



Perspectives of Women with Intellectual Disabilities Regarding Affective Sexual Relationships: a Systematic Literature Review

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Abstract

Introduction Despite the recognition of the right to sexual identity and expression for all people, individuals with intellectual disabilities continue to face significant restrictions in these aspects of their lives. The prevailing myths and stereotypes surrounding their sexual-affective relationships place people with intellectual disabilities—especially women—in a position of great vulnerability.

Methods A systematic literature review was conducted, examining the content of the following databases: BASE, Dialnet, ERIC, La Referencia, Microsoft Academic, Redalyc, REDIB, Redined, Science Direct, Scopus, Web of Science, and World Wide Science. A total of 178 potentially relevant articles were identified, out of which 11 met the eligibility criteria. Finally, the themes covered in the articles were identified and analyzed.

Results The results obtained were classified into six categories: perceptions regarding sex and sexuality, experiences of abuse, views and experiences of relationships between couples, the LGTBIQ+ community, knowledge about contraception and related experiences, and, finally, beliefs regarding gender scripts.

Conclusions This study offers valuable insights into the knowledge (or lack thereof) and beliefs regarding sex and sexuality, experiences of abuse among women with intellectual disabilities, the lack of independence and external intervention, and the influence of traditional gender scripts. Furthermore, this research also establishes a theoretical foundation for future support resources and initiatives, as well as social and public implications.

Keywords Intellectual disability · Women · Relationships · Sexuality · Gender · Inclusion · Affectivity

Introduction

Achieving gender equality is one of the United Nations' goals for 2030. It strives towards ending discrimination against women and girls (target 5.1), putting an end to all violence towards them (target 5.2), ensuring full participation in decision-making (target 5.3), guaranteeing universal access to reproductive health and rights, adopting and strengthening policies and enforceable legislation for gender equality (target 5.9), and, overall, eradicating prejudice and work towards equal rights and respect for all collectives

(United Nations, 2020). The Convention on the Rights of Persons with Disabilities also establishes another of the main theoretical pillars, since it recognizes the right to non-discrimination of people with disabilities and assumes the need to combat all forms of discrimination against women in this group, working towards a social model that puts people at the center and seeks to eliminate barriers in the environment (United Nations, 2006). This organization also enshrines the right to sexual identity and expression, parenthood, marriage, and cohabitation (Ignagni et al., 2016). The World Health Organization defines sexual health as a fundamental aspect of human development which must include a respectful approach to sexuality and the opportunity for pleasurable and safe sexual relations, free from discrimination and violence (World Health Organization, 2017). However, despite the growing trend in the recognition of these rights, they are often unfulfilled, and the needs of people with disabilities are not met (Borawska-Charko et al., 2017; Carter et al., 2022; Fish & Björnsdóttir, 2022; Neuman, 2022).

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There is a generalized idea that people with intellectual disabilities are ill-suited to the free expression of their sexuality (Huaiquián et al., 2018). Myths and stereotypes surrounding the sexuality of people with intellectual disabilities reinforce this notion. These mistaken beliefs range from the conception of them as “asexual beings” or “eternal children,” oblivious to sexuality (Neuman, 2022; Retznik et al., 2021; Starke et al., 2016; Tamas et al., 2019) to the conception of them as being promiscuous and dangerous individuals whose sexuality should not be awakened (Fish & Björnsdóttir, 2022; Tamas et al., 2019; Wos et al., 2020). These stereotypes lead people with intellectual disabilities to often apply a “self-censorship in the experience of their sexuality” (Díaz-Rodríguez et al., 2016) or to have a negative self-image about it (Stevens, 2012). A study developed in Spain pointed out that people with intellectual disabilities tend to have a less liberal view on their conception of their own sexuality (6.1% of people have conservative attitudes and 93.9% moderate) comparing them with the attitudes of people without intellectual disabilities (0.5% conservative attitudes, 64% moderate attitudes and 35.5% liberal attitudes), thus excluding themselves from a full, healthy affective-sexual life (Díaz-Rodríguez et al., 2016). It needs to be emphasized that beliefs and attitudes towards sexuality are not universally shared. They are strongly influenced by the individual, relational and sociocultural factors of each person, such as social scripts, religious beliefs, or gendered cultural scripts (Basson, 2000; Hidalgo & Dewitte, 2021).

The lack of research, information, and education on the sexuality of people with intellectual disabilities results in a greater vulnerability to abuse (Ballan & Freyer, 2012). Many investigations have found that people with intellectual disabilities are at greater risk from unsafe practices, manipulation, sexual assault, abuse, and violence in general (Borawska-Charko et al., 2017; English et al., 2017; Fitcher, 2011; McCarthy, 2009; Muswera & Kasiran, 2019; Stevens, 2012). At the same time, the lack of information and adapted resources hinder the possibility of both avoiding and also reporting these situations (Borawska-Charko et al., 2017; De Mello et al., 2021; Frawley & O’Shea, 2019; Frawley et al., 2012; Muswera & Kasiran, 2019). Likewise, in cases where this issue is studied, a broad definition of disability is often used, encompassing all types of physical, sensory, and cognitive disabilities under the same umbrella (McCarthy, 2017). In addition, these difficulties are exacerbated by a double discrimination when gender is taken into account since women are “in an unequal position with respect to the population in general, and men with disabilities in particular” (Morcillo & Pérez, 2018, p. 63).

Access to sex education is crucial in the sexual empowerment of people with intellectual disabilities. The lack of sexual literacy excludes them from the possibility of sexual expression and pleasure (Adams, 2015; Alexander & Gomez, 2017). However, recent research has shown that

people with intellectual disabilities seldom receive an adequate, reliable sexual education (Adams, 2015; Wos et al., 2020; Namkung et al., 2021; Schmidt et al., 2020). Although some sex education programs aimed at people with intellectual disabilities have been developed (Anderson, 2015; Schaafsma et al., 2013), these have generally been linked to conflictive aspects of affective-sexual relationships such as abuse, or a more biological and medical point of view (Fish & Björnsdóttir, 2022; Wos et al., 2020). Consequently, the knowledge that people with intellectual disabilities have on this subject is quite superficial and limited to aspects such as safe sex, contraception, or sexually transmitted diseases (Schaafsma et al., 2013).

Voicing one’s opinions and talking about personal experiences is a powerful tool for self-advocacy and empowerment, especially regarding a topic as personal as sexual-affective relationships (Azzopardi-Lane & Callus, 2014). Nevertheless, although the first research that gave the opportunity to women with intellectual disabilities to talk in-depth about this topic was published almost twenty-five years ago (McCarthy, 1999), literature researching their experiences and opinions is still scarce (Azzopardi Lane et al., 2019; Bernert & Ogletree, 2013; McCarthy, 2014). Discovering the perspective of women with intellectual disabilities is essential to obtain a deep understanding of their experiences. Only by learning about their opinions and experiences will we be able to obtain information about what their needs are and the supports they want (McCarthy, 2014). From a legal perspective, and considering that the enjoyment of one’s sexuality is a right for all people (Fish & Björnsdóttir, 2022; United Nations, 2006, 2020; World Health Organization, 2017), it is necessary to investigate the intersection between intellectual disabilities and sexuality, while emphasizing women’s point of view.

In order to highlight the voices of women with intellectual disabilities, this systematic literature review focuses on research that has specifically and solely gathered information from women’s points of view. The objective of this paper is to explore the main needs, experiences, and concerns expressed by women with intellectual disabilities in relation to their affective-sexual relationships and to reflect on how to advance in the formulation of the desired supports to help women improve this dimension of their lives.

Method

Search Sources and Strategy

This Systematic Literature Review was undertaken following the guidelines proposed by Petticrew and Roberts (2006) and conducted in five steps: (1) searching for potentially relevant articles; (2) reading the abstracts of the articles

identified in the previous phase; (3) in-depth evaluation of the articles included in the second phase; (4) identification of the articles relevant for research; and finally, (5) analysis of the selected articles. Additionally, three other papers linked to social sciences were also analyzed (Brown & McCann, 2018; Ferreras-Fernández et al., 2016; García-Peñalvo, 2016) to determine the process. Figure 1 presents the procedure chosen in line with the PRISMA statement (Rethlefsen et al., 2021):

Identification

To access international research in English, 8 databases were chosen: BASE, ERIC, The Reference, Microsoft Academic, Science Direct, Scopus, Web of Science, and WorldWideScience. To retrieve literature from Spanish-speaking countries, the following databases were chosen: Dialnet, REDIB, and

Redined. In accordance with the objective of the research, the search terms used are those shown in Fig. 2. The search was undertaken in both the English and Spanish versions.

An additional search of records was carried out by exploring the references of the papers that fulfilled the eligibility criteria described below. Adding the two sources—the databases and the references—116,828 documents were retrieved. Subsequently, 1128 duplicated records were removed, resulting in 115,700 documents to analyze in search of potentially relevant papers.

Eligibility Criteria

Given the objective of the systematic literature review, the following inclusion criteria were established: (1) The participants could only be adult women with intellectual disabilities; therefore, the research studies that contributed to the perspectives of other groups of people were excluded;

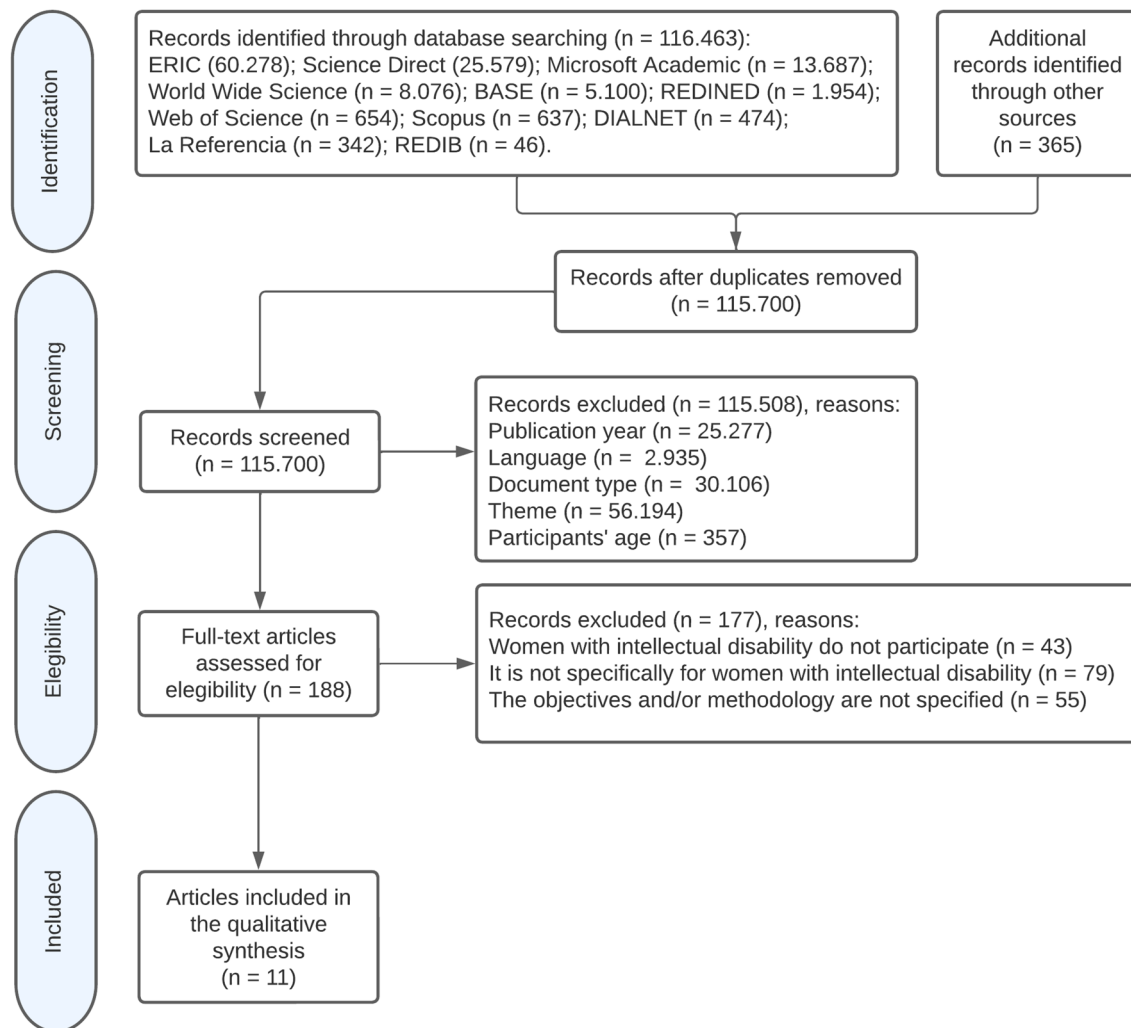
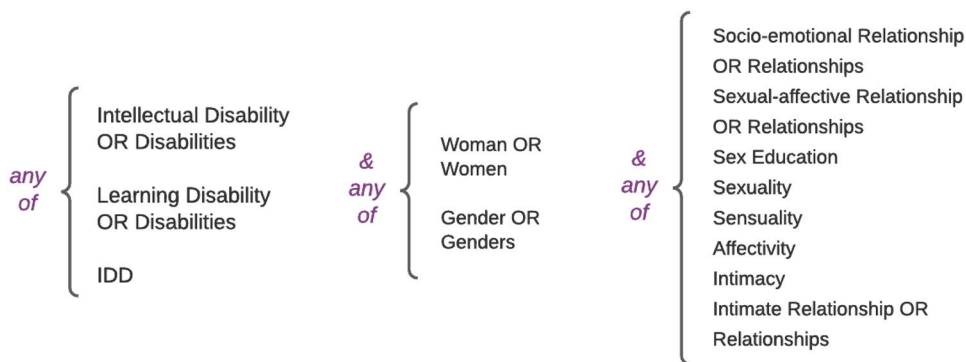


Fig. 1 PRISMA diagram of the systematic literature research process

Fig. 2 Search terms and groups used



(2) the documents had to be peer-reviewed papers or doctoral theses; (3) the papers had to clearly specify their objectives and the methodology followed; (4) the papers had to be directly related to the subject of affective-sexual relationships, without treating it from a strictly medical point of view; (5) the documents had to be written in English or Spanish; and (6) only articles published in the last twenty years were included to ensure their validity and suitability, so the articles published before 2002 were excluded from the systematic review of literature.

Screening

A screening of potentially relevant articles was conducted. First, the filters of the year of publication, document type, and language were applied. Documents were then screened for their relationship to the topic by reading the titles and abstracts. In this way, 115,700 documents were located.

However, 115,518 were discarded as they did not meet the inclusion criteria. The 182 that did meet all the criteria were selected for the next phase.

Eligibility

The full texts of the 182 papers selected as potentially relevant were read to assess their eligibility by inspecting their methodologies and objectives. The process showed that 11 of these articles met the inclusion criteria and that 171 did not. The reasons for not meeting the criteria are shown in Table 1.

Included

Eleven articles were selected for the analysis, synthesis, and data relationship phase. The information about the selected articles and the research developed in each of them is described in Table 2.

Table 1 Reasons of exclusion after full-text assessment

	Reason of exclusion	Number of records (n = 171)
1	No information about the objectives and/or the methodology of the paper	55
2	No participation of adult women with intellectual disabilities	23
2.1	Professionals (n = 16)	
2.2	Minors with intellectual disabilities (n = 2)	
2.3	General public (n = 2)	
2.4	Men with intellectual disabilities (n = 1)	
2.5	Family and general public (n = 1)	
2.6	Family and professionals (n = 1)	
3	The voice of women with intellectual disabilities is not specifically reflected	82
3.1	Also included other people with intellectual disabilities (n = 48)	
3.2	Also included other disabilities (n = 11)	
3.3	Also included professionals (n = 8)	
3.4	Also included minors with intellectual disabilities (n = 6)	
3.5	Also included general public, families, and professionals (n = 4)	
3.6	Also included the general public (n = 2)	
3.7	Also included families and professionals (n = 2)	
3.8	Also included families (n = 1)	

Table 2 Characteristics of the articles selected and the research process

Reference	Country	Aim of the study	Method
1 (Bornman & Rathbone, 2016)	South Africa	Create four social stories that can be part of sex education and sexual education programs for women with intellectual disabilities	Systematic literature review Focus group made up of women with intellectual disabilities
2 (Burns & Davies, 2011)	UK	Investigate the knowledge and attitudes of women with intellectual disabilities regarding homosexual relationships, and check if they coincide with those of the general population	Three self-reporting questionnaires for the assessment of knowledge and attitudes
3 (Eastgate et al., 2011)	Australia	Explore knowledge about sexuality, experiences with relationships, and protective skills in a group of women with intellectual disabilities	Individual semi-structured interviews with 9 women with intellectual disabilities
4 (Fitzgerald & Withers, 2013)	UK	Investigate the sexuality and gender orientation of women with intellectual disabilities without focusing on issues of abuse, contraception and sexual education	Individual semi-structured interviews with 10 women with intellectual disabilities
5 (Gil-Llario et al., 2014)	Spain	Analyze the effect that various characteristics may have on attitudes, knowledge, and behavior in order to prevent the sexual abuse of which they are often victims	Individual structured interviews with 39 women with intellectual disabilities
6 (McCarthy, 2009)	UK	Investigate the extent to which women with intellectual disabilities are able to make decisions about the use of contraceptive methods	Individual semi-structured interviews with 23 women with intellectual disabilities
7 (O'Shea & Frawley, 2020)	Australia	Understand how gender manifests itself in the lives of young women with intellectual disabilities, and analyze how it can contribute to a better understanding of their lives	Systematic literature review Individual in-depth interviews with 6 women with intellectual disabilities
8 (Pestka & Wendt, 2014)	Australia	Examine how the need for belonging contributes to the vulnerability of women with intellectual disabilities regarding abuse in their intimate relationships	Semi-structured individual interviews with 4 women with intellectual disabilities
9 (Servais et al., 2002)	Belgium	Analyze the proportion of women with intellectual disabilities using contraceptive methods, which are the most used and why	Two questionnaires, one of them focused on the institutional profile and the other on the participant's profile
10 (Stoffelen et al., 2018)	Netherlands	Learning about the experiences of lesbian and bisexual women with intellectual disabilities	Individual semi-structured interviews with 10 women with intellectual disabilities
11 (Walter-Brice et al., 2012)	UK	Learn about the experiences of domestic abuse from the point of view of women with intellectual disabilities who have experienced them in their intimate relationships, and analyze whether intellectual disability affects access to services and help in these cases	Systematic literature review Semi-structured individual interviews with 5 women with intellectual disabilities

Table 3 Characteristics of the participants

Reference	N. °	Age ranges	Intellectual disability diagnosis	Marital status	Sexuality	Race and ethnicity
1 (Bornman & Rathbone, 2016)	10	20–29 (n=2) 40–49 (n=6) 50–59 (n=2)	Not specified	Current partner (n=7) Single, previous partner (n=3)	Not specified	Not specified
2 (Burns & Davies, 2011)	27	23–65 (no ages specified)	Not specified	Single (n=23) Married (n=1) Divorced (n=2) Widowed (n=1)	Heterosexual (n=27)	White (n=22) Black (n=4) Mixed race (n=1)
3 (Eastgate et al., 2011)	9	20–29 (n=2) 30–39 (n=4) 40–49 (n=3)	Mild (n=9)	Current partner (n=6) Single, previous partner (n=2) Single, no previous partner (n=1)	Heterosexual (n=9) Past same-sex experiences (n=2)	Not specified
4 (Fitzgerald & Withers, 2013)	10	19–64 (no ages specified)	Not specified	Not specified	Heterosexual (n=10)	White British (n=10)
5 (Gil-Llario et al., 2014)	39	27–35 (n=6) 36–43 (n=14) 44–52 (n=19)	Mild (n=22) Moderate (n=17)	Not specified	Not specified	Not specified
6 (McCarthy, 2009)	23	20–51 (no ages specified)	Mild or moderate	Not specified	Not specified	White British (n=19) Black British (n=2) Mauritanian (n=1) Eastern European (n=1)
7 (O’Shea & Frawley, 2020)	6	18–30 (no ages specified)	Not specified	Single (n=3) Married (n=2) Engaged (n=1)	Heterosexual (n=5) Sexually diverse (n=1)	Culturally diverse backgrounds
8 (Pestka & Wendt, 2014)	4	20–30 (n=1) 40–50 (n=2) 60–70 (n=1)	Not specified	Single (n=1) Married (n=1) Divorced (n=2)	Not specified	Not specified
9 (Servais et al., 2002)	397	18–46 (no ages specified)	Mild (n=60) Moderate (n=177) Severe (n=160)	Not specified	Not specified	Not specified
10 (Stoffelen et al., 2018)	10	20–29 (n=4) 30–39 (n=4) 40–49 (n=2)	Not specified	Single (n=6) Current partner (n=2) Married (n=2)	Bisexual and homosexual	Native Dutch (n=10)
11 (Walter-Brice et al., 2012)	5	27–50 (n=5)	Not specified	Not specified	Not specified	White (n=5)

The characteristics of the women participating in the studies were varied. Table 3 shows a summary of some of the characteristics of participants, maintaining the same terminology used in the articles cited.

Characteristics of the Research

A total of eleven studies were analyzed from the following countries: three of them from Australia and two from England. In addition, there was one article from each of the

following countries: Belgium, Spain, the Netherlands, and South Africa. Regarding the years of publication, the majority were published in the last ten years.

All but one of the studies solely included participants with sufficient communicative competence to participate in group discussions, formal and informal conversations, communicate in an understandable way, and, finally, be able to independently give their consent to participate in the research. In the case of the study that did not have communicative competence as a criterion for the exclusion of the

participants (Servais et al., 2002), the research was undertaken through closed and adapted questionnaires. However, the article did not specify if the women received any type of support when answering.

The age of women participating in the studies ranged from 18 to 89 years, but only a few were at the age extremes mentioned. The adaptive skills and cognitive functioning in relation to daily life ranged from women who lived independently, to those who had direct supervision or those who lived in centers where they received direct assistance. Research participants were cisgender women with and without children, unmarried, engaged, married, divorced, and widowed. As for the sexuality of these, the majority identified themselves as heterosexual, although a few described having had homosexual relations or having them at the time of the research. Finally, the participants come from six different countries—Australia, the UK, South Africa, Spain, Belgium, and the Netherlands—and, although not all articles specify ethnic and cultural origins, a majority of white women can be observed.

Regarding the sample size of the different articles, this ranged from the study with the fewest participants being 4 women (Pestka & Wendt, 2014), to the most numerous research study where a sample of 397 women was analyzed (Servais et al., 2002). Even so, in most of the studies, the sample was around 10 to 15 women.

Observing the objectives of the articles (summarized in Table 4), three of the articles focused on exploring affective-sexual experiences (Fitzgerald & Withers, 2013; O’Shea & Frawley, 2020; Stoffelen et al., 2018); three others referred to experiences of abuse and/or protection from them (McCarthy, 2009; Pestka & Wendt, 2014; Servais et al., 2002). A third objective was to analyze the knowledge they had about sexuality and relationships (Burns & Davies, 2011; McCarthy, 2009; Servais et al., 2002) including knowledge about homosexuality (Burns & Davies, 2011). Some of the studies identified measures that could be taken to protect themselves from abuse (McCarthy, 2009; Servais et al., 2002; Walter-Brice et al., 2012). One of the articles investigated how to create adapted sexuality

resources and programs (Bornman & Rathbone, 2016). Finally, only two of the articles focused on the exploration of decision-making capacity linked, in particular, to contraception (Eastgate et al., 2011; Gil-Llario et al., 2014).

Data Analysis

A thematic analysis was carried out following the guidelines defined by Braun and Clarke (2006) where the process is divided into six steps: familiarization with the data collected; generating the initial codes; searching for the themes; reviewing them; defining and naming these themes; and, lastly, producing the report.

The analysis started with a first in-depth reading of the “results” and the “discussion” sections of the selected articles to get acquainted with the information presented in them. Once this first step was concluded, a set of initial codes was created. These were determined by the ideas and the data shown in the papers. In this way, eleven categories were identified: beliefs and attitudes; experiences; knowledge; sources of information; reporting; consequences; support and help; mental health; reasons; relationships; and, finally, belonging. After this process, a second reading was undertaken to find the themes covered by each of the initial codes. Six themes were identified: perceptions regarding sex and sexuality; experiences of abuse; views and experiences of relationships between couples; the LGBTIQ+ collective; knowledge about contraception and experiences; and beliefs regarding gender scripts. Finally, a report of the findings was developed, and the results are described in the results section. Table 5 presents the codes, themes, and articles that covered each of them.

Results

The results are presented following the structure presented in Table 5, moving from the most common codes to the least used codes. Likewise, the topics within these codes have also been organized from highest to lowest prevalence in the

Table 4 Objectives of the articles analyzed

	Objective	References
1	To explore affective-sexual experiences	Fitzgerald and Withers (2013) O’Shea and Frawley (2020) Stoffelen et al. (2018)
2	To explore decision-making capacity regarding contraceptives	Eastgate et al. (2011) Gil-Llario et al. (2014)
3	To analyze knowledge on sexuality, relationships and protection from abuse	McCarthy (2009) Servais et al. (2002)
4	To create adapted sexuality resources and programs	Bornman and Rathbone (2016)
5	To analyze knowledge and attitudes towards homosexuality	Burns and Davies (2011)
6	To explore their experiences of abuse	Pestka and Wendt (2014)
7	To identify the ways to prevent sexual abuse	Walter-Brice et al. (2012)

Table 5 Relation between the codes, themes, and references

	Codes	Themes	References
1	Perceptions regarding sex and sexuality	Knowledge	Bornman and Rathbone (2016) Eastgate et al. (2011) Fitzgerald and Withers (2013) Gil-Llario et al. (2014)
		Beliefs and attitudes	Fitzgerald and Withers (2013) Gil-Llario et al. (2014) O’Shea and Frawley (2020)
		Experiences	Eastgate et al. (2011) Fitzgerald and Withers (2013) Gil-Llario et al. (2014)
		Sources of information	Eastgate et al. (2011)
2	Experiences of abuse	Consequences	Eastgate et al. (2011) Pestka and Wendt (2014) Stoffelen et al. (2018) Walter-Brice et al. (2012)
		Experiences	Eastgate et al. (2011) Pestka and Wendt (2014) Stoffelen et al. (2018) Walter-Brice et al. (2012)
		Reporting the abuse	Eastgate et al. (2011) Walter-Brice et al. (2012)
		Support and help	Walter-Brice et al. (2012)
3	Views and experiences of relationships between couples	Beliefs and attitudes	Eastgate et al. (2011) O’Shea and Frawley (2020) Pestka and Wendt (2014)
		Belonging	O’Shea and Frawley (2020) Pestka and Wendt (2014)
4	LGTBIQ+ collective	Experiences	O’Shea and Frawley (2020)
		Experiences	Stoffelen et al. (2018)
		Beliefs and attitudes	Burns and Davies (2011)
		Knowledge	Burns and Davies (2011)
		Support and help	Stoffelen et al. (2018)
		Mental health	Stoffelen et al. (2018)
5	Knowledge about contraception and experiences	Experiences	McCarthy (2009) Servais et al. (2002)
		Knowledge	McCarthy (2009)
		Reasons	McCarthy (2009)
6	Beliefs regarding gender scripts	Beliefs and attitudes	Burns and Davies (2011) O’Shea and Frawley (2020)

articles analyzed. The number of participants who agreed with each result obtained has been detailed in the cases that were possible because the articles specified this information.

Perceptions Regarding Sex and Sexuality

This was the most frequently discussed topic in the literature selected for this review, with five of the eleven articles chosen dealing with the perceptions regarding sex and sexuality (Bornman & Rathbone, 2016; Eastgate et al., 2011; Fitzgerald & Withers, 2013; Gil-Llario et al., 2014; O’Shea & Frawley, 2020). Within this code, four themes were identified: *the knowledge they have about sex and*

sexuality, the beliefs and attitudes held by the participants, their experiences, and sources of information.

Four articles analyzed women’s *knowledge on the subject*: Bornman and Rathbone (2016), Eastgate et al. (2011), Fitzgerald and Withers (2013), and Gil-Llario et al. (2014). The four of them described different views: One described how the women interviewed knew how to manage their sexuality and displayed healthy sexual behavior (Bornman & Rathbone, 2016); in a second study, the knowledge of the participants varied from a very simplistic understanding—apparently not understanding the process of sexual relationships—to a broad comprehension of the subject (Eastgate et al., 2011), Fitzgerald and Withers (2013) pointed out that most of the women

interviewed did not have knowledge regarding sex or sexual health, thus denying their options to experience their sexuality fully; and finally, Gil-Llario et al. (2014) noted that, although women had formed behaviors and attitudes—especially those who went to residential centers—there was a necessity for affective-sexual education adjusted to their needs.

Three studies asked participants about *their beliefs and attitudes regarding sex and sexuality*: Fitzgerald and Withers (2013), Gil-Llario et al. (2014), and O’Shea and Frawley (2020). The answers obtained in the different studies did not show a uniform result. In any case, a pattern was observed where younger women tended to have a more positive attitude, while older participants were less favorable with regard to sex and sexuality (Gil-Llario et al., 2014). Participants who described the issue in negative terms showed difficulty in talking about it because they saw it as a taboo subject. These women also denied their own sexuality as they saw sex as a dirty, disgusting act, associated with disease. The eight participants of Fitzgerald and Withers’ study (2013) said that sex could be something pleasant and desired, not for them, but for other people. In general, sex was perceived as a secret and unpleasant activity that was undertaken to meet the biological needs of men. In the case of women who were in favor of sex, it was perceived not only as a source of pleasure but also as a resistance to the system that treated them as asexual people or individuals with a highly restricted sexuality (O’Shea & Frawley, 2020).

Three studies analyzed *women’s experiences with sex and sexuality*: Eastgate et al. (2011), Fitzgerald and Withers (2013), and Gil-Llario et al. (2014). Research showed that women were highly regulated by their environment, especially by family and staff members (Fitzgerald & Withers, 2013). Some of the interviewees specified limitations such as being advised not to have children, needing permission from the center to have sex, having their interactions restricted to kissing and hugging, or being fearful of the staff discovering them having sex (Fitzgerald & Withers, 2013). The nine participants in one of the studies (Eastgate et al., 2011) were able to describe strategies for initiating a relationship as well as appropriate locations for sexual activity. However, none of the female participants described themselves as having initiated contact (Eastgate et al., 2011; Fitzgerald & Withers, 2013), and only one woman described having perceived sexual pleasure (Fitzgerald & Withers, 2013).

Finally, Eastgate et al. (2011) analyzed the *sources of knowledge and information* that they had at the time of the research. The participants mentioned having received training programs, as well as having read books or having talked with sex educators, counselors, or family members. Even so, the women acknowledged that they had not had any regular source of information since leaving school.

Experiences of Abuse

Four of the articles addressed experiences of abuse (Eastgate et al., 2011; Pestka & Wendt, 2014; Stoffelen et al., 2018; Walter-Brice et al., 2012). Four themes could be identified within this code: *the consequences of the abuse, the experiences of abuse, the reporting of the abuse, and the support and the help received*. Three studies were focused on the experiences of women in heterosexual relationships (Eastgate et al., 2011; Pestka & Wendt, 2014; Walter-Brice et al., 2012), while a fourth investigated the narratives of abuse of lesbian and bisexual women (Stoffelen et al., 2018). This study shows that abuses suffered by women of the LGTBIQ+ group did not occur between the couple.

The four studies discussed the *consequences of abuse and ill-treatment*: Eastgate et al. (2011), Pestka and Wendt (2014), Stoffelen et al. (2018), and Walter-Brice et al. (2012). The women described the psychological impact it had had on both them and their children. Women who had been sexually abused described consequences such as the inability to have sex or a fear of having sex and/or avoiding it (Eastgate et al., 2011; Stoffelen et al., 2018). Some said that they had developed mental health problems, and a few women even described self-harm and suicidal thoughts (Pestka & Wendt, 2014; Stoffelen et al., 2018; Walter-Brice et al., 2012).

Four articles analyzed *their experiences*: Eastgate et al. (2011), Pestka and Wendt (2014), Stoffelen et al. (2018), and Walter-Brice et al. (2012). These studies showed the women were willing to talk about *their experiences*, in addition to conveying the need to be heard, believed, and supported (Eastgate et al., 2011). Participants described abuses that occurred in childhood and adolescence, where stories of rape-based domestic violence predominated (Eastgate et al., 2011; Pestka & Wendt, 2014). However, most of the stories developed in adulthood. Women reported having experienced different types of violence: physical, psychological, and emotional abuse, sexual abuse, verbal harassment, theft, and revictimization. In addition, when the abuse occurred within the couple, the aggressors had threatened and harassed their partners to trap the women in the relationship through fear (Walter-Brice et al., 2012). Many women reported serious physical assaults, in some cases life-threatening, with the use of various types of weapons (Pestka & Wendt, 2014). Sexual violence was also common, as several women reported sexual assault (Stoffelen et al., 2018).

Two articles analyzed the experiences of women when *reporting the abuse*: Eastgate et al. (2011) and Walter-Brice et al. (2012). All five women in the research of Walter-Brice et al. (2012) reported the situation to the police, and most did so to the Social Services; these women described having received inadequate or useless responses. The injustice they had experienced was a common experience and they

expressed feelings of anger, annoyance, and frustration at the lack of effective action (Eastgate et al., 2011; Walter-Brice et al., 2012). The two women with children who had reported the abuse to Social Services described how their initial pleas were ignored and that, when the abuse intensified, they took custody of the children away from them (Walter-Brice et al., 2012). The injustice and lack of understanding experienced were common in all interviews. Those assaulted stated that the experience of being interrogated and cross-examined made them feel as if they were the ones accused. Often, services seemed to protect aggressors' rights more than women's; yet, despite the injustice suffered, all participants agreed that abuse should be reported (Eastgate et al., 2011; Walter-Brice et al., 2012).

Finally, one article analyzed *the support and help received*: Walter-Brice et al. (2012). The participants described how most of them experienced help from women's organizations. They also described having found a safe place to share their experiences and reduce physical and emotional isolation. In addition, they mentioned that being heard and believed by services made them feel comforted and supported.

Views and Experiences on Couple Relationships

The topic of couple relationships was investigated in three articles (Eastgate et al., 2011; O'Shea & Frawley, 2020; Pestka & Wendt, 2014). Three main themes were identified: *the beliefs and attitudes of the participants, the feeling of belonging, and their experiences*. All of which dealt with relationships from a solely heterosexual perspective.

All three articles analyzed the *beliefs and attitudes regarding couple relationships*: Eastgate et al. (2011), O'Shea and Frawley (2020), and Pestka and Wendt (2014). It was seen that the participants exhibited positive attitudes and described couple relationships as an important part of their lives (Eastgate et al., 2011; O'Shea & Frawley, 2020; Pestka & Wendt, 2014). Most of the participants showed in the interviews that they clearly preferred non-sexual relationships, others that they wanted physical intimacy but not sexual relationships, while another smaller group wanted to have satisfactory sexual relationships (Eastgate et al., 2011; O'Shea & Frawley, 2020).

Two papers dealt with the *feeling of belonging*: O'Shea and Frawley (2020) and Pestka and Wendt (2014). Participants in one of the studies (Pestka & Wendt, 2014) described feeling rejected in their childhood. Instead, when they talked about their adulthood, they identified being married, in love, or being mothers with a great feeling of happiness, love, and belonging (O'Shea & Frawley, 2020; Pestka & Wendt, 2014). According to their testimonies, these examples of traditional heterosexual relationships gave meaning to their lives (O'Shea & Frawley, 2020).

One of the studies analyzed *women's experiences of their relationships*: O'Shea and Frawley (2020). A recurring theme was the intervention and often the lack of acceptance of such relationships by families. Even so, women found ways to continue their relationships without their knowledge. This way of resisting external intervention, although satisfactory, required a significant effort to be able to experience their relationships. In addition, these ways of experiencing them led the general population to treat their relationships as imaginary or not to take them seriously because they did not coincide with traditionally established canons.

LGTBIQ+ Collective

Two of the selected articles dealt with the theme of the LGTBIQ+ collective: Burns and Davies (2011) and Stoffelen et al. (2018). Within this code, the following themes were identified: *experiences as people in the LGTBIQ+ collective, beliefs and attitudes towards homosexuality, knowledge on the subject, support and help received, and mental health*. One of them took a group of heterosexual women with intellectual disabilities as a reference (Burns & Davies, 2011), and the other examined the perspective of lesbian and bisexual women with intellectual disabilities (Stoffelen et al., 2018).

Stoffelen et al. (2018) asked bisexual and lesbian women about their *experiences as people in the LGTBIQ+ collective*. Participants talked about coming out of the closet between the age of 13 years and adulthood. Some of the women received support in this process, and others had to navigate this process alone. All the participants of the study described feeling insecure when talking for the first time about their sexual orientation with their friends and acquaintances. The reactions they received from doing this varied: For seven of them, the reactions had been positive; one woman had both positive and negative reactions; and finally, another woman mentioned having received negative reactions due to her sexuality. When interviews were conducted, six of the ten participants said that they openly expressed their sexuality in their everyday environments (Stoffelen et al., 2018).

Burns and Davies (2011) analyzed the *beliefs and attitudes* heterosexual women had regarding the LGTBIQ+ collective. The group of heterosexual women held mostly negative attitudes towards homosexuality. Although the attitudes of the participants towards male and female homosexuality did not show great differences, the women felt homosexuality in men was something more unnatural. However, they presented more opposing views on marriage between women. In addition, it was observed how some women accompanied their responses with hostile comments towards female homosexuality.

In the same study (Burns & Davies, 2011), the authors also examined the *knowledge of the subject* observed in the group of heterosexual women. The authors found that these opposing attitudes and beliefs towards homosexuality might have been related to the lack of knowledge on the subject and observed that 74% of the participants did not respond correctly when asked about the meaning of homosexuality; although the percentage of knowledge was higher when asked about the word “gay,” the information about it remained sparse.

Stoffelen et al. (2018) analyzed *the support received* from professionals when it came to women with intellectual disabilities finding their way in the LGBTBIQ+ community. The paper showed that more than half of the participants were satisfied with the support received from the professionals when it came to finding their way in the LGBTBIQ+ community and felt safe and accepted by them. Other women complained about the lack of confidence to talk about certain issues with workers, such as sex. Therefore, some women had had to seek information about this without any support or contribution from third parties.

Finally, this same study analyzed the *mental health of LGBTBIQ+ women with intellectual disabilities* (Stoffelen et al., 2018). The women openly described feelings of great loneliness and mental problems such as depression, alcohol addiction, anxiety, or harassment arising from experiences related to their sexuality.

Knowledge About Contraception and Experiences

The two studies that deal with the issue of contraception (McCarthy, 2009; Servais et al., 2002) analyzed three main themes: *women’s experiences, women’s knowledge, and the reasons for the use of contraceptives*.

Both studies analyzed *the experiences the women regarding the use and prescription of contraceptives*: McCarthy (2009) and Servais et al. (2002). Women reported that they played a generally passive role in their interactions with doctors. Most of the women in McCarthy’s study (2009) appreciated having been accompanied to the medical consultation so as to have been able to count on someone they trusted, but also for their role as an intermediary or interpreter. All the participants agreed that they would have appreciated accessible information on contraception from health workers (McCarthy, 2009). Servais et al. (2002) observed how neither medical nor personal factors usually influenced the decision-making process. In most of the cases, the decision was made by the family or staff members of the services they attended. However, some women had decided to use contraceptive measures and which methods to use; it should be highlighted that these women were among those who needed the least support.

McCarthy (2009) analyzed the lack of *knowledge on contraception and reproduction*. The participants stated that they had received some training in the services they were attending. Still, a general lack of knowledge was noted: Most did not know or could not imagine how their method of contraception worked. There was also a lack of knowledge regarding reproduction, such as not knowing about the menopause or the relationship between fertility and the need for contraception. In addition, while some women explained that they had received information on the subject too early, others said that they had not known anything until after they had become pregnant.

This same study (McCarthy, 2009) also analyzed the *reasons for the use of contraceptives*. The majority alluded to the need to avoid pregnancy; however, only a minority of these women made it clear that they were sexually active. Some other women used them to regulate their periods. A participant said that she took them as she was considered especially vulnerable to sexual abuse; although from the testimonies of women, it can be assumed that this can also be the case of many others. When asked about the decision to stop the use of contraceptives, most said that they would have to ask permission from a third party as it was not under their own control or because they thought other people would be better informed about the issue.

Beliefs Regarding Gender Scripts

Two studies analyzed gender scripts (Burns & Davies, 2011; O’Shea & Frawley, 2020) and centered on the *beliefs and attitudes around them*.

Both these articles agreed that women with intellectual disabilities presented stereotypical and traditional beliefs regarding male and female gender scripts. Some participants (Burns & Davies, 2011) perceived men as the dominant gender, these being harsher and technically more efficient, while identifying women as the weaker and more emotional gender. From what was perceived in the interviews, gender and classical femininity had become a source of “power” that made them feel desired, valid, and productive through the reproduction of traditional cultural scripts (O’Shea & Frawley, 2020) contrary to the tendency to classify people with intellectual disabilities as people without gender.

Discussion

This study aimed to review the perspectives of women with intellectual disabilities regarding their sexual-affective relationships and reflect on the policy implications that might arise from these perspectives. The results obtained offer valuable insights (*understanding*) into the needs, experiences,

and knowledge of adult women with intellectual disabilities from different parts of the world. These findings can be used as a valuable resource or foundation for families and professionals when providing assistance, supporting, and educating in the field of affective-sexual relationships. Recognizing their voices and understanding the factors that impact their experience of sexuality is vital to creating appropriate and meaningful resources (Bernert, 2011).

Spaces and situations must be created for this group to talk about their sexuality; people without intellectual disabilities should not fill this lack of information with their own voices (Hoorn, 2015).

The selected studies present varying perspectives on knowledge about sex and sexuality; however, the studies concur on the need for information and education tailored to women's specific needs, something which aligns with results from previous literature (Brkić-Jovanović et al., 2021; Friedman, 2023; McClelland et al., 2012). Although the articles present diverse and even contradictory scenarios in some cases on attitudes towards this topic, they coincide with other research in presenting a more negative outlook on sex and sexuality among women with intellectual disabilities than that of the rest of the population (Gil-Llario et al., 2021; Siebelink et al., 2006). These negative perceptions often stem from the belief that sex is risky and is a desirable act only for men (Schaafsma et al., 2015). The inability to express one's sexuality positively increases personal vulnerability (Anderson, 2015; Hughes et al., 2012) and the risk of mental health problems (Conder et al., 2015).

Unfortunately, the experience of abuse was a shared experience among the women; most of these had happened in adulthood and within the couple (Anderson, 2015; Ballan & Freyer, 2012; Dixon & Robb, 2016; Morcillo & Pérez, 2018). Compared to the rest of the population, people with intellectual disabilities are more likely to be sexually abused and less likely to report it (Tomsa et al., 2021; Wilson, 2016). Many women described feeling ignored, judged, and revictimized when reporting their abuse to the police. It is important that the reporting processes are adapted to their needs and that professionals know how to properly address these needs (McCarthy et al., 2017; Tomsa et al., 2021). At the same time, the women had felt safe and supported in women's organizations or in the services they had attended.

The lack of knowledge and accessible information is another common point that has been noted. The lack of information about the LGTBIQ+ collective led to negative, even hostile, attitudes towards it among the heterosexual women while bringing about feelings of loneliness and isolation in the case of bisexual and lesbian women. Another area in which this lack of knowledge could be appreciated was that of contraception. It is necessary to provide accessible information and sex education tailored to the needs of each person. In addition, it is crucial to consider the needs of

future recipients and the participation of the target group in the development of these resources (Schaafsma et al., 2013).

Another common point was the lack of independence and external intervention. It has been seen how the environment significantly regulates their lives and decisions. People with intellectual disabilities often experience resistance from their loved ones when exercising their sexual rights (Wos et al., 2020). In most cases observed, these interventions are perceived as an intrusion into their lives and their rights.

Finally, the reproduction of traditional heteropatriarchal roles in their couple relationships makes women feel empowered in the sense of making them feel desired, valid, and productive. These roles offer women a mechanism of power and defense against the citizen's vision of them as people without gender. Being married, in love, or being a mother makes them feel desired, happy, and loved, in addition to developing a greater sense of belonging. The influence of the classical vision of gender can be also reflected in the stereotypical beliefs regarding male and female roles, identifying the former with the dominant gender and themselves with the weak gender (Hoorn, 2015; Huaiquián et al., 2018).

During the development of this research, it has been possible to observe a series of limitations that must be considered when interpreting the results obtained, since they may have given rise to unknown biases.

The primary limitation is associated with the systematic literature review process itself. The limited selection of literature analyzed may not provide a comprehensive understanding of the differences in perceptions and beliefs regarding sex and sexuality derived from the participants' cultural backgrounds. However, it does comprise a sample of 540 women from seven countries of the world with different realities, experiences and characteristics.

Another limitation was the lack of representation, since the sample of participants was entirely made up of cisgender women and dissident sexual orientations were underrepresented. Therefore, for future research, it is recommended to pay attention to this aspect, seek a more diverse sample of participants, and give a voice to the LGTBIQ+ collective with intellectual disabilities.

Conclusions: Policy Implications

Thanks to the systematic literature review conducted and the resulting findings, it has been possible to derive four main conclusions that are further developed below, all of which are related to *social and public policy implications*.

This study provides results in terms of the knowledge, or lack thereof, that we have regarding the topic; so, the first conclusion that has been drawn from the current systematic review of literature is the need to investigate the

socio-affective relationships of women with intellectual disabilities. Many of the studies were discarded for not undertaking research from the point of view of the collective of women with intellectual disabilities, so we want to remember the need for and importance of listening to the voices of these women. Research into their opinions, experiences, and needs has the potential to contribute to the improvement of the lives of this group—a group which is doubly punished and vulnerable by jointly suffering both as women and also as people with intellectual disabilities. The results of this study not only show the need for research but also suggest that the women in the studies analyzed have significant problems when it comes to developing positive sexual identities. Research shows that women with intellectual disabilities often have negative perceptions regarding sex and sexuality, often leading to self-imposed abstinence based on fear of relationships or intimacy.

Therefore, the first implication is related to the need for a continuous affective-sexual education beyond the schooling stage. The support and knowledge must adapt to the different phases and life challenges faced by the users of this service and break with the traditional health model of sex education. This study highlights that, in addition to the prevention of risks and contraceptive methods, socio-affective issues need to be addressed, working on self-esteem, sensuality, limits, homosexual relationships, and gender scripts, among others.

The second conclusion shows the need to make room for dissident forms of sexuality and gender within affective-sexual education. On the one hand, it is important to work on the issue of gender and the roles associated with it, since there is a tendency to see women with intellectual disabilities as “not real women” who do not experience gender-related issues, but as eternal children or people without gender. However, for some women, gender becomes a point of resistance to fight against restrictive ideas about their disability. It has been possible to see how not only alternative gender scripts create these places of resistance, but that women who voluntarily choose to follow traditionally female gender scripts also perceive them as valuable and productive. On the other hand, it is necessary to create awareness and knowledge about dissident sexualities and genders. This must be done in such a way that these are not an “extra” or something out of the ordinary but treating them in an interwoven way with traditional constructs both in research and in practice. In addition, it has been found that women with intellectual disabilities, in general terms, are less aware of these types of relationships and identities and that they harbor more traditional and stereotyped beliefs, sometimes even negative, towards them than the general population. This makes it clear that there is a need to address this issue, as well as the issue of gender in affective-sexual education raised previously. Finally, the need to conceptualize sex education in this way is emphasized

to promote the social identification of LGBTIQ+ women within the group of women with intellectual disabilities to end the invisibility and internalized homophobia that they suffer in some cases.

Thirdly, this literature review also aims to highlight the importance of creating and distributing accessible information on topics related to affective-sexual relationships. The need for information on dissident sexualities, contraception, or abuse support structures is revealed through the articles investigated. It also stresses the need for services as intermediaries and distributors of this information, since if it is created but does not reach the target group, the effort to create adapted information using images and easy-to-read texts would have been in vain.

Finally, this review suggests developing and enhancing training for the family, for services and the creators of policies related to the socio-affective relationships of women with intellectual disabilities. The negative vision that society frequently has towards the socio-affective relationships of people with intellectual disabilities is added to the tendency to restrict the sexuality of women in general. This fact ends up affecting not only the perceptions of these women but also the knowledge, resources, and supports they can count on. This is why we want to emphasize the importance of training for the people and institutions that accompany them so that they do not perpetuate these trends and attitudes. It has been seen that these behaviors often come from an attempt to protect the women against unpleasant experiences since it is a group that is particularly vulnerable to harassment, abuse, and mistreatment. However, sometimes this idea has led to the curtailment of these women’s freedom of sexual expression. This review contributes to highlighting the need to provide women with better defense mechanisms. For this reason, it is necessary for professionals and families to receive training that enables them to accompany women with intellectual disabilities in a positive way in their affective-sexual relationships. This support must be based on the idea that they, with the necessary aids and resources, are able to prevent negative sexual consequences and develop safe, healthy, affective-sexual relationships.

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Declarations

Ethics Approval This study was performed in line with the principles of the Ethics Committee's normative. Approval was granted by the Ethics Committee of the University of Girona (April 25th, 2022/No. CEBRU0009-22).

Consent to Participate Informed consent was obtained from all individual participants included in the study.

Competing Interests Not applicable.

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