication and social interaction across contexts; deficits in social reciprocity; nonverbal communicative behaviours used for social interaction; and skills in developing, maintaining, and understanding relationships (APA, 2013, p. 31). Currently used diagnostic systems describe autism as a spectrum disorder, with subtypes described according to the degree of communication and social interaction, the ability to plan and organise behaviour, and the presence of repetitive and stereotyped behaviours (APA, 2013).In this study, all children whose

parents were included in the study had a clinical diagnosis of ASD, performed by a professional specialised in paediatric psychiatry.

Both genetic and non-genetic factors (such as environmental factors) are involved in the aetiology of ASD (Sauer et al. 2021). In the literature, the majority of studies conducted indicate that ASD is a complex genetic disorder with high heritability (Bailey et al. 1995; Spiegelman et al. 2011; Sauer et al. 2021). The pathogenesis of ASD is multifactorial, but the exact pathomechanism has not yet been described. Heterogeneous causes may play a very important role. For example, autism has been found to be a risk factor in the presence of umbilical cord complications, low Apgar scores, nutritional difficulties, and in cases of blood type conflict between parents (Bailey et al., 1995; Gardener et al., 2011).

There are several studies showing that siblings of offspring with autism have a higher incidence of autism than the general population (Oonoff et al., 2011; White et al., 2013; Genovese et al., 2020). The Simons Foundation Autism Research Initiative gene database lists 1000 genes associated with ASD (Sauer et al., 2021). Non-genetic factors implicated in the aetiology of ASD are: parental age (as older age may contribute to genetic mutations), maternal nutritional and metabolic status (micronutrient excess or deficiency, folic acid deficiency), various infections during pregnancy, prenatal stress, prenatal and perinatal exposure to certain toxins (perinatal zinc metal deficiency, congenital infections, etc.) (Hagmeyer et al., 2015, Sauer et al., 2021; Wu et al., 2017). A recent meta-analysis found that perinatal drug use was positively associated with the risk of ASD in children. The etiology and pathogenic mechanisms of autism are not fully understood, but different categories of factors, such as genetic and environmental, are known to be involved (Modabbernie et al., 2017). Epidemiologically, the estimated global prevalence of ASD is 1 in 100 children (Zeidan et al., 2022). In the meta-analysis by Zeidan et al. (2022), which included 71 studies and 99 estimates, the global mean prevalence of ASD is 100/10,000 (range: 1.09/10,000 to 436.0/10,000).

1.3 Sexual development and behaviour in children and young people with ASD

Sexual development, like every aspect of human development, begins at birth and is a complex process involving sexuality in relation to self and others. The World Health Organization defines sexuality as "a central aspect of being human throughout life, encompassing gender, gender

identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors. (WHO, 2006). As the WHO (2006) definition indicates, sexuality encompasses a wide range of physical, emotional and social interactions. It includes sexual beliefs, attitudes, knowledge, values and behaviours, and is related to the anatomy, physiology and biochemistry of the sexual response system. Sexuality includes thoughts, feelings, behaviours, relationships, roles, identity and personality (Travers, 2010).

Sexual development is a complex process involving sexuality towards oneself and others. This process is often used in normal developmental contexts; however, people with developmental disabilities go through sexual stages as they physically mature. This concept can be difficult for some care providers to accept as they tend to view people with developmental disabilities as perpetual children (Ballas, 2012). The overall problematic factor for people with ASD to develop a normative sexual identity, sexual orientation and sexual behaviour is social disability, which in turn affects the person's opportunity and availability for romantic and intimate relationships (McPartland, 2012). Current literature suggests that the majority of people with ASD have a clear interest in sexuality and intimate relationships and engage in sexual behaviours (Dewinter et al., 2013; Dewinter et al., 2017), but due to the behavioural characteristics of people with ASD (e.g. difficulties in understanding and interpreting non-verbal behaviours and emotions), sexual experience and expression may be negatively affected.

The sexual development of children with ASD may differ from the sexual development of other people; very often they do not receive comprehensive sex education, which leads to more barriers in their sexual development (Pecora et al., 2020).

Studies in the literature show that most people with ASD engage in solitary sexual behaviour and masturbation is the most common form of sexual behaviour for them (Chandra et al., 2011, cited by Pecora et al., 2020). Sexual interest is often expressed through masturbation, which may occur in the presence of others and may take a pathological form, such as self-stimulation using foreign objects, hypermasturbation, undressing, or initiating unwanted physical contact with

others (Hellemans, 2007). In addition to problems with sexual behaviour, other problems may occur, such as paraphilias (Stokes et al., 2017; Kellaher, 2015) or fetishism (Schöttle et al., 2017 cited in Peroca, 2020). Griffin-Shelley (1994) examined the relationship between the frequency of hypersexual behaviours and the extent of autistic symptoms. The results of the study show that the more severe the autism, the more likely compulsive sexual behaviour is to occur. Some studies have reported that people with ASD may engage in violent sexual behaviour or inappropriate behaviour such as masturbation in a public place (Ray et al., 2004; Alley, 2016). All of these issues may contribute to the risk of people with ASD, particularly males, coming into contact with the justice system for sexual behaviours that are considered problematic (Alley et al., 2016). Another important aspect highlighting the importance of sexuality education in ASD is provided by studies investigating the risk of sexual abuse in people with ASD (Brown-Lavoie et al., 2013; Pecora et al., 2019). Pecora et al (2020) found that individuals diagnosed with ASD were two to three times more likely than typically developing individuals to have experienced some form of sexual abuse, such as unwanted sexual contact or sexual coercion. This suggests that sex and relationship education is very important for people with ASD, regardless of their level of functioning, and can prevent a range of problems in everyday life.

1.4 Sexual health and sexual health education

The Sexuality Information and Education Council of the United States (SIECUS, 2009) defines sexuality education as a lifelong process of acquiring information and forming attitudes, beliefs and values. It includes: sexual development, sexual health, interpersonal relationships, affection, emotions and self-thoughts, intimacy, body image and gender roles (SIECUS, 2009). Thus, sexuality education is not just about the act of sex itself, but encompasses many areas and plays an important role in community integration.

In the world of educational science, health behaviour promotion/health education has always had a peripheral position, within which sex education has a similar position. Sex education is defined as "a curriculum-based process of teaching and learning about the cognitive, emotional, physical and social aspects of sexuality. It aims to equip children and young people with the knowledge, skills, attitudes and values that will help them to achieve their health, well-being and dignity; to develop respectful social and sexual relationships; to consider how their choices affect their own

and others' well-being; and to understand and ensure the protection of their rights throughout their lives" (UNESCO, 2018, p.16).

Sexual health education covers a variety of topics and, with the support of parents and the community, can help young people. Firstly, sex education can help avoid the negative consequences of some sexual activities, such as the increasing number of teenage pregnancies in Romania. According to a study by UNICEF (2013), adolescents are at higher risk of sexually transmitted infections than adults. Sex education teaches them how to prevent such consequences. Young people need to be taught effective ways of communicating in relationships, conflict management and strategies for avoiding or ending abusive relationships. In addition, sexuality education can help young people identify factors that contribute to a positive or negative self-image (Bridges & Hauser, 2014). Another issue related to sexual health education is the meaning of sexual violence. Sexual health education can also help young people to accept, respect and treat with dignity those around them, regardless of their sexual orientation (Bridges & Hauser, 2014). Sexuality education can therefore play an important role in young people's lives as a way of helping and supporting them to achieve optimal physical, emotional and moral development.

1.5 Theories underpinning the approach to sexuality education from a psychosocial and learning perspective.

Lev Vygotsky (1978) highlights the crucial role of social interaction in an individual's cognitive development. The author asserts that learning is a universal and necessary aspect of the culturally organized development process, particularly in terms of human psychological function. Vygotsky argues that a significant portion of children's learning takes place through social interaction with their teacher/educator, who models their behaviour and provides verbal instructions; this is known as *cooperative dialogue* (Vygotsky, 1978, p.90).

Sex education and education for healthy relationships can be better understood through the lens of sociocultural theory. Our cognitions about the world are shaped by the environment we live in and the information and knowledge we acquire from adults. During childhood, parents introduce children to important aspects of their environment, such as healthy relationships, intimacy, and reproduction, using age-appropriate language. This knowledge is then applied in their daily lives

and further developed with new information. According to the **sociocultural theory**, the development of children is shaped not only by their environment, but also by their influences on the environment.

Ecological systems theory (Bronfenbrenner & Morris, 1998) outlines five interconnected systems that impact human development: the microsystem, mesosystem, exosystem, macrosystem, and the chronosystem. The theory emphasizes the importance of examining the individual learner and their environment, as well as the relationships between systems. This is because there is an interconnectedness between the five systems, and how one system influences human development is highly dependent on its relationship to the others (Evans, 2020). The Bioecological Model of Human Development (Bronfenbrenner and Morris, 2007, cited in Alaluf, 2017) suggests that the cognitive, moral, and relational development of individuals is directly influenced by the different environments in which they participate. The model by Bronfenbrenner and Morris (2007) provides an overview of multilateral interactions in family, school, and community environments and their influence on an individual's development. The Bioecological Model of Human Development (Bronfenbrenner and Morris, 2007) offers a valuable perspective for comprehending the influence of family, school, and cultural environments on parental attitudes and practices concerning comprehensive sexuality education for children with special education needs.

To adequately function in society, it is necessary to understand the emotions of other people, intentions, knowledge, and beliefs (Rosello et al., 2020). Deficits in Theory of Mind (ToM), such as mind-reading skills, can partially explain the social deficits observed in individuals with Autism Spectrum Disorder (ASD). The concept of ToM was introduced by Premack and Woodruff (1978), and since then, numerous studies have explored its development. The initial studies aimed to comprehend how children acquire mental state representations, such as beliefs, desires, and intentions, of others, which enables the explanation and prediction of behaviour (Wimmer et al., 1983). To distinguish between beliefs and reality, Wimmer and Perner (1983) developed the False Belief Task, a test. The results of this test indicate that Theory of Mind (ToM) typically develops around the age of four in children with typical development (Wimmer et al.). It has been widely discussed in the literature that ToM deficits are highly prevalent in individuals with Autism Spectrum Disorder (ASD) (Baroh-Cohen et al., 1985), a

neurodevelopmental disorder that impairs verbal and nonverbal communication, social interaction, repetitive behaviors, and restricted interests (APA, 2013). Several studies in recent years have investigated Theory of Mind (ToM) in individuals with autism spectrum disorders (ASD) (Steele et al., 2003; Senju, 2012; Kimhi et al., 2014; Schneider et al., 2013). These studies confirm the presence of ToM deficits in individuals with ASD. In daily social situations, we are expected to intuitively understand what is happening and react spontaneously to various events. For example, if we see an acquaintance on the street, we know that we should greet them, even if it was not initially planned. The absence of Theory of Mind (ToM) can result in difficulties in many areas necessary for appropriate individual functioning, as ever-changing social and emotional inputs require rapid, immediate, parallel processing of information (Bauminger-Zviely, 2013). Such difficulties can manifest as early as preschool age, particularly in symbolic play, leading to challenges in social interactions.

Transformative learning theory (Mezirow, 1996) is employed to describe how parents acquire new knowledge, including knowledge for their children's sex education. The theory views learners as active participants in the learning process, rather than passive recipients of information from educators. It emphasises the importance of critical reflection and the examination of assumptions and beliefs. Mezirow (2000) argues that transformative learning can lead to significant personal and social change. Understanding how parents develop their knowledge and attitudes towards sex education can aid in the development and implementation of sex education programmes for their children. The use of transformative learning theory is applicable when implementing parenting programmes, where parents are active participants and can share their experiences and relationships with their children. This information can be incorporated into parenting programmes. Mezirow's transformative learning theory suggests that individuals have a responsibility to exercise their right to learn as adults. Parenting programmes can be developed and delivered with the help of a group leader, such as a psychologist, psychoeducator, teacher, or family doctor, who demonstrates empathy and trust in the learner and works with them in an open and non-judgmental way (Tennant, 2006).

The **bio-psycho-social model** (Engel, 1977) explains the physical and mental health of children with special educational needs as being influenced by biological, psychological, and environmental factors. The **family-centered care model** (Arango, 2011, cited in Carrigon et al.,

2021) is a model based on the bio-psycho-social approach that describes the medical and social care of individuals with ASD. This model highlights the importance of involving both the family and professional community in the decision-making process regarding the health and well-being of patients with special needs. It promotes a respectful partnership between families and professionals, including doctors, psychologists, and psychoeducators. In this model, parents of children with ESC are considered key decision-makers in their children's care (Carrigon et al., 2021). The biopsychosocial model of family-centered care is considered an international standard for describing and understanding health and disability intervention outcomes (Carrington et al., 2021). However, some researchers have noted the need for clearer definition and operationalization of the model (Shields, 2015; Kuo et al., 2012).

1.6 Parents' Attitudes towards and Communication with Children's Sexual Education

The responsibility for sex education of adolescents with autism spectrum disorders primarily falls on parents. However, parents often report a lack of professional and material support in this regard (Nichols & Blakeley-Smith, 2009; Melissa, 2016; Ballan, 2012). Ballan's (2012) research revealed that parents acknowledged their primary responsibility for providing sex education to their children and expressed the need for resources to support them in this role. All parents in this study agreed that some level of sex education was necessary and important for their children, although the extent to which they introduced sexual information varied. The parents demonstrated an understanding of their children's learning styles and recommended the use of technology interfaces with engaging displays and individualized content for future interventions (Ballan, 2012). Nichols and Blakeley-Smith (2009) conducted research using focus groups, with 21 parents (20 mothers and 1 father) participating. Parents in all groups acknowledged that people generally associate sexuality and disability negatively and fearfully for people with disabilities, rather than the positive association that occurs for neurotypical individuals (Nichols & Blakeley-Smith, 2009).

1.7 Parental Sex Education Programmes in Romania

Due to the lack of scientific literature on parental sex education programmes in Romania, it is difficult to describe or analyse the specificity and effectiveness of these programmes, if they exist. This PhD work aims to address this knowledge gap and identify and examine relevant

psychological factors that contribute to the effectiveness of future parenting sex education programmes in Romania. The literature search conducted for this research did not identify any studies describing or evaluating any parenting sex education programmes for parents and young people with special needs in Romania. Only studies on parental needs for sex education of children and adolescents in Romania were found (e.g. Pop & Rusu, 2017).

1.8 Objectives of the PhD thesis

- STUDY I.: The aim of this PhD thesis is to identify the attitudes and needs towards sexual health education among parents of children with clinically diagnosed ASD through a qualitative study. The aim of this study is to determine the level of sexual health education readiness among parents of children clinically diagnosed with ASD.
- STUDY II.: The second major objectives is a quantitative study that validates the Attitudes Toward Sexuality scale (Fisher and Hall, 1988) and the Attitudes about Sexuality for People with Disabilities scale (Porat, 2009) from the Reuth Open Door - IFPA's (Israel Family Planning Association) questionnaire package. The study focuses on linguistic and psychometric validation. The aim of this research is to translate and conduct a psychometric investigation of two instruments for Romanian and Hungarian speakers. These instruments will be used to assess parents with children who have been clinically diagnosed with ASD.
- STUDY III: Quantitative study - Predictors of Parental Attitudes towards Sex Education of People with Disabilities. The objective of this research is to identify associations between parental self-efficacy, parental sexuality-related knowledge, attitudes towards sexuality, and parental stress using a quantitative methodological approach. The study aims to determine whether these factors predict parental attitudes towards sex education for people with disabilities.
- STUDY IV: Development and Pre-Testing of a Parenting Curriculum for Sexual Health Education for Children with Autism Spectrum Diagnosis. This qualitative study aims to: Develop curriculum content based on consultations with parents of children with ASD. Improve parental knowledge about the sexual development of children with ASD and sexually transmitted infections. Encourage parents to talk about sexuality with their

children with ASD. Provide a guide for parents to use in providing sex education for children with ASD.

2 CHAPTER II: RESEARCH METHODOLOGY

2.1 STUDY I. Identifying through a qualitative approach the attitudes and needs towards sexual health education among parents of children with clinically diagnosed ASD

2.1.1 Introduction and objectives of the study

Sex education for individuals with special educational needs (SEN) is a complex topic for parents and others in the social network. Nowadays, psychosexual development of children is problematic because they often receive information from digital media, such as pornographic websites or advertisements, rather than from their micro-social environment, such as parents or teachers. An important aspect of providing sexual health education for individuals with ASD is the role of parents as primary educators. This study aims to identify the attitudes and needs of parents of children diagnosed with ASD towards sexual health education through a qualitative approach using thematic content analysis.

The study's overall objectives are: O1) to determine the level of sexual health education readiness of parents with children diagnosed with ASD, and O2) to identify the attitudes and needs of parents with children diagnosed with ASD towards sexual health education in the family. The aim of this study is to identify the level of sexual health education readiness and the attitudes and needs of parents with children diagnosed with Autism Spectrum Disorder (ASD) towards sexual health education within the family. Two objectives have been identified: O1) to determine the level of sexual health education readiness of parents with children diagnosed with ASD, and O2) to identify the attitudes and needs of parents with children diagnosed with ASD towards sexual health education in the family. O1) to determine the level of sexual health education readiness of parents with children diagnosed with ASD, and O2) to identify the attitudes and needs of parents with children diagnosed with ASD towards sexual health education in the family.

2.1.2 Research Questions

In line with the general objectives, this study formulated research questions for the purpose of conducting qualitative content analysis:

1. How do parents of children diagnosed with ASD react when discussing sexuality with their children?

2. How do parents of children diagnosed with ASD react when discussing sexuality with their children?

3. What are the SHE needs of parents with clinically diagnosed ASD children?

4. How do these parents imagine formal sexual health education for their children?

5. What recommendations do they have for sex education for children with ASD?

6. Why do parents believe that sex education is important for their children?

2.1.3 Research Design

The study employed a qualitative research design and was exploratory in nature. The data was analysed qualitatively, following the steps outlined in the content analysis guide presented by Erlingsson and Brysiewicz (2017), which involved structuring content and identifying themes, codes, and code categories within themes.

2.1.4 Study Participants

Nineteen parents with children clinically diagnosed with autism spectrum disorders participated in the study. The parents hailed from various counties in Romania, including Bucharest, Brasov, Cluj, Covasna, and Iasi. Figure 2 presents the demographic data of the parents.

2.1.5 Procedure

This study was conducted using data collected online between October 2020 and January 2021 on the Google Forms platform from 19 adult participants who provided all requested information. The sampling method used was convenience sampling, obtained through self-selection using the 'chain' or 'snowball' method (Clark-Carter, 2010), and with the assistance of social media platforms, online groups dedicated to parents, and by distributing the advertisement to relevant non-governmental organizations (such as the Autism Association Transilvania Cluj-

Napoca and the Crystal Children Association Brasov). The study only included adult respondents who were parents of children diagnosed with ASD (aged < 18 years).

Participants were invited to take part in a study on sexuality and sexual education in Romania for children with ASD via electronic means (with online connection). By clicking on a link, participants could choose whether or not to take part in the study after reading a brief description of its nature and the safety and anonymity conditions that the authors have committed to providing for the data and information provided by participants. Informed consent to participate in the data collection was the parents' choice to choose to participate further in the study after reading this information. Parents were provided with an email address, created for the purpose of this study, at which they could contact the authors of this study for any additional questions or clarification.

2.1.6 Instruments

In this research, a questionnaire developed by the author of the PhD thesis based on the literature and in consultation with the coordinating teacher was used to identify parents' attitudes and knowledge and needs. In this questionnaire, a series of specific questions covering the research questions were formulated (Appendix I) .

2.1.7 Results

- *How do parents with children clinically diagnosed with ASD react when it is necessary to talk to their children about sexuality?*

Qualitatively analysing the parents' responses, we can see that most parents have not yet received questions about sexuality from their children, or may not have realised whether their child has asked about sexuality, or has expressed curiosity about sexuality in some form. Knowing that children's thinking is abstract, perhaps questions are formulated indirectly, tailored to their level of communication.

- *What are the needs of parents of children with clinically diagnosed ASD regarding SHE for their children?*

Analysing the responses received from parents we can see that most parents maintain that in sex education there should be a strong emphasis on protection, prevention and recognition of sexual

abuse, as well as self-control skills, and very few of the respondents write about children's sexual health.

- *How do parents with children clinically diagnosed with ASD imagine formal SHE should be done for their children?*

Analyzing the responses to this question, two categories of codes were identified: adaptation on their level of understanding, and the other category, sexuality education regardless of disability, expresses that things are the same as for children with neurotypical development.

- *What recommendations do parents have for sex education for children with ASD?*

Analyzing the responses, it was observed that parents describe and suggest how some form of sex education can be done, others even wrote methods, tools that can be used for sex education. Most parents only write that sex education is needed, but do not make recommendations. There are parents who say that sex education is just a discussion between a teacher and students, others say that sex education should be done in the form of therapy, it is a process and not just a discussion.

- *Why do parents think sex education is/isn't important for their children with ASD?*

Analysing the parents' responses, 4 categories of codes were identified: sexual education against abuse, right to education, mental health and interpersonal relationships.

2.1.8 Discussion, conclusions and limitations of the research

The aim of this study was to identify through a qualitative approach (thematic content analysis) the attitudes and needs towards sexual health education among parents of children with a clinical diagnosis of ASD. Some parents believe that sexual health education should be delivered in a therapeutic manner. The PLISSIT model (Permission, Limited Information, Specific Suggestions, and Intensive Therapy) (Annon, 1976) is an example of a model that incorporates therapy into sexual health education. The present research has identified several limitations that should be taken into account in future studies. Therefore, it is important to consider the small number of participants. Additionally, the study has limitations as respondents/participants may not have been motivated to complete the questionnaires seriously due to the sensitive nature of the research topic (sexuality) which could have discouraged honest responses, despite the

anonymity of the assessment instruments. In conclusion, the study results indicate that parents recognise the significance of sex education for their children, with the majority stating that it is very important for children with ASD. However, only 32% of parents received sex education during their childhood. Additionally, 42.10% of parents believe that sex education should commence between the ages of 8-12. Most parents feel adequately prepared to provide sex education, but a third of them acknowledge that there are areas or topics where they need to educate themselves further.

2.2 STUDY II. Quantitative study - Linguistic and psychometric validation of the Attitudes to Sexuality Scale (Fisher and Hall, 1988) and the Attitudes to Sexuality Scale for People with Disabilities (Porat, 2009).

2.2.1 Introduction

Identifying parents' attitudes and knowledge towards sexuality is crucial for developing intervention programmes for sexual health education (SHE) for people with special educational needs. This includes attitudes towards sexuality education in the family. Training programmes for parents should be provided to ensure objective and accurate sexuality education tailored to their needs, levels of understanding, and communication. Sexual health and sexual health education (SHE) are psychological constructs that have been studied at the European and international levels (e.g. UNESCO, 2009; WHO, 2010; Orji & Esimai, 2003; Zambra et al., 2017). The main aim of SHE is to provide information to different age groups, especially young people, that enables them to understand how their bodies function and facilitates the understanding that sexuality is a normal part of life (Marozsi, 2018).

2.2.2 Study aims

The objectives of this study are as follows:

O1: Translation into Hungarian and Romanian of two instruments measuring people's attitudes towards sexuality: the Attitudes Toward Sexuality Scale (ATSS, Fisher and Hall, 1988) and the Attitudes about Sexuality for People with Disabilities Scale (ASPD, Porat, 2009).

O2: Psychometric investigation of the Attitudes Toward Sexuality Scale (Fisher and Hall, 1988) and the Attitudes about Sexuality for People with Disabilities Scale (Porat, 2009).

These instruments will subsequently be used to investigate variables among parents of children with special needs, including children with a clinical diagnosis of ASD.

2.2.3 Study hypotheses

H1: The Attitudes toward Sexuality Scale (ATSS) is expected to demonstrate acceptable or increased internal fidelity and consistency for both Hungarian and Romanian-speaking participants.

H2: Similarly, the ASPD (Attitudes about Sexuality for People with Disabilities) scale is expected to demonstrate acceptable fidelity and internal consistency for participants in both categories.

2.2.4 Study design

The research design is non-experimental correlational, which means that the correlation between the Romanian translated version of the ATSS and the ASPD and the Hungarian translated version represents the similarity (linguistic equivalence) between the two versions. The scales were translated based on the guidelines of the International Test Committee (ITC, 2018), i.e. after the first translation, a pilot study was conducted (N=5 participants) and the test items were modified based on the results of the pilot study. The translation was obtained using the back-translation method (ITC, 2018).

2.2.5 Instruments

- *ATSS Scale (Attitudes toward Sexuality Scale)*

The scale was developed by Fisher and Hall (1988) and contains a total of 14 items. The instrument covers a range of issues related to sexuality, including nudity, abortion, contraception, premarital sex, pornography, prostitution, homosexuality and venereal disease. Responses can be recorded on a Likert scale, where responses range from strongly disagree (1) to strongly agree (5). Some of the items were grouped such that an agree response indicated a liberal sexual orientation, and some of the items were grouped such that an agree response indicated a conservative sexual orientation. Also, some of the items allow for the assessment of moral/ethical aspects of sexuality. Thus, the ATSS measures 3 dimensions (3 subscales): liberalism; conservatism; and moral/ethical issues related to sexuality.

- Scala *Attitudes about Sexuality for People with Disabilities* (Porat, 2009)*:*

The Attitudes about Sexuality for People with Disabilities scale was developed by Porat (2009) and contains 12 items. The instrument is composed of statements such as "Everyone has the right to exercise their sexual potential, regardless of their physical or mental condition". Responses can be recorded on a Likert scale, and the response format ranges from strongly disagree (1) to strongly agree (5) (Appendix 4). In the pilot study conducted by Gerchenovich (2019) the scale had a very good internal consistency (α = .85), and in the Romanian version the internal consistency of the ASPD scale was very good (α = .76), while in the Hungarian version it was α = .78 (Table 7).

2.2.6 Participants

A study was conducted with a total of 246 participants from various localities in Romania, including 130 Romanian speakers (M= 30.87, STD= .87) and 116 Hungarian speakers (M= 31.03; STD= 1.09).

2.2.7 Procedure

This study was conducted using data collected online between January, 2022-February, 2022 on the Google Forms platform from N=246 adult participants who provided the full information requested in the study. In order to adapt the Fisher & Hall, 1988) Attitudes to Sexuality scale and the Attitudes to Sexuality for People with Disabilities scale from the Reuth Open Door package (Porat, 2009) into Romanian and Hungarian languages, a translation procedure was carried out using the back-translation technique (ITC, 2009). The scale items were initially translated from English into Romanian and Hungarian by a professional translator, and then another professional translator was included in the adaptation procedure for the purpose of translating the Romanian and Hungarian versions of the scales into English. The English-language items obtained at this stage were compared with the original English-language test items. On the basis of the identified correspondences, the Romanian and Hungarian translations were considered as appropriate versions of the original instruments.

2.2.8 Results

Inferential statistical analysis

The Kaiser-Meyer-Olkin (KMO) test was used to test the suitability of our data for factor analysis. The test measures the sampling adequacy for each variable in the model and for the full model. Tabachnick & Fidell (2013) state that the KMO index ranges from 0 to 1, with 0.6

suggested as the minimum value for good factor analysis (Tabachnick & Fidell, 2013). The results of the present study show a score greater than 0.6 on all 4 scales, and the Barlett test results are statistically significant: for the ATSS scale, Romanian variant (KMO=.827; p<.01); ATSS, Hungarian variant (KMO=.72; p<.01); and for the ASPD scale, the KMO test results are as follows: ASPD, Romanian variant (KMO=.79; p<.01); ASPD, Hungarian variant (.79, p<.01).

Confirmatory Factor Analysis (CFA)

Confirmatory factor analyses (CFA) were conducted to validate the ATSS and ASPD scales for the Romanian and Hungarian speaking populations. Confirmatory factor analysis (CFA) was performed on the three-factor structural model (see Figure 1). The standard chi-square, $\chi 2/df = 4.12$, indicates an acceptable model fit in this case. The two correlation coefficients between the scales in the two groups (RO-HU) were compared using the Comparison of Correlations in Independent Samples method (Eid, Gollwitzer & Schmidt, 2011). The difference between the coefficients is not significant (N=246, p>.05).

Reliability/Internal Consistency

The scales have very good internal consistency. In the case of the ATSS scale, the Romanian version has $\alpha = .83$, while the Hungarian version has $\alpha = .71$. In the case of the ASPD scale, the Romanian version $\alpha = .76$ and the Hungarian version $\alpha = .78$.

Construct validity (convergent validity)

ATSS - RO version

All three subscales were highly correlated with the total score of the full scale (liberalism $r(130) = .862$, $p \leq .01$; conservatism $r(130) = .727$, $p \leq .01$; moral/ethical issues towards sexuality $r(130) = .807$, $p \leq .01$), and the subscales were positively correlated with each other: moral/ethical issues towards sexuality with liberalism $r(130) = .582$, $p \leq .01$; moral/ethical issues towards sexuality with conservatism (130) = .403, $p \leq .01$; liberalism with conservatism $r(130) = .553$, $p \leq .01$).

ATSS - HU version

All three subscales showed a high correlation with the total score of the full scale (liberalism $r(130) = .776$, $p \leq .01$; conservatism $r(130) = .672$, $p \leq .01$; moral/ethical issues regarding

sexuality r(130) = .795, p ≤ . 01), and the subscales were positively correlated with each other: moral/ethical issues towards sexuality with liberalism r(130) = .518, p ≤ .01; moral/ethical issues towards sexuality with conservatism r(130) = .295, p ≤ .01; liberalism with conservatism r(130) = .451, p ≤ .01).

2.2.9 Discussion, conclusions and limitations of the study

The results of this study indicate that at the psychometric level, the scales and subscales of the ATSS (Fisher & Hall, 1988) and ASPD (Porat, 2009) questionnaires (as modified by Gerchenovitch and Rusu (2019)) in the Romanian and Hungarian versions have good internal consistency, indicating that the versions can be used as psychometric instruments to measure attitudes towards sexuality in two different populations.

The results show that there are no significant differences between the two language versions, nor between the scales and subscales, indicating that the two language versions (Romanian and Hungarian) are linguistically equivalent. Our recommendation is that these scales should be tested on a larger sample in the future.

2.3 Study III. Sexuality-related knowledge, parental self-efficacy and parental stress as predictors of parental attitudes towards sex education of people with disabilities

2.3.1 Introduction

Parents' knowledge and attitudes towards sexuality play an important role in their children's sexuality education, and parents are recommended as key educators in the sexuality education process (SIECUS, 2012). Parents' sexual knowledge refers to the correct level of parents' understanding of their children's knowledge about sexuality, a basic prerequisite for achieving sexuality education. If parents lack knowledge about sexuality, their willingness to provide sexuality education will be low (Byers et al., 2008; Holmes et al., 2014). Previous studies in the literature show that parents of typically developing children have positive attitudes towards sexuality education in school and have general knowledge about sexuality (Morawska et al., 2015; Shin et al., 2019). Another psychological construct that is often used in the literature when

discussing parenting practices is parental self-efficacy (Albanes et al., 2019). Parental self-efficacy (PSE) is defined as "parents' belief in their ability to influence their child in ways that promote health and success" (Eccles & Harold, 1996, as cited by Albanes et al., 2019).

Previous studies in the literature show that parental self-efficacy is a strong predictor of parenting practices (Albanes et al., 2019; Boruszak-Kiziukiewicz et al., 2020), but specific studies investigating the role of parental self-efficacy in sex education could not be identified. Most studies investigating the effect of parental self-efficacy in different areas of parenting practice show that higher perceived self-efficacy is associated with lower perceived parental stress (Bloomfield et al., 2012; Sugiana et al., 2020; Jhingoeri et al., 2022).

Study objective and hypotheses

The objective of this study is to identify associations between parental self-efficacy, parental knowledge of sexuality, attitudes towards sexuality in general, attitudes towards sexuality of people with disabilities and parental stress.

I1: There will be a positive correlation between the level of parental knowledge about sexuality and their favourable attitude towards sexuality of people with disabilities.

I2: High parental self-efficacy and high level of knowledge about sexuality are strong predictors of parents' attitudes towards providing sex education for their children.

I3: There is a negative correlation between parental stress and parental attitudes towards sexuality in general.

1.1.1. Research design

The research design is quantitative, non-experimental predictive and correlational.

1.1.2. Study participants

The research was conducted on a sample of 58 participants aged between 26 and 57 years (M= 39.52, SD= .82), who are parents of children with different disabilities (Autism Spectrum Disorders, ADHD, physical disability, etc.). The staff come from different counties in Romania.

1.1.3. Procedure

A total of 58 parents of children with special educational needs were included in this study. This study was conducted with online data collection from February 2023 to July 2023 on the Google

Forms platform. After completion of the data collection period, data analysis followed using the statistical analysis software Statistical Package for Social Sciences (SPSS version 19.0). In the first phase, tests for normality of the data frequency distribution (Kolmogorov-Smirnov), descriptive statistics, correlation analyses, and tests for internal consistency of scales were used. At each subscale the distribution is non-parametric. Spearman rank correlation and linear regression tests were used in this study. Linear regression analysis requires only that the residuals be normally distributed, not the variables themselves (Field, 2013). The Durbin-Watson statistic was used to test for autocorrelation in the residuals. The regression line residuals are approximately normally distributed.

1.1.4. Tools

Demographic Questionnaire - A comprehensive questionnaire measuring the demographics of the participants (gender, age, residence, educational level, educational level of parents, occupation, number of children in the family, number of children with ESC in the family) (Appendix 6).

Parent's knowledge of sexuality questionnaire (Nur et al., 2020)

The scale was developed by Nur et al. (2020) and contains 20 statements related to sexuality, e.g. "Playing sports can be harmful during menstruation." Or "Chlamydia is a sexually transmitted infection that only affects women." The questionnaire asks participants to answer "true", or "false" to statements related to sexuality. A total score between 16 and 20 indicates good knowledge about sexuality (Nur et al., 2020).

Brief Parental Self Efficacy Scale (BPSES)

The Brief Parental Self Efficacy Scale (BPSES; Woolgar et al., 2023) is a 5-item brief instrument that can be completed by parents or caregivers of children and youth. A total score is then calculated by summing all five items and ranges from 5 to 25. Higher scores indicate a higher level of parental self-efficacy.

Parental Stress Scale (PSS) (Berry and Jones, 1995)

The scale contains a total of 18 items representing positive (e.g. emotional benefits, personal development) and negative (resource demands, limitations) aspects of parenting. The

questionnaire asks participants to rate the extent to which each item corresponds to their own experience using a 5-point Likert scale. The total score is obtained by summing the responses to each item and is related to the baseline scores.

Attitudes about Sexuality for People with Disabilities Scale (Porat, 2009), from the Reuth Open Door - IFPA (Israel Family Planning Association) questionnaire package: Hungarian and Romanian population version (Gergely& Rusu, 2022) (Appendix 5). The scale was developed by Omer Porat (2008) and contains 12 items, responses can be recorded on a Likert scale, the response format ranges from strongly disagree (1) to strongly agree (4). The scale contains reversed items (2, 3, 4, 5, 9, 11, 12) and the maximum score on this scale is 48.

Attitudes towards Sexuality Scale (Fisher & Hall, 1988) - Hungarian and Romanian versions

The scale was developed by Fisher and Hall (1988) and consists of 16 items. Responses can be recorded on a Likert scale and the Likert response format ranges from strongly disagree (1) to strongly agree (5). In previous studies this instrument has had very good psychometric properties ($\alpha < .70$), although the scale has suffered from changes in item composition (Fisher & Hall, 1988; Fisher, 2007; Fisher, 2009).

1.1.5. Results

I1: There will be a significant correlation between the level of parental knowledge about sexuality and attitudes towards the sexuality of people with disabilities.

Spearman's correlation coefficient was used to test this hypothesis. The results of the test show that there is a positive correlation between the level of parental knowledge about sexuality and their attitudes towards the sexuality of people with disabilities (rho= .29; p< .01). Specifically, this result shows that the more parents have correct knowledge about sexuality, the more open they are to providing a comprehensive form of sexuality education for their children with special educational needs.

I2: Parental knowledge about sexuality is a predictor of parental attitudes towards the sexuality of people with disabilities.

To test this hypothesis, linear regression was used, where the dependent variable in this model is parental attitudes towards sexuality of people with disabilities and the independent variable is parental knowledge about sexuality.

Linear regression results show that parental knowledge significantly explains 14% of the total variance (R2 = 0.14, F (1,56) =9.23 p <.01.). Parental knowledge about sexuality significantly predicts parental attitudes towards sex education for people with disabilities (β = .93, t = 3.03, p <.01).

Tabel 12. Linear regression results

Variabile	B	SE B	β
Constant	30.16**	5.24	
Parental knowledge about sexuality	. 93**	.30	.37
R^2	.14**	5.26	.28
Adj. R^2	.12**	5.26	.28

* p< .05; **p< .01

Table 12 shows the effect of parental knowledge about sexuality on parents' attitudes towards sex education for people with special educational needs. The R2 value of 0.14 indicated that the predictor variable explained 14% of the variation in the outcome variable with Fchange (1.56) = 9.23 p < 0.01. The results showed that parents' level of knowledge about sexuality positively predicted their attitudes towards sex education for people with special educational needs (β = .93, p < .001).

I3: There is a negative correlation between parental stress and parental attitudes towards sexuality in general.

Spearman's correlation coefficient was used to test this hypothesis. The test results show that there is a significant negative correlation between the level of parental stress and parents' favourable attitudes towards sexuality in general (rho = .24; p < 0.05). This hypothesis was also tested using simple linear regression with parental stress as the predictor. The results show that parental stress negatively predicts conservative attitudes towards sexuality (R2 = 0.05, F_{change} (1.56) = 3.53), but the t-test was not significant (p> 0.05). This result tells us that parents with high parental stress may be more closed to their children's sexuality and sex education.

1.1.6. Discussion, conclusions and limitations of the study

This study provides an overview of the barriers that may exist in the sex education of children with special educational needs (in addition to the lack of materials that can be used by parents). According to the first two hypotheses, which were confirmed, there is a significant correlation between the level of parental knowledge and their attitude towards the sexuality of people with disabilities. Similar studies investigating the correlation between the level of knowledge about sexuality and attitudes towards sexuality (Zhao et al., 2023; Shin et al., 2019) found similar results, indicating that people who have more knowledge about sexuality also have more favourable attitudes towards the sexuality of people with disabilities. The result of the first hypothesis has been confirmed by other studies (e.g. Ademuyiwa et al., 2022; Kassa et al., 2017; Ayalew et al., 2019) and we can argue that knowledge about sexuality plays an important role in shaping attitudes towards the sexuality of people with disabilities (and neurotypical development). These findings highlight the importance of sex education and knowledge training for parents, as the more informed individuals are about sexual health, the more likely they are to have positive attitudes towards sexuality.

The linear regression model shows that the level of parental knowledge about sexuality has a strong influence on parents' attitudes towards sex education for people with special educational needs. A study by Shin et al. (2019) found a moderate correlation between parents' knowledge about sexuality and their attitudes towards sexuality. The results of hypothesis two show that parents who have a high level of knowledge about sexuality and sexual health can provide accurate and developmentally appropriate information to their children with special educational needs. We can see that the test results show that parental knowledge contributes to the formation of healthy perceptions and appropriate approaches to sexuality issues.

The limitations of this research are the relatively small number of people involved in the study, but sufficient for rigorous statistical analysis. The results of the study are promising with regard to the importance of developing and providing future educational programmes for parents on the sexual health of their children with special needs. Parents' low level of knowledge about sexuality can be seen as a barrier to their children's sexuality education and can lead to a range of changes in their children's mental and relationship health.

2.4 STUDY IV: Development and pre-testing of a parenting education curriculum content for sexual health of children with clinically diagnosed ASD

2.4.1 Introduction

Studies in the literature show that individuals diagnosed with ASD (autism spectrum disorder), particularly high-functioning individuals, may have the same level of sexual interest as neurotypical individuals (Dewinter et al., 2017; May et al., 2017). Parents face many challenges in educating their children about sexual health, particularly during the critical period of adolescence (Dewinter et al., 2017; Holmes & Himle, 2014). SIECUS (2012) recommends that parents take on the role of primary educators in their children's sexuality education, recognising that sexuality education is a lifelong process that begins in early childhood and continues into adulthood. Holmes et al. (2014) believe that some parents may avoid some important topics in the sexuality education process, leaving their child to seek information on these topics from other sources, which may have low fidelity. In Romania, no studies describing or evaluating sex education programmes for parents and young people with special needs have been identified.

2.4.2 Study Objectives

This material has several specific aims, including the following

O1: To increase parents' knowledge of the sexual development of children with ASD;

O2: To develop parental knowledge of sexually transmitted infections;

O2: To encourage parents to communicate about sexuality with their children with ASD;

O3: Provide guidelines that parents can use to educate their children with ASD about sexual health education for children with ASD.

2.4.3 Participants

This study involved 10 parents (8 mothers and 2 fathers) selected from a non-governmental organisation in Cluj-Napoca, Romania, which focuses on providing educational and therapeutic programmes for people diagnosed with ASD. The only inclusion criterion was that the participants were parents of children with a clinical diagnosis of ASD who were enrolled in the organisation's programmes.

2.4.4 Procedure

The curriculum material was developed following Kirkpatrick's (2006) model. The first step was to define parents' needs in relation to sex education for children diagnosed with ASD by conducting a qualitative study based on their online survey (Gergely& Rusu, 2021). In the second phase, meetings were held with the scientific director of the research to establish the general objectives of the parental sex education programme, after which the structure and content of the programme were developed, the proposed objectives being based on the literature review and the parental needs identified in the qualitative study. The next step was to contact the management of a non-governmental organisation in Cluj-Napoca, Romania, where meetings were arranged with parents of children diagnosed with ASD who were involved in the organisation's programmes. At the first meeting, attended by parents of children with ASD, the structure of the programme was presented. Leaflets were distributed with information on how to register for the next meetings. Parents had the opportunity to express their needs regarding the topics to be covered in the meetings. Parents who were interested in joining the programme received an invitation in a WhatsApp group and together they set the date and time for the next meetings.

The programme was coordinated by the scientific director of the study, which is part of the doctoral thesis of the first author, and the trainer was the author G|R, who has the right to practice under supervision in the specialty of clinical psychology, issued by the College of Psychologists of Romania, and is in training in cognitive-behavioural psychotherapy. The materials have been organised on the basis of the literature and international guidelines (e.g. SIECUS, WHO).

2.4.5 Discussions, conclusions and future research directions

This curriculum material has several specific aims, is based on Kirkpatrick's (2006) model and consists of four sessions. The first session focused on sex education and sexual health in the context of autism spectrum disorders. Topics such as ASD and sexual health were discussed. At the end of the meeting, parents had the opportunity to ask questions for the next meeting. The second meeting focused on the importance of sex education in the context of ASD. In this meeting, parents learned criteria for selecting materials for their children's sexual education, and

topics related to sexual development and sexual behaviour in children with ASD were discussed. The third session is built around topics such as differentiating relationships in ASD, signs of sexual abuse and sexually transmitted infections. We can see that this programme addresses issues that are fundamental to comprehensive sexuality education for children with ASD. The activities and materials presented in the sessions were selected based on consultation of the literature. In terms of identified limitations, we note that this programme has not been tested on a representative population, and no psychometric instruments were used in the pre-testing phase to measure the effect of curriculum content on psychological variables relevant to this study, such as parental stress related to sexual communication, parental knowledge related to sexuality, or participants' attitudes.

2. CHAPTER III. DISCUSSION, CONCLUSIONS AND LIMITATIONS OF THE RESEARCH

3.1. Introductory considerations

This doctoral research had several aims. Firstly, it explored parents' attitudes, needs and knowledge in relation to sex education for people with clinically diagnosed autism spectrum disorders. This research approach involved collecting information from parents of children with a clinical diagnosis of ASD and analysing it using a qualitative approach. Secondly, the work aimed to translate and psychometrically validate two instruments into Romanian and Hungarian in order to measure parents' attitudes towards sexuality and towards the sexuality of people with disabilities using evidence-based instruments. Thirdly, the paper aimed to provide a clear picture of the psychological variables involved in the process of sex education of people with special educational needs. It is important to mention that the results of the studies were used to develop a curriculum material/psycho-educational programme to help parents in providing sex education to people with autism spectrum disorders and other types of disabilities.

3.2. Methodological contributions

This research provides a rigorous understanding of the methodology used to study parental attitudes and knowledge in sex education for children with autism spectrum disorders, as well as to study parenting programmes in sex education. On the other hand, the contributions of the dissertation also concern the enrichment of the literature with two psychometric instruments, available in two different languages, that can be used by professionals in different educational

and clinical fields. Another methodological contribution is to examine the relationship between the psychological variables involved in the process of sexuality education and to identify the barriers and challenges of this approach.

The first study consisted of a qualitative approach that provides an in-depth view of parents' attitudes and experiences in relation to their children's sexual education. Qualitative analysis in education provides the opportunity to explore a range of perspectives, reflections and opinions. Using this approach we were able to understand the diversity of parental experiences when it comes to sex education in the context of disability. This methodological flexibility allowed us to uncover complex relationships and patterns, which were used to better understand parents' needs in relation to their children's sex education.

Another methodological contribution is the translation of two instruments (Attitudes towards Sexuality and Attitudes towards Sexuality of People with Disabilities) into Romanian and Hungarian and the providing of the psychometric validation of these scales. A back-translation procedure was carried out and they were tested on a significant sample in Romania. This translation and psychometric validation of the scales brings significant contributions to educational research and practice. We can state that the scales used in the studies have very good psychometric properties, which increases the validity and reliability of the results obtained.

Another methodological contribution is the study of the relationship between psychological factors involved in the sex education of children with special educational needs. The results of this study revealed the importance of knowledge about sexuality in the formation of parental attitudes towards sex education of people with disabilities. Few studies in the literature have examined sexuality knowledge, parental self-efficacy and parental stress in relation to parental attitudes towards the sexuality of people with disabilities. The results of Study III may be of practical use in the development of parental interventions/programmes to achieve sexuality education for children with special educational needs.

3.3. Empirical and Practical Contributions

This dissertation makes empirical and practical contributions to the field of educational sciences and related fields, as follows:

First, the objectives of Study I focused on parental needs and attitudes towards sex education for children with clinically diagnosed autism spectrum disorders. By identifying and analysing these parental needs and attitudes, a clearer picture of sexuality education for children with ASD was obtained. This is the first study in the literature to address parental attitudes and needs related to sexuality education of children with ASD in Romania. In addition, the results of the study were used for the development and implementation of the sexuality education programme in the context of autism. We believe that these promising results can also be applied by other professionals proposing the development of parenting programmes with the theme of sexuality education.

The second study in this dissertation enriches the literature with two instruments with very good psychometric properties, available in two different languages. These instruments can be used by different professionals who wish to investigate parental attitudes towards sexuality and towards the sexuality of people with disabilities.

Another important aspect of this work is the investigation of associations between parental self-efficacy, parental knowledge of sexuality, attitudes towards sexuality and parental stress. The assessment of parental knowledge will highlight the misconceptions that parents have about sexuality. We believe that the results of the study can be used in the development of educational policies that promote parental involvement in the sexual education of children with special educational needs.

Another empirical and practical contribution is the development and preliminary testing of a parent education curriculum content on sexual health for children with a clinical diagnosis of ASD. The study provides practical guidelines and resources for parents, tailored to the characteristics of children with ASD. The material has been developed and tested in a participatory way, with parents, and can be used in whole or in part by different professionals, such as psychologists, therapists or teachers.

3.4. Research limitations

One of these limitations is related to the characteristics of the samples of participants in these studies. Given the convenience sampling nature of all studies with a participant design, the representativeness of these samples for the general population is very low. Another limitation of Study I is the use of a single semi-structured interview instrument designed to answer the

research questions and allow for content analysis of the responses. As for Study III of this doctoral research, the study design was cross-sectional, which limits our ability to clarify the causal relationships between the variables of interest. Also, the predominant use of the online environment and the electronic data collection format will implicitly select only those participants who are literate in this regard and have access to such means. Another limitation of the study is that the respondents/participants may not have been sufficiently motivated to complete the questionnaires in a serious manner due to the research topic (sexuality and the difficulty of communicating about this topic), which may have discouraged open responses, although the assessment instruments could be completed anonymously.

In addition, it should be noted that a small number of parents participated in the development of the curriculum content in Study Card IV, and we were not able to test the effectiveness of the programme on relevant psychological variables in this study, which is a future direction of research.

3.5. Future research directions

- For Study I, one future direction of research is to use instruments with psychometric properties and to collect demographic data on the parents' children, but also on their level of functioning and the ASD symptoms manifested by each individual. In this way it will be possible to describe the needs of parents in the light of their children's level of functioning.
- Another line of research is to investigate in detail the associations between parenting knowledge, parenting self-efficacy, family type (mono- or bi-parental) and other relevant variables in the context of sexuality education. It is recommended that the study be repeated with a representative sample in order to carry out more rigorous statistical analyses, such as examining the moderating role of parental knowledge in the sexuality education of children with special educational needs.
- A possible direction for Study IV would be to investigate the impact of such a programme on the level of sexual communication anxiety among parents of children diagnosed with ASD.
- Another important aspect that emerged from the discussions with parents, and which we believe is essential in the delivery of curriculum content for a sexual health education

programme, is the need to take into account the developmental and functional level of the children, as well as the specific cultural aspects of the family of origin.

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