Sexuality of People with Intellectual Disabilities: A Proposal to use the Positive Sexuality Model

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Accepted: 4 July 2021 / Published online: 21 July 2021
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Abstract

The aim of this research was to determine the trends in the field of analyzing positive aspects of sexuality of people with intellectual disabilities (ID). In relation to these findings, the possibilities of applying the model of positive sexuality were presented. A literature search covering studies published between 1980 and 2020 was conducted. 19 studies were included. Researchers focus on partnerships, mainly heterosexual ones, associated experiences, plans and ideas. The results show that people with ID are able to report on experiences accompanying relationships and their depiction is relatively rich. People who do not have such experiences expect them in the future, treating them as a very important aspect of life. Referring to the model of positive sexuality, the areas of research in the population of people with intellectual disability were specified, and the theoretical justification of the model, general methodological aspects and practical usefulness were provided.

Keywords Positive sexuality · People with intellectual disability · Experiences · Research

Introduction

Human sexuality is a complex phenomenon in terms of manifestations, preferences, values, difficulties and conditions. The complexity of human sexuality, which concerns every human being regardless of their psychophysical condition, is reflected in the definition proposed by the World Health Organization which states that human sexuality includes “sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, reproduction” and “is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships” (Loeber et al., 2010, p. 170). Human sexuality is shaped in the context of

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specific biological, psychological and socio-cultural conditions. The latter aspect is particularly important when it comes to recognizing, expressing and exploring one's sexuality. The way people deal with their sexuality largely depends on the image of sexuality created in the socialization process as well as the values, norms and beliefs associated with this process. Sexuality can be a source of satisfaction and pleasure that promotes well-being and even personal development manifested in the acquisition of specific competences (Black & Kammes, 2019). These phenomena constitute the components of the positive sexuality model. The main assumptions of the positive sexuality model (or sex-positivity) are as follows: a) the model emphasizes the importance of sexual pleasure, freedom and diversity, but it does not exclude risk and difficulties; b) referring to the assumptions of positive psychology, the model assumes that the strengths and uniqueness of each person's sexuality should be taken into account as well as the fact that people who make use of their strengths are able to solve problems, experience happiness and fulfillment and consequently develop their sexual identity and sexual expression; c) the model takes into account the multiplicity of internal and external factors that shape sexuality and it emphasizes the importance of not only conscious choices but also experiences gained in life through participation in new contexts and situations. The authors of the model see its role in humanization and prevention of social exclusion. They also see its application at many levels of social life, including micro-, meso- and macrostructural ones. In its justification and application in research, the authors see the usefulness of many epistemological and methodological outlooks (Williams et al., 2015a, 2015b).

Considering high cognitive and application value of the positive sexuality model, it should be noted that this perspective has not been thoroughly explored when it comes to people with intellectual disability (ID). It is worth mentioning, however, that the method of analyzing sexuality in this group of people has changed shifting towards the verification of the group representatives' experiences (numerous qualitative studies) at the same time enabling the people with ID to express their views and preferences (Stoffelen et al., 2019) and to increase their participation in projects (numerous studies with self-advocates and other participatory studies) (McCarthy, 1999; Stoffelen et al., 2019). However, as valuable empirically as these works may be, they do not seem to sufficiently focus on the positive phenomena. Some authors confirm this tendency by stating that the negative issues, problems and dysfunctions are given priority over positive aspects (Bates et al., 2017; McCarthy, 2014; Sitter et al., 2019; Turner & Crane, 2016). Whittle and Butler (2018) see some progress in solving the aforementioned problem as they write about more positive views expressed in recent publications that reflect contemporary trends in changing people's attitudes. Nevertheless, it cannot be equated with the realization of the model of positive sexuality. This paper addresses the issue of positive sexuality of people with, presents the systematic review of the research and aims to determine the extent of interest in positive phenomena presented by the authors of the reviewed papers. The key intention here is an attempt to show the usefulness of the positive model of sexuality for the future exploration of this issue, as well as its significance from a practical point of view.

For the discussed issues, it is important to state that intellectual disability was considered in the literature in terms of at least two traditional and extreme

models—the individual/medical and the social one. The first of them, assuming the primacy of biological dysfunction, ignored the importance of sociocultural determinants of this disability and the importance of environmental factors for the development of the potential of a person with a disability (Boxall, 2002). The individual model, also known as the medical model, relies largely on the conceptual category of impairments to explain the nature of disability, claiming that these impairments create difficulties in fulfilling tasks and roles, and participating in various spheres of life. Disability is a consequence of impairment and the aforementioned difficulties; it is a personal problem (personal tragedy) which should be tackled by means of activities focused on the individual. This model was developed in the times when medical service dominated, which was visible in how institutions, created to realize various goals (not only treatment and rehabilitation, but also care), operated. It included elements of the medical approach to a human being, unique for those times: treating people like objects, and the primacy of the physical sphere over all the others. In the social model, the essence of disability lies in complex mental and material barriers. Disability results from insufficient service and inadequate organization of society (Lang, 2001). One of the more important mechanisms which determine the way individuals with disability function is oppression in the forms of: exploitation, marginalization, discrimination, cultural imperialism, and violence (Boxall, 2002; Williams et al., 2007). Oppressive activities begin when “otherness” is recognized; this recognition relies on socio-cultural factors, and especially social agreements describing the so called normality in every sphere of human functioning. As soon as a deviation from norm (moral, or health norm) is identified and labelled (in the form of a diagnostic category, e.g. intellectual disability or mental illness), the process of social “disabling” starts (Lang, 2001). Identification of dysfunctions and limitations is a complex process, depending on, among other things, their type and severity (which also influence the process of social oppression). According to these assumptions, disability is a social construct. The definition of intellectual disability (mental retardation) is not an absolute, but a result of an agreement. The construct of disability greatly depends on social and cultural contexts, expectations and the level of social tolerance—and all of these change in time and space. On the basis of the postmodern paradigm, a proposition arose sometimes referred to as the universal model. In this model disability is constructed taking into account material phenomenon (corporeality) and symbolism (interpretation of corporeality and / or social oppression) (Gabel & Peters, 2004). Thus, it emphasizes personal experiences as well as their individual interpretation. It is often forgotten in the social model (in both its versions) that an individual with a disability is not passive towards specific interactions. This individual is the causative subject, shaping, at least to some extent, the quality of his/her being in the material and the non-material dimension. In this approach, “disability” is not the essence of an individual’s life, but only an accompanying element (cf. Speck, 2005). This approach is important for examining the phenomena of positive sexuality.

Materials and Methods

When systematically reviewing the studies, there were no limitations to any particular research type, as both qualitative and quantitative analyses were included. When collecting the material, meta-analytical studies were also taken into account assuming that their authors indicate certain tendencies which may be important at the stage of drawing conclusions. The assumptions of the model proposed by Williams et al. (Williams et al., 2015a, 2015b) provided the conceptual basis for the analysis of individual aspects that make up the model of positive sexuality of people with ID. Individual perennial research interests related to the attitudes of people with ID towards sexuality or its particular aspects (such as sexual health or parenthood) (Parchomiuk, 2012, 2013a, 2013b, 2014, 2016, 2017) were of significant importance. They also allowed for an insight into the problem and its recognition in terms of specific needs, limitations and opportunities.

Inclusion Criteria and Search Strategy

Peer-reviewed articles written in English, published between 1980 and 2020, were included in the review. First of all, the following databases were reviewed: Scopus, Web of Science, ERIC, Academic Search Ultimate, SocINDEX with Full Text, APA PsycArticles, Academic Research Source eJournals, Health Source—Consumer Edition, Health Source: Nursing / Academic Edition, MEDLINE. The following terms were used: “sexual satisfaction” or “sexual pleasure,” or “sexual self-esteem”, or “sexual self-efficacy” or “sexual well-being” or “happiness” or “love” or “romantic relations” (Anderson, 2013; Williams et al., 2015a, 2015b) and “intellectual disability” or “mental retardation” or “learning disabilities” or “developmental disorders”. At this stage, after rejecting duplicates, 381 records were compiled. On the basis of the abstracts and key words 52 full-text articles were selected from this compilation. The literature cited in these articles was analyzed which resulted in 16 articles. Out of 68 works, whose full texts were reviewed, 49 items were rejected. The criterion for rejecting articles from the collected pool of full texts was the lack of a precise definition of the research goal and the lack of issues related to positive sexuality the selection of which depended on specific keywords. The search process and its effects are presented in Fig. 1.

Quality Assessment

Articles based on qualitative research were assessed with the use of the Quality Appraisal Skills Program (CASP) (Critical Appraisal Skills Programme & Qualitative Studies Checklist, 2018). In order to evaluate quantitative research, a proprietary tool has been developed, using some of the guidelines from the Cohort Study Checklist (Critical Appraisal Skills Programme. CASP Cohort Study Checklist, 2018). While scoring individual criteria for quantitative and qualitative research, the following proposal was applied, used by (Lama et al., 2019): 0 points for no or

Fig. 1 Flow diagram of literature search and study selection

insufficient information; 1 point for moderate information; 2 points for full information. The results of the evaluation performed in relation to the qualitative and quantitative studies are presented in Tables 1 and 2.

Results

Study Characteristics

19 articles were included in the analysis. Four of them show the results of quantitative research (Arias et al., 2009; Gil-Llario et al., 2018; Morales et al., 2015; Siebelink et al., 2006), one of them refers to quantitative and qualitative research (Stoffelen et al., 2019), and the remaining articles relate to qualitative research. In the last

Table 1 Results of the quality assessment of selected qualitative studies (CASP Qualitative Studies Checklist)

References	Clear state- ment of aims	Qualitative methodology appropriate	Appropri- ate research design	Appropri- ate recruitment strategy	Considera- tion of data collection	Consider- ation of research relationships	Ethical issues con- sidered	Rigor- ous data analysis	Findings clearly stated	Value of the research	CASP score
Neuman (2020)	2	2	2	2	2	1	2	2	2	2	19
Ćwirynkalo and Żyta (2019)	2	2	1	1	1	0	0	1	1	2	11
Bates et al. (2017)	2	2	2	2	1	1	2	1	2	2	17
Karellou (2017)	0	0	—	—	—	—	—	—	—	—	0
Matila et al. (2017)	2	2	2	2	1	2	1	1	1	2	16
Bates et al. (2016)	2	2	2	2	1	1	2	1	1	2	16
Turner and Crane (2016)	2	2	2	1	2	1	2	1	2	2	17
Rojas et al. (2014)	1	2	2	2	2	0	2	1	1	2	15
Rushbrooke et al. (2014)	2	2	2	2	1	1	1	2	2	2	17
Lafferty et al. (2013)	2	2	2	2	2	0	2	1	1	1	15
Sullivan et al. (2013)	2	2	2	1	2	2	2	1	2	2	18

Table 1 (continued)

References	Clear statement of aims	Qualitative methodology appropriate	Appropriate design	Appropriate recruitment strategy	Consideration of data collection	Consideration of research relationships	Ethical issues considered	Rigorous data analysis	Findings clearly stated	Value of the research	CASP score
Bane et al. (2012)	2	2	2	0	1	0	1	1	1	1	11
Healy et al. (2009)	2	2	2	1	1	0	1	1	1	1	12
Kelly et al. (2009)	2	2	2	1	1	0	1	1	1	1	12
Yau et al. (2009)	2	2	2	1	1	0	1	1	1	1	12

Table 2 Results of the quality assessment of selected quantitative studies (author's proposal)

References	Clear statement of aims	Group selection (representativeness, selection criteria)	Research tools (description of the tools, psychometric properties, adaptation to the needs of persons with ID)	Including intermediary variables	Statistical analysis (justification, description, relevance to the purpose of the research)	Results clearly stated	Precise results	Reliability of the results	Ethical issues considered	Research implications	Total score
Gil-Llario et al. (2018)	2	1	1	1	2	2	2	2	1	1	15
Morales et al. (2015)	2	0	0	0	1	1	2	2	0	1	9
Arias et al. (2009)	2	1	2	1	1	2	2	2	0	1	14
Siebelink et al. (2006)	2	2	2	2	2	2	2	2	0	2	18

group of the aforementioned articles methods allowing for the analysis of respondents' experiences, such as semi-structured interviews were often used. All works were created in the 2000s. No articles from the 1980s were found in the explored databases ($n=381$). Most of the research was carried out in Europe. The number of people participating in the qualitative research ranged from 5 to 97. In quantitative studies, from 40 to 376. In all studies, the subjects were people with ID. The age of the respondents with intellectual disability varied significantly: from 13-year-olds to 60-year-olds and older. Most studies did not specify the degree of intellectual disability, and the inclusion criterium was often the ability to communicate. One of the quantitative studies included a comparative group, i.e. non-disabled people (Morales et al., 2015).

Research Quality Assessment

One of the studies did not meet the basic criteria and was excluded from further analyses. The original research intention here was of quantitative character, and the presented analysis was conducted in accordance with the qualitative approach (Karellou, 2017). The assessment of the remaining qualitative studies shows that they do not fully meet all the relatively strict criteria, but nevertheless meet the most important ones (the first two), which allow for recognizing their methodological values and for appreciating their contribution to the subject matter (Table 1). In most cases we deal with incomplete information in relation to a given criterion. For example, there is no justification for the selection of respondents, no information where the research takes place, and no discussion on the data. Most often, there is no reflection on the participation of persons with ID as entities who may reveal specific difficulties during the implementation of qualitative methods (Finlay & Lyons, 2001; Rapley & Antaki, 1996). The same concerns the ways of eliminating any potential problems. In most studies, their authors ignored the aspects explaining the relationship between the researcher and participants that could affect the recruitment of the sample group, the formulation of questions, or the method of analyzing the results. Ethical issues were discussed in most of the analyses, though the appropriate formal consent was not always obtained. In the majority of studies, the analysis of the material was detailed and based on specific procedures, but there was no explanation for the selection of the presented data illustrating the analysis process. Only a few researchers discussed the methods of confirming the reliability of findings (e.g. triangulation). The analyzed papers include one study prepared in cooperation with people with ID which is based on inclusive research (Bane et al., 2012).

In the case of quantitative research, a significant problem lies in the lack of information on the representativeness of the studied groups, insufficient data on the psychometric properties of the tools and the justification for their selection (Table 2). Some analyses were extensive, but variables potentially important for the nature of the results, such as gender, or age of the respondents, were not included. The latter may be important, especially if the significant age range of the respondents is taken into account (Table 3). Not all authors justified the choice of specific statistical analyses. There was no reference to formal ethical consent in any of the studies. Two

Table 3 Characteristics of selected studies

References	Aims/research questions	Method/ analysis	Participants/ sex (female/male), age	Key findings relevant to the review
Neuman (2020), Israel	To acquire insight into what couple relationships mean to persons with intellectual disability (ID) and determine what forms of supports and assistance they need accordingly	Semi-structured interview/ qualitative-thematic content analysis	20 couples with ID, 22–76	External appearance of partner and the similarity of partner as an important criterium in building a relationship; mutual support and assistance, providing the partner with personal space as the base of a relationship; desire for a lasting relationship and its formalization
Ćwirynkato and Żyta (2019), Poland	To gain insight into self-advocates' with intellectual disabilities perception and experiences associated with love and intimate relationships	Focus group interview/ qualitative—interpretative phenomenological analysis (IPA)	31 persons with mild and moderate ID (self-advocates), 13 F/18 M, 20–59 (M = 39)	Various ways of understanding love—love as special actions, attitudes and other feelings. Love as a necessary condition of coitus. The importance of intimate relations. The importance of personal competences acquired during self-advocating actions. The significance of the attitudes of specialists and other people from the closest environment. Negative attitudes hindering privacy

Table 3 (continued)

References	Aims/research questions	Method/ analysis	Participants/ sex (female/male), age	Key findings relevant to the review
Stoffelen et al. (2019), Netherlands	To acquire insight into what people with ID believe is important, with respect to sexuality and their sexual rights	Nominal group technique/ qualitative	39 persons with mild ID (6 group), 14F/25 M, 23–70 (M = 44)	Great value attached to relationships with the partner, not only in the scope of physical sex life, but also in terms of its emotional aspects. Difficulties with getting intimacy and security. Incomplete recognition of sexual rights by the environment
Gil-Llario et al. (2018), Spain	To describe and analyse areas of sexuality: history of sexual activity, sexual practices, knowledge and use of contraceptives, sex education received and sexual abuse in adults with ID and to explore the existence of possible differences in relation to gender and age	Questionnaire about sexuality for people with intellectual disability (CUSEXD)/ quantitative	360 persons with mild and moderate ID, 180F/180 M, 19–55 (M = 39.97)	Varied sexual activity. Approximately 40% expressing sexual satisfaction, more often men and younger people

Table 3 (continued)

References	Aims/research questions	Method/ analysis	Participants/ sex (female/male), age	Key findings relevant to the review
Bates et al., (2016, 2017), UK	To get to know the preferences related to the choice of a partner among people with ID	In-depth interview/ qualitative—not specified	11 persons z ID, 5F/6 M, <35–60+	The need for love, feeling cared for and having a loved one with whom it is possible to develop a special and lasting relationship, based on emotional and practical support. The partner's personality and companionship are valued to the greatest extent, whereas their physical features are of a lower value. Feeling proud and normal about having a partner. Physical contact as an essential basis of a relationship and a source of satisfaction
Mattila et al. (2017), Finland	To research how people with ID perceive love and bring out their own way of defining love and its meaning, from their own perspective	Semi-structured interview/ qualitative—theory led content analysis	7 persons with ID, 5F/2 M; 18–31	Love as a series of positive emotions, positive meaning of love perceived in terms of quality of life; actions that are an expression of love received and bestowed: intimacy and care. Love as a source of personal empowerment and strength. Hope associated with experiencing love in the future

Table 3 (continued)

References	Aims/research questions	Method/ analysis	Participants/ sex (female/male), age	Key findings relevant to the review
Turner and Crane (2016), USA	To check how adults with ID describe their experiences and expression in a romantic and / or sexual relationship	Semi-structured interview, observations/ qualitative – thematic analysis	5 persons with mild ID, 2F/3 M, 21–54	Pleasure understood as: 1) sensuality (physical sensations); 2) intimacy (emotional); 3) sexual expression; 4) sexual attitudes; 5) sexual self-identity. Confirming the ability of people with ID to experience a spectrum of sexual, physical and emotional sensations. Having a sexual identity—awareness of being a sexual being, endowed with needs, desires, values and beliefs

Table 3 (continued)

References	Aims/research questions	Method/ analysis	Participants/ sex (female/male), age	Key findings relevant to the review
Morales et al. (2015), Mexico	To explore the way in which adults with Down's syndrome may conceptualize love	Scale/quantitative	12 persons with ID, 3F/9 M, 15–48 (M = 31.16); 28 persons with typical development, 18F/10 M, 16–45 (M = 30.14)	People with Down's syndrome assessed the level of romantic love in a way that was similar to the way people from the typical population assess it. Despite their cognitive characteristics, they were able to integrate the information about level of passion, level of intimacy, and level of commitment in a meaningful way. They were sensitive to the fact that the impact of degree of passion and degree of intimacy on romantic love can change as a function of the level of commitment considered
Rojas et al. (2014), Spain	To find out what people with ID think about emotional and sexual relationships	Semi-structured interview/ qualitative—thematic analysis	16 persons with ID, 6F/10 M, 18–39	Having a partner as one of the most important things in life; defining a relationship with a partner as closeness, trusting and respecting each other

Table 3 (continued)

References	Aims/research questions	Method/ analysis	Participants/ sex (female/male), age	Key findings relevant to the review
Rushbrooke et al. (2014), England	To assess sexuality and intimate relationships from the perspective of people with ID	Semi-structured interview/ qualitative—IPA	9 persons with ID, 5F/4 M, 21–58	Intimate relationships as essential and desirable, allowing for the fulfillment of important needs, which are essential for the quality of life; plans related to having a loved one, getting married, having children. Physical expression as an important element of experiences in relationships
Lafferty et al. (2013), Ireland	To uncover the experiences of couples in a close personal relationship, the nature of these relationships and the meanings they ascribe to them	Semi-structured interview/ qualitative—grounded theory	16 persons with ID (8 couples, including 4 marriages), 26–65 (M=47)	Strong feelings connecting relationships, joint activities; experiencing happiness and satisfaction; increase in independence, self-trust and self-esteem; mutual support and complementation; awareness of difficulties in a relationship and the ability to deal with them; sense of security and making plans for the future
Sullivan et al. (2013), Scotland	Experiences and perceptions of close relationships in persons with ID	Semi-structured interview/ qualitative—IPA	10 persons with ID, 4F/6 M, 31–60	Physical intimacy as an important factor in a partner relationship, and its various manifestations; emphasizing the important role of touch

Table 3 (continued)

References	Aims/research questions	Method/ analysis	Participants/ sex (female/male), age	Key findings relevant to the review
Bane et al. (2012), Ireland	Feelings and beliefs of people with ID associated with friendship and relationships	Focus group interview/ qualitative—not specified Participatory research	22 persons with ID—co-researchers; 97 persons with ID (16 focus group), 52F/45 M, > 30–30 +	Relationships as a source of care, closeness, intimacy and support. Great importance given to partnership relations. The feeling of being treated like a child—relevant in the case of difficulties in creating a relationship. The need to acquire knowledge about problems in relationships; family support expected. The importance of having one's own apartment
Arias et al. (2009), Spain	To contribute to the analysis and understanding of couple relations and the perception of love in adults with ID, as well as its relation with emotional well-being	Specific Scale to Assess Love in Persons with ID/ quantitative	376 persons with ID, 189F/187 M, 18–71 (M = 34.58)	High positive assessment of realized love, satisfaction with partnership and sex. Positive relationship between the assessment of love and satisfaction and emotional well-being. Smaller family interference and higher level of self-determination as important factors in the assessment of love and emotional well-being

Table 3 (continued)

References	Aims/research questions	Method/ analysis	Participants/ sex (female/male), age	Key findings relevant to the review
Healy et al. (2009), Ireland	To gather information from people with ID about their knowledge, experiences and attitudes towards sexuality	Focus group interview/ qualitative—not specified	32 persons with ID, 12F/20 M, 13–31 +	Perceiving the reciprocity of relationships, getting positive experiences favouring self-improvement. Aspirations of being in a relationship and having children. Associating marriage with happiness and better future. Lack of acceptance by the environment, both with regard to current and potential relationships; emphasizing the right to privacy
Kelly et al. (2009), Ireland	To provide an understanding of the views of Irish people with intellectual disabilities, experiences and aspirations and to examine the type of assistance they would like from services for the disabled in this area	Focus group interview/ qualitative—not specified	15 persons with ID, 7F/8 M, 23–41 (M = 32)	The need to be in a relationship and the related aspirations. Positive evaluation of relationships—the source of support and companionship. Limited, selective and disordered knowledge on sexuality, coming from various sources. Awareness of restrictive attitudes from the personnel of institutions providing services. Limited abilities to realize sexual rights, or the need to raise the awareness in that matter. Hiding the fact of having intimate relationships

Table 3 (continued)

References	Aims/research questions	Method/ analysis	Participants/ sex (female/male), age	Key findings relevant to the review
Yau et al. (2009), China	To identify the sexual issues and concerns among adult persons with intellectual disability, including dating, intimate relationships, and marriage	Semi-structured interview/ qualitative—not specified	12 persons with mild ID, 9F/3 M, 22–44	Strong desire for having an intimate relationship. Sexual activity as confirmation of a romantic relationship. Strong desire to get married in the future. Positive notions about marriage. Willingness to have a non-disabled person as a partner
Siebelink et al. (2006), Netherlands	To gather information on sexual experiences of people with intellectual disabilities and analyze the relationships among sexual and relational needs, experiences, knowledge, and attitudes	Questionnaire/ quantitative	76 persons with mild and moderate ID, 29F/47 M	Positive attitude toward heterosexual kissing, hugging, and sexual intercourse. Neutral attitude toward the “impersonal” sexual activities (masturbation, adult movies, and prostitution), and a somewhat less accepting attitude regarding homosexuality. Many conventional sexual needs (kissing, intercourse, and masturbation) and even more relational needs (hugging and having a boy- or girlfriend). Hugging, kissing, and sexual intercourse as a prominent activities in intimate relations

studies highlighted the possible difficulties resulting from intellectual disability in the field of tools used (Arias et al., 2009; Siebelink et al., 2006).

A significant problem was related to the assessment of the paper in which the nominal group technique was used (Stoffelen et al., 2019). Only the basic criteria important for the evaluation of qualitative and quantitative research were applied here. The aim of the research was clearly and precisely formulated, and the research method was applied accordingly. The collected data were analyzed in detail in the context of the current achievements and made it possible to approach the aim adequately. Ethical issues were taken care of as well.

Problem Analysis

The analysis of the studied issues was carried out on the basis of 1) getting acquainted with the research findings; 2) selecting general thematic categories; 3) assigning particular cases to general categories (summary of research findings presented in Table 3). The research mostly focuses on issues related to the heterosexual couples among people with ID. It includes psychosocial and physical aspects of sexuality which occur most frequently in the reported experiences, thoughts and plans of people with ID. The analyzed perspective included the previous, current and planned experiences of the respondents. Only a few analyses were carried out with the participation of both partners (Lafferty et al., 2013; Neuman, 2020). The following general and specific aspects were identified:

- 1) Establishing relationships: preferences and choosing a partner, phases of creating a relationship (Bates et al., 2017; Neuman, 2020).
- 2) The essence of partnerships: emotional bonds, love; joint activity; mutual support and help, partner autonomy, respect, trust, the role of communication (Kelly et al., 2009; Neuman, 2020; Rojas et al., 2014; Rushbrooke et al., 2014)
- 3) The importance of partnership relations: the need to be in a relationship, perceiving positive personal development, sense of pride, normality (Bane et al., 2012; Bates et al., 2016; Healy et al., 2009; Lafferty et al., 2013; Rushbrooke et al., 2014).
- 4) Love: understanding, desire for love and experiencing love; the importance of love for the quality of life; love as the source of empowerment (Arias et al., 2009; Bates et al., 2016; Ćwirynkało & Żyta, 2019; Mattila et al., 2017; Morales et al., 2015).
- 5) Pleasure: desire for pleasure, physical expression as an important element of relationships (Bates et al., 2016; Lafferty et al., 2013; Rushbrooke et al., 2014; Siebelink et al., 2006; Stoffelen et al., 2019; Sullivan et al., 2013; Turner & Crane, 2016; Yau et al., 2009).
- 6) Sexual satisfaction: diversified sexual activities, a positive relationship with emotional well-being (Arias et al., 2009; Gil-Llario et al., 2018).
- 7) Sexual identity and sexual autonomy: functioning as a sexual being, the desire for autonomy, looking for the ways of realizing one's sexuality in environmental

- constraints; awareness of one's potential in the sexual sphere (Turner & Crane, 2016).
- 8) Emotionally-sexual integration: desire for an emotional relationship combined with physical pleasure; love necessary for commencing sexual relations (Yau et al., 2009).
 - 9) Dreams, plans and thoughts: being with a loved one, marriage and parenthood, marriage as the basis of a happy future (Healy et al., 2009; Kelly et al., 2009; Lafferty et al., 2013; Mattila et al., 2017; Rushbrooke et al., 2014).
 - 10) Contextual factors: negative and positive role of the environment (family and specialists); structural and organizational limitations resulting from the specific organization of life, transport and material barriers, low level of sexual education; coping with limitations (Arias et al., 2009; Bane et al., 2012; Ćwirynkało & Żyta, 2019; Healy et al., 2009; Kelly et al., 2009; Siebelink et al., 2006; Stoffelen et al., 2019).

It should be noted that the selected thematic categories are not separate, although they have been presented as such for the purpose of emphasizing them. Personal development and a sense of normality are achieved thanks to relationships based on love, friendship, autonomy, taking responsibility for oneself and one's partner, and the possibility of providing support and help. Plans and ideas about one's future are based on positive experiences in relationships and indicate the need to be continued, formalized and developed (by having greater housing independence or children). Relationships are the source of satisfying psychosocial needs, love and pleasure, but physical experiences are not perceived as the most important criterium. Love is as important as being with a loved one with whom activities, interests, support, help and care can be shared. For some people, love is a precondition for physicality in relationships, hence the former often accompanies the latter. Sexual activity becomes a source of pleasure, but it is not limited to sexual intercourses, as it covers a spectrum of other behaviors such as kissing, petting or necking. When choosing a partner, people with ID are guided by many aspects, such as their personality traits and appearance. The impressions related to getting to know such a person are decisive as they often may lead to infatuation. People with intellectual disability who have already been in a relationship are aware of the fact that its duration and quality depend on the effort taken by both partners, their communication and autonomy, as well as mutual respect and trust.

The experiences of people with ID are realized in a specific environment in which attitudes towards sexuality and partnerships of people with ID are not always favorable, often restrictive and usually aim to suppress psychosocial needs. The majority of the respondents with intellectual disability live in protected conditions, i.e. with their families, in residential forms or sheltered housing. Living in such conditions does not always let people with ID fulfill their needs because intimacy, autonomy and sense of security are not provided. Only a few people with ID live with their partners, and even fewer have a chance to formalize their relationship. People with ID somehow manage to cope with external limitations adopting different methods which partly enable them to maintain autonomy and sexual identity, and let them fulfill their needs, which they do not want to and cannot give up. They choose a

compromise of being only in an informal, or a distant relationship, or they hide their relations. They emphasize their right to fulfill sexual needs, express their desires, values and beliefs that confirm their sexual identity.

Discussion

The authors of the analyzed papers focused on the perspective of people with ID which in their opinion was important and accurate in the analysis of certain phenomena. Such research is in line with the contemporary trend assuming that these people are able to report their own experiences, express preferences and make choices. This approach and the concepts of self-determination, self-advocacy and life normalization are closely related (McCarthy, 1999; Shogren & Weymeyer, 2006; Wehmeyer et al., 2000; Weymeyer, 2012). The research findings confirm that people with ID are able to: sense the spectrum of sexual experiences, both emotional and physical; learn from their experiences in relationships; make use of conclusions for their personal development and well-being (Turner & Crane, 2016). The results of the analyses contradict the notion that these people are "emotionally disabled" (Sinason, in Johnson et al., 2001). What is more, the results show that the respondents strongly want to realize their affective and emotional potential. They also show the compensatory role of love in the face of unpleasant interpersonal relationships experienced in the past (Bates et al., 2016). The sexual experiences, desires, needs and thought of people with ID presented in the studies have a lot in common with behaviors typical of non-disabled people (Black & Kammes, 2019; Neuman, 2020). This confirms the assumption that positive experiences in relationships, such as love, intimacy and others, are the source of people with ID life normalization. The people with ID sexuality, however, contains the features specific only to the people with ID population, thus distinguishing this group of people from their non-disabled peers. These features reflect the dominant influence that others have on people with ID, their relationship and their sexual life (Fulford & Cobigo, 2018; Lam et al., 2019; Rushbrooke et al., 2014). This influence is exerted by the people who are important for people with ID in terms of: sexual education, the forms and ways of lives, the level of autonomy, future prospects and the possibility of establishing and cementing relationships. The partnership life of people with ID raises concerns in their environment, including their parents, therapists and educators, who perceive it as risky because of unwanted pregnancy, sexual abuse or lack of control (Aderemi, 2014; McConkey & Leavey, 2013; Young et al., 2012). Consequently, restrictive attitudes, overprotection and helplessness are revealed as well as the neglect of somebody's important needs (Howard & Handy, 2004; Stansfield et al., 2007). What is not noticed is the potential of a human being with intellectual disability in this sphere of life, perhaps because it is realized only to a small extent, and what is more, it is recognized to an even smaller extent. When talking about the potential, the earlier stages of life, i.e. childhood and adolescence are worth referring to as this is the time when the foundations of sexuality are being shaped, such as sexual and gender identity, emotional-sexual integration, attachment style and others; this is the time when a person develops sexual meanings by assimilating values,

norms and beliefs (Bancroft, 2011). The perception of normality is crucial here, as it can lead to rational responses to the needs of growing-up individuals, rather than ignoring such needs and associating any difficulties with the disability itself (e.g. masturbation in public places) (Turner & Crane, 2016). One of the limitations of some studies is the lack of contextual approach which is essential for understanding somebody's experiences, especially in the interpretive paradigm. Such a context is created not only by environmental factors in the form of social attitudes. It is shaped by previous experiences, including relationships, places and ways of life. The groups of respondents in the analyzed articles were very heterogeneous when it comes to their age, which affects the quality of experiences. The contextual analysis is particularly important here because these experiences might have been gained in various socio-cultural conditions, in different historical and political times, in changing attitudes towards disability as well as changing legal and organizational issues, and consequently different concepts of the support for people with ID. In some analyses, the depiction of certain phenomena is imagined rather than based on experience. Nevertheless, it is cognitively valuable, as it allows for understanding the aspirations, goals and needs of people with ID. All of the research on partnership experiences involved heterosexual relations, although the people with ID population is also homosexual or bisexual (Bedard et al., 2010; Hellemans et al., 2010). However, there is little empirical evidence in this regard which mainly shows the difficulties of people with ID as a group functioning within the LGBT community (Abbott, 2015; Abbott & Howarth, 2007; Withers et al., 2001; Yacoub & Hall, 2008). Perhaps an in-depth exploration of positive experiences would allow us to see the significance of such relationships for strengthening the sexual orientation and gender identity of the people with ID. It would also provide important premises for the acceptance of people with ID in their environment (Abbott & Burns, 2007; Löfgren-Mårtenson, 2009; McCann et al., 2016; Stoffelen et al., 2013).

Considering the issue of positive aspects in terms of sexuality of people with ID, it should be emphasized that in many studies the description of the positive aspects was accompanied by reports on negative phenomena that indicated personal difficulties, dissatisfaction, and limitations (Gil -Llario et al., 2018; Neuman, 2020; Rushbrooke et al., 2014; Stoffelen et al., 2019; Sullivan et al., 2016; Turner & Crane, 2016). They were largely caused by external factors. A paradoxical situation is revealed here: external limitations make it difficult to gain positive psychosexual and physical experiences, they lead to the deprivation of important needs (e.g. sexual needs, the need for security, acceptance and belonging), they reduce the opportunity to acquire competences important in counteracting threats (e.g. sexual abuse) and decrease the possibility of posing a threat from the side of people with ID (e.g. as perpetrators of sexual abuse), which in turn leads to negative states, low quality of life and dissatisfaction (Bernert, 2011; Hollmotz, 2009; Lunskey et al., 2007; Sullivan et al., 2016). Negative scripts provided by the environment and the lack of proper knowledge favor the perception of sexuality in a pejorative way, i.e. as something shameful, sinful and not pleasurable (Azzopardi-Lane & Callus, 2014; Bernert & Ogletree, 2013; Fitzgerald & Withers, 2011; Stoffelen et al., 2018; Yau et al., 2009). The people with ID image of sexuality must consist of a multitude of components. However, a positive perspective is of a key importance here as it lets us

see the complexity of human sexuality, its individuality and related life contexts as well as the potential and resources necessary in resolving difficulties.

Theoretical and Practical Implications

Application of the Positive Sexuality Model in Relation to People with Intellectual Disability

The justifications and theoretical foundations the application of the positive sexuality model in relation to people with ID are primarily provided by the following:

1. The definition of sexuality and sexual health provided by the WHO in which the latter is defined as “a state of physical, emotional, mental, and social well-being... not merely the absence of disease, dysfunction, or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence” (in Anderson, 2013, p. 208).

2. A paradigm of disability that derives from the assumptions of positive psychology, in which the socio-ecological perspective of disability is of key importance, striving of the people with disability to strengthen their self-determination, empowerment or self-advocacy; increasing awareness of the effects of marginalization and discrimination. The key points are functional limitations, personal well-being, individual support, personal competences and adaptation (Schalock, 2004).

According to Dykens's proposal (2006) referring to the paradigm of positive psychology, the research on people with ID should focus on positive emotional states, such as happiness, commitment, hope, engagement and strength. People achieve happiness in several ways: they feel positive emotions because of the past and future experiences, such as contentment and hope respectively (Seligman, 2002, in Dykens, 2006). In the analyzed studies, both ways of arousing positive emotions were shown: previous partnerships provided the respondents with good experiences that are important for a positive evaluation of sexuality and building its positive image; current relationships can provide positive experiences that compensate for negative ones experienced in the past, and the planned future brings hope and optimism when it comes to being in a relationship, experiencing love, fulfillment in marriage and parenthood. Making use of personal resources and their implementation in various areas of life is another way of achieving happiness. The aforementioned resources include, *inter alia*, loving and being loved (Peterson & Seligman, 2004, in Dykens, 2006). The analyses show that living in a relationship and experiencing love can contribute to developing the potential of people with ID as well as favoring their well-being and empowerment.

Competences of people with ID related to their self-determination and self-advocacy are critical to: understanding, claiming and exercising their sexual rights; building personal, social and sexual identity; establishing and maintaining relationships. Self-advocating activities create an opportunity to develop intimate relationships and strengthen social competences, which was shown in the research. There is the concept of sexual self-advocacy in the literature and it means: “feeling good

about yourself, knowing your rights and responsibilities when in relationship, and knowing about birth control and safe sex” (self-advocating group from Vermont, in Friedman et al., 2014, p. 516). In self-advocates’ view, in order to achieve self-advocacy understood in this way, it is necessary to expand access to information and sexual health services, remove systemic barriers, educate others, increase access to counseling and develop opportunities for sexual expression (Friedman et al., 2014).

Methodological Aspects of the Positive Sexuality Model in Relation to People with Intellectual Disability

Understanding the positive aspects of people with ID sexuality requires the paradigms and methods that allow personal experiences of people with ID to be revealed and interpreted in the context of environmental and individual determinants. The interpretative paradigm along with the life history method or phenomenography play the key role here. It is important to recognize the ability of people with ID to describe their own experiences and to give their own interpretations (Björnsdóttir et al., 2014; Booth & Booth, 1996). Referring to self-determination and self-advocacy in the people with ID positive sexuality model also allows for talking about the application of the emancipatory paradigm. Within this paradigm, one may observe successful efforts of people with ID in terms of inclusive projects which address sexual rights issues (Johnson et al., 2014; Northawy, 2013; Swain, 1998). Participation projects are seen as an introduction to emancipation research (Zarb, 1992, in French & Sawin, 1997) which, in a broad general sense, can help empower individuals and groups changing their social image and influencing disability policies (Mercer, 2004). The usefulness of quantitative methods applied in the research cannot be underrated as they are embedded in the positivist paradigm and therefore may provide some general trends defining the levels of qualitative analyses. Quantitative research can be valuable when it comes to verifying the relationships between various aspects of sexual life, psychophysical well-being and quality of life.

Research Directions

Taking into account the issues that have been raised so far, in particular the areas insufficiently recognized, the following directions of research embedded in the model of positive sexuality can be indicated, although they certainly do not exhaust the subject: a) the sources and manifestations of gender and sexual identity of people with ID; b) sexual self-esteem and self-efficacy; c) sexual well-being; d) happiness in relationships. It is worth mentioning that in the analyzed cases there were no studies that would directly address sexual self-esteem and sexual self-efficacy. When analyzing experiences in relationships, their various options should be taken into account, including heterosexual and homosexual, although access to the latter may be difficult. It is a good idea to present the experiences in dyads as such a perspective of analyses allows for the inclusion of mutually transferred expectations and needs.

It is necessary to take into account the environmental perspective that creates the context of people with ID experiences, as it has already been mentioned in this

study. It consists of both environmental and socio-cultural variables as well as personal factors such as gender, age, race, and nationality. It is also worth emphasizing that the positive perspective does not exclude the analysis of negative phenomena, i.e. difficulties and problems that people with ID may confront in the sphere of sexual life, such as sexual violence.

Usefulness of the Positive Sexuality Model in Practice

When analyzing the usefulness of the application of the positive sexuality model with the reference to its authors' assumptions, the following three levels can be proposed 1) microstructural level: individual, personal level; 2) the meso level referring to the living environment and 3) the macro level covering broader social structures. According to the authors of the model, its usefulness at the micro level can be reflected in supporting individuals in understanding and expressing their own sexuality, also in a way, which, from the social perspective is perceived as unacceptable, i.e. different and atypical. People with intellectual disability may have problems understanding their own identity, behavior and preferences due to a smaller range of sexual experiences or unfavorable attitudes of the environment (Barron, 2002; Miller et al., 2017). In terms of the micro level, what should be considered is the significance of positive and multifaceted sexual education, i.e. its importance in many areas of sexual functioning of individuals, including protection against abuse (Williams et al., 2015a, 2015b). Williams et al., (2015a, 2015b) state that many people may feel ashamed and guilty because of their sexual desires and needs, which is the result of negative scripts. A similar phenomenon is observed among people with ID (Azzopardi-Lane & Callus, 2014; Bernert & Ogletree, 2013; Yau et al., 2009). At the meso level, the usefulness of the model can be related to solving sexual problems in relationships, including heterosexual and homosexual people with ID. However, it also concerns changing the attitudes of parents / caregivers towards people with ID sexuality. At the macro level, one can mention changes in the policy and organization of life in people with ID rehabilitation and support institutions (e.g. nursing homes) so that this group of people can fulfill their psychosexual needs. As these levels are closely related, it is difficult to separate them and single out particular areas where the model can be applied in research and practice. By specifying the issue, it is possible to indicate the usefulness of the model of positive sexuality in terms of:

- diagnosis and therapy of sexual offenders with intellectual disability. Williams et al., (2015a, 2015b) emphasize a positive approach to perpetrators, based on an attempt to learn the motives for their behavior; but above all on trying to activate their personal and environmental resources. This is a particularly important approach to the people with ID issues, where criminal behavior is not always based on (paraphilic) disorders, but more often on environmental neglect and problems related to fulfilling the needs (Griffiths et al., 2013; Lunsky et al., 2007).
- implementation of inclusive projects involving, inter alia, self-advocates and other people with ID with the intention to optimize the realization of sexual rights of people with ID in the sphere of heterosexual and homosexual relationships, both formal and informal;

- positive and integrated sex education for people with ID, in order to, inter alia, transform the existing negative sexual scripts, or create new positive ones;
- support and education for parents / caregivers so that 1) the "normality" of children's sexual development and functioning are accepted, 2) any possible difficulties faced by people with ID are recognized as problems conditioned by many factors (such as environmental);
- changes in the attitudes of specialists employed in institutions providing care, education, rehabilitation, social and health services so that sexual rights of people with ID are recognized and their development and functioning in the psychosexual sphere are perceived as "normal".

Limitations

The conducted review analysis focuses on articles found in widely available databases. Future analyses could consider problems raised by researchers in dissertations and gray literature. Perhaps it is also worth expanding the spectrum of search terms, including other neurodevelopmental disorders, such as ASD, or terms that describe specific diagnostic categories of ID, such as Down Syndrome. Perhaps with time, there will be more studies assessing the contribution of variables such as sexual orientation, gender identity, biological sex, and socio-cultural background, hopefully of an international reach.

Conclusion

This paper focuses on the model of positive sexuality. Systematic analysis of the peer-reviewed articles allowed for determining the extent of their authors' interest in the issues of positive sexuality related to people with ID. The results of the analysis showed a growing interest of researchers in the issues. Apart from empirical works, in most cases based on qualitative research carried out in the interpretative paradigm, there are cognitively interesting meta-analytical articles in which the authors summarize the assessed research achievements and look for new interpretations. It seems, however, that the positive issues of sexuality presented in these works are not sufficiently developed and do not find their proper place in the resources of our knowledge about the sexuality of people with ID.

The model of positive sexuality, whose general outlines have been proposed, may first of all set the directions for systematic and in-depth research, the results of which may provide data for further practice. The aforementioned aspect is very important for individuals with intellectual disability as well as their living environment. The obtained findings may also be used in: providing professional training for specialists who carry out activities for people with ID in various forms; providing the support and education for parents and caregivers; and finally providing therapies and education for people with ID. In order to implement this model it is necessary to change the perspective, i.e. shift the focus from the negative to the positive aspects. However, carrying out only one-sided analyses is not advisable because it would provide a simplified picture of people with ID sexuality. This type of research should be

consistent with the assumptions of modern psychology, medicine as well as pedagogy and it should present human sexuality as a significant factor shaping quality of life, well-being and health. Moreover, this type of research should also be consistent with the tendencies focusing on the strengths and resources of people with ID.

Funding This study was not funded.

Declarations

Conflict of Interest Author declares that she has no conflict of interest.

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