Sexual Health Communication Between Healthcare Professionals and Adolescents with Chronic Conditions in Western Countries: An Integrative Review

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Abstract

Adolescent patients and healthcare professionals find it difficult to initiate the discussion on sexual health in consultations. The aim of this integrative review is to give an overview of determinants in the communication about sexual health between adolescents with chronic conditions, their parents, and their healthcare professionals. A systematic literature search for the period of January 2000 to October 2018 was conducted in four databases (Cinahl, Cochrane, PsycINFO, and Pubmed) and resulted in fifteen included studies. Four determinants were found in these studies: attitude, beliefs, knowledge, and self-efficacy. Patients, parents, and healthcare professionals experienced sexual health as a taboo topic and felt not comfortable talking about it. Both patients and professionals expressed a need to discuss sexual health, however personal and practical barriers withhold them from initiating the discussion. This in-depth overview suggests that all four determinants should be targeted to improve communication about sexual health in healthcare settings. Future research should be conducted to give more insight in the experiences and support needs of adolescent patients. On the long term, the discussion about sexual health should become normalized by improving knowledge, training, and support for healthcare professionals and integrating sexual health in education and hospital policies.

Keywords Adolescent · Healthcare professionals · Sexual health · Chronic condition · Health communication · Integrative review · Netherlands

Introduction

Sexual health information is insufficient for adolescents with chronic conditions [1]. The World Health Organization defines sexual health as “a state of physical, emotional, mental, and social well-being in relation to sexuality; it is 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

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experiences, free of coercion, discrimination, and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.” [2]. However, common myths of people with disabilities are that they are asexual, over-sexed, and should be protected [3]. The social stigma on disability and sexuality is in some cases more hindrance to disabled individuals than the physical impairment itself [4].

Adolescents with chronic conditions are often seen as less sexually active and show delayed development of intimate relationships. For example, young adults with spina bifida are often sexually active, but incontinence is seen as an important obstacle in sexual contact and having a partner. The results show that 67% of the young adults with spina bifida have worries about having an intimate relationship because of incontinence (26%) and having a disability in general (30%) [5]. Patients with hydrocephalus are less sexually active than spina bifida patients without hydrocephalus. Wiegerink et al. [6] demonstrate in their review that adolescents and young adults with physical disabilities are less experienced in dating, intimate relationships, and sexual activity. However, some less recent studies suggest that young people with chronic conditions show the same or higher levels in engaging in sexual activity and lower age of sexual debut compared to adolescents without chronic conditions [7–10].

Additionally, adolescents with chronic conditions are affected by negative sexual health consequences. For example, identity issues and a low self-image associated with their disease [11]. Adolescents with chronic conditions report higher body dissatisfaction than adolescents without chronic conditions [12, 13]. Body image and the development of sexual sense are especially impaired by chronic physical conditions [14]. Among others, these factors result in increased risk of sexual abuse and exploitation, unwanted pregnancies, and sexually transmitted diseases [15].

Sexual health communication is essential to health and wellbeing of all adolescents [16]. However, the negative consequences of chronic conditions on sexual development suggest a higher need for adolescents with chronic conditions to receive sexual health education. Nevertheless, studies show that adolescents with chronic conditions are less educated than their peers without disabilities [17, 18]. This is partly due to misconceptions about people with disabilities, like the idea that these people are not interested in sexual activities [1]. It is also due to practical reasons like school attendance, for example young people with chronic conditions might not attend school regularly. As a result, they might miss out on sexual health education at school and on chances to experiment with their sexuality [1]. Thereby, the standard sexual health education is insufficient for adolescents with chronic conditions. Adolescents need additional and specific information about the consequences of the illness to help adopt safe sexual practices and gain confidence in managing their sexual self [19]. This indicates the importance of discussing and assessing sexual health topics in healthcare settings.

Healthcare professionals play a role in sexual health promotion by providing education and counseling about sexual development, sexually transmitted infections, and pregnancy prevention [5, 20]. They are in a unique position to provide information about the consequences of chronic conditions on sexual health. Although healthcare professionals are aware of the importance, they provide insufficient information about (disease specific) health to adolescents with chronic conditions [3, 5]. For example, in one-third of adolescent patients in a medical center, sexual issues are not subject at the annual visit [20]. In the other two-third of the visits, sexuality is discussed brief: 36 seconds on average. In these visits, adolescents never initiated the conversation about sexual health, which suggests that physicians need to be proactive on this topic. Especially adolescents with mobility

limitations are less likely to discuss sexual and reproductive health with their healthcare provider [21].

Professionals and patients agree that sexual health should be discussed and is a part of healthcare to improve wellbeing of adolescents with chronic conditions. In-depth insight into the determinants (facilitating factors and barriers) is required to improve communication and sexual health of adolescents with chronic conditions. However, an overview of the literature on determinants in communication about sexual health is currently lacking. Therefore, the aim of the current study is to give an overview of determinants for communication about sexual health from perspectives of adolescents with chronic conditions, their parents, and healthcare professionals, from the available literature. In this study, both adolescents with congenital and acquired disabilities are meant by adolescents with chronic conditions.

Methods

To provide a complete picture of the available literature, we conducted an integrative review in which a systematic search was performed allowing articles with diverse research methodologies to be included [22]. Consistent with the standards for integrative literature reviews, this review contains a systematic search and a critical analysis of the literature, to create new understanding on the targeted topic, categorization and thematic analysis of past qualitative and quantitative research studies to summarize available literature, and answer a targeted clinical question [23, 24]. It was not possible to pool the results in a meta-analysis because of the given heterogeneity of the study designs, samples, interventions, outcomes, and results [25].

Data Collection

Four scientific databases (CINAHL, Cochrane, PsycINFO, and Pubmed) were searched for English-language studies in the period between January 2000 and October 2018. Box 1 provides the Pubmed search string; equivalent search strings were used in the other databases. The search string contained four major topics that had to be included in all the studies: (1) adolescents/children, (2) chronic conditions, (3) sexual health, and (4) communication. Medical Subject Headings (MeSH) in Pubmed were determined for these four topics and synonyms of these MeSH terms were used for the rest of the search string.

After exclusion of duplicates, we included studies when they met the following inclusion criteria: studies on (1) adolescents/children (aged 25 years or younger), their parents, or healthcare professionals, (2) disabled or chronic diseased adolescents/children, (3) sexual health, (4) reporting factors and barriers that influence communication. Figure 1 shows the process of selecting studies. After removal of duplicates, two researchers (ME and BvG) separately screened the articles applying the inclusion criteria on titles and abstracts. Subsequently, full text articles were screened for relevance. Discrepancies for studies were resolved through consensus.

Box 1 Search string of integrative review

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((Chronic Disease[Mesh] OR Disabled children[Mesh] OR Long-term care[Mesh] OR chronic*[Text Word] OR long-term condition*[Text Word] OR long term condition*[Text Word] OR long-term care[Text Word] OR long term care[Text Word] OR disabilit*[Text Word] OR handicap*[Text Word] OR hospital[Text Word]) AND (Adolescent[Mesh] OR Child[Mesh] OR Young Adult[Mesh] OR adolescent*[Title/Abstract] OR teen*[Title/abstract] OR child*[Title/Abstract] OR young adult*[Title/Abstract] OR adult young[Title/Abstract] OR young people[Title/Abstract] OR young person[Title/Abstract]) AND (Sexual behavior[Mesh] OR Sexual development[Mesh] OR Psychosexual development[Mesh] OR reproductive health[Mesh] OR Sex*[Title/Abstract] OR romantic relation*[Title/Abstract] OR psychosexual*[Title/abstract] OR reproductive*[Title/abstract] OR relationship health[Title/abstract]) AND (Professional-patient Relations[Mesh] OR professional patient relation*[Text Word] OR professional-patient relation*[Text Word] OR patient professional relation*[Text Word] OR patient-professional relation*[Text Word] OR contact* client*[Text Word] OR client* contact*[Text Word] OR nurse-patient relation*[Text Word] OR nurse patient relation*[Text Word] OR patient-nurse relation*[Text Word] OR patient nurse relation*[Text Word] OR physician-patient relation*[Text Word] OR physician-patient relation*[Text Word] OR patient-physician relation*[Text Word] OR patient physician relation*[Text Word] OR doctor-patient relation*[Text Word] OR doctor patient relation*[Text Word] OR patient-doctor relation*[Text Word] OR patient doctor relation*[Text Word] OR sexual* talk[Title/abstract] OR sex education[Title/abstract] OR sexual health education[Text Word]))
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Evaluation of the Data

Characteristics of the studies were extracted in four stages: (1) Bibliometric data (authors, year, country, journal, title); (2) Study design features (aim, study design); (3) Target group (sample, age, gender, disease); and (4) Methods (country, setting, procedure, intervention, measurements). All studies were reviewed on their methodological quality. Prior to the assessment, it was decided to include all research studies but less weight was given to studies with poorer methodological quality. The checklist of Kennelly [26] for qualitative designs was used to assess quality of the study, study design, consistency, and to address issues related to internal and external validity and reliability. The MASTARI assessment tool, Critical Appraisal Tools Descriptive/Case Series Studies, was used to appraise the methodological quality of the descriptive studies [27]. Two researchers (ME and BvG) independently assessed all studies.

Data Analysis and Interpretation

The extracted data of the included articles was organized in a file. Besides the above named characteristics of the studies, we made an overview of all influencing factors named in the articles. These factors were thematically coded with possible determinants, for example ‘attitude’ and ‘self-efficacy’. All data was divided in three main groups: adolescents with chronic conditions, parents, and healthcare professionals. One researcher (ME) extracted the data and a second researcher (BvG) reviewed the data of all studies. After organizing these data, a conclusion for determinants in communication about sexual health in healthcare settings could be drawn.

Fig. 1 Flow diagram of integrative review

Results

This review included 15 of the 1194 screened studies on determinants in communication about sexual health in healthcare, presented in Table 1. Studies were assessed on quality and no studies were excluded. The included studies contained qualitative designs ($n=7$), quantitative descriptive studies ($n=6$), and mixed designs ($n=2$). All studies were conducted in Western countries, of which the most in the United States of America ($n=5$) and the United Kingdom ($n=4$). The other studies were conducted in Canada, Scotland, Turkey, Netherlands ($n=2$), and Australia. Determinants in the communication about sexual health are established from the perspective of three population groups: adolescent patients ($n=5$), parents ($n=3$), and healthcare professionals ($n=11$). The thematic analysis of the 15 included studies determined four main determinants in communication about sexual health, namely: attitude, beliefs, knowledge, and self-efficacy. Tables 2, 3, and 4 provide an overview of the results per group (patients, parents, healthcare professionals).

Table 1 Characteristics of included studies ($n = 15$)

First author, year	Study aim	Design	Methods	Country	Participants
Akre, 2015 [30]	Examine the sexual knowledge, concerns, and needs of adolescents with spina bifida.	Qualitative	Video analyzing and interviews	USA	14 Adolescents with spina bifida
Bray, 2012 [39]	Explore how healthcare professionals discuss sexual and relationship health with young people within an acute care context.	Qualitative	Focus groups	UK	24 Professionals
Bray, 2013 [42]	Investigate the evaluations of healthcare professionals (on a computer-based resource) designed to improve discussions about sexual and relationship health.	Descriptive	Online questionnaire	UK	114 Healthcare professionals
East, 2014 [34]	Understand what learning about sexuality is like for adolescents with a physical disability and how this experience influences the way they view themselves as sexual beings.	Qualitative	Interviews and focus groups	UK	4 Patients with physical disability; 4 parents; 4 professionals
Kazmerski, 2016 [31]	Explore the attitudes, preferences, and experiences of young women with cystic fibrosis young and healthcare professionals toward sexual and reproductive health care.	Qualitative	Interviews	USA	22 Young women; 16 professionals
McCabe, 2014 [33]	Examine the experiences of nurses in relation to the provision of sexual healthcare to youth with disabilities, with special attention to how nurses either contributed to or challenged the status quo.	Qualitative	Interviews, discussions, observations, collection of documentary evidence	Canada	9 Professionals of youth with congenital and acquired disabilities

Table 1 (continued)

First author, year	Study aim	Design	Methods	Country	Participants
Murphy, 2016 [35]	Determine if genetic counselors were being asked to provide sex education counseling on a variety of topics to patients and what their barriers and comfort levels were.	Descriptive	Online questionnaire	USA	38 Genetic counselors of youth with intellectual disabilities
Pownall, 2012 [37]	Identify the particular challenges for parents dealing with the developing sexuality of their children with intellectual disabilities.	Descriptive	Questionnaire	Scotland	30 Mothers of patients with mild intellectual disabilities
Rana, 2007 [41]	Determine the view and approaches of nurses caring for adolescent patients regarding communication about sexuality in Turkey.	Descriptive	Questionnaire	Turkey	571 Nurses working in hospital units
Rueda, 2016 [38]	To better understand social workers' roles in supporting the developing sexuality of children with disability.	Qualitative	Semi-structured interviews	USA	12 Social workers
Sanders, 2011 [28]	Explore young people's expectations and experiences of discussing sexual and relationship health with healthcare professionals at an acute children's hospital.	Mixed	Questionnaires and focus groups	UK	63 Young patients in an acute children's hospital
Stein, 2018 [36]	Assess parental attitudes to sexuality and sexuality education and determine how parents of children with intellectual development disorder prefer access to sexuality education.	Quantitative	Online questionnaire	USA	62 Parents, of which 32 parents of children with intellectual development disorder
Van der Stege, 2016 [40]	Evaluate the use of the board game SecZ Talk by professionals in healthcare and special education.	Mixed	Questionnaires and interviews	Netherlands	154 Healthcare professionals and special education workers

Table 1 (continued)

First author, year	Study aim	Design	Methods	Country	Participants
Van der Stege, 2010 [29]	Evaluate the feasibility and appreciation of SeCZ Talk in youth with chronic conditions and in healthcare professionals.	Descriptive	Questionnaires with Likert scale items	Netherlands	85 Adolescents with a chronic condition and 12 healthcare professionals
Wilson, 2016 [32]	Explore if and how the support from healthcare professionals is offered to young people transitioning to adulthood.	Qualitative	Focus groups	Australia	17 Transition staff members of people with intellectual and developmental disability

Table 2 Description of the results from included articles concerning adolescents with chronic conditions (n = 5)

First author: title	Determinant: attitude	Determinant: beliefs	Determinant: knowledge	Determinant: self-efficacy	Conclusion
Akre [30]: What young people with spina bifida want to know about sex and are not being told	<ol style="list-style-type: none"> 1. Patients did not want their parents to know about their sexual/romantic life 2. Patients explicitly requested professionals to talk about sexual health 3. Patients wanted information directly from their physicians 	<ol style="list-style-type: none"> 1. Patients have the feeling that doctors see sexuality as a forbidden topic to talk about 	<ol style="list-style-type: none"> 1. Patients want more information regarding sexual realities, sexual intercourse and fertility 2. Sexuality education needs to be individualized, start early and continue into adolescence/young adulthood 	<ol style="list-style-type: none"> 1. Patients feel inhibited to have open conversations about sexual health when parents are present 	The study revealed a need for help from the medical community to inform and empower youth with spina bifida in the area of sexual health
East [34]: Somebody Else's Job: Experiences of Sex Education among Health Professionals, Parents and Adolescents with Physical Disabilities in Southwestern Ontario		<ol style="list-style-type: none"> 1. Patients experience societal stigma between sexuality and disability 2. Patients believed it would be beneficial to talk about sexuality and disability in a mainstream class (to breakdown myths and misconceptions) 	<ol style="list-style-type: none"> 1. Patients showed frustration about lack of disability specific sex education 2. Patients said to look for information on the internet 3. Patients shared the view that they could benefit from better quality sex education from trusted adults 		The importance of improved sex education resources and services tailored to youth with disabilities was highlighted, as well as for parents, educators and professionals

Table 2 (continued)

First author: title	Determinant: attitude	Determinant: beliefs	Determinant: knowledge	Determinant: self-efficacy	Conclusion
Kazmerski [31]: Provider and Patient Attitudes Regarding Sexual Health in Young Women With Cystic Fibrosis	<ol style="list-style-type: none"> 1. Patients believed sexual health discussions were important 2. They felt sexual health discussions should start with the first signs of expected puberty or before 3. Nearly all women believed that healthcare professionals have a key role and should initiate the conversation 	<ol style="list-style-type: none"> 1. Many women (patients) felt that some sit-down conversation with the healthcare professional would be vital to “get any confusion about sexual health out of the way” 			Both cystic fibrosis providers and patients agree that the provider has a fundamental role in providing disease specific sexual health care
Sanders [28]: Exploring young people’s expectations and experiences of discussing sexual and relationship health with professionals in a children’s hospital	<ol style="list-style-type: none"> 1. 38 of patients suggested they did want to be able to ask their professionals about sexual and relationship health issues (15 were unsure) 2. Young people do not want to be asked directly but want to know the healthcare professional is available for discussing sexual health 3. 33 of the patients stated that a nurse is the most approachable person to discuss sexuality 		<ol style="list-style-type: none"> 1. Young people sought information from school or clinicians, family clinics, internet, friends, siblings and parents 	<ol style="list-style-type: none"> 1. No sufficient time (especially in outpatient clinics) 2. Some patients preferred a one-to one basis 3. A safe and secure environment and trusting bond with healthcare professional 	<p>Young people wish to have the opportunity to talk about sexual and relationship health with professionals</p>

Table 2 (continued)

First author: title	Determinant: attitude	Determinant: beliefs	Determinant: knowledge	Determinant: self-efficacy	Conclusion
Van der Stege [29]: using the new board game SeCZ TaLK to stimulate the communication on sexual health for adolescents with chronic conditions.	1. 62.4% of the patients strongly agreed they find it important to be able to discuss sexuality and relationships				SeCZ Talk is a promising tool to encourage discussion about sexuality and intimate relations with adolescents with chronic conditions and disabilities

Table 3 Description of the results from included articles concerning parents of adolescents with chronic conditions (n = 3)

First author (year)	Determinant: attitude	Determinant: beliefs	Determinant: knowledge	Determinant: self-efficacy	Conclusion
East [34]: Somebody Else's Job: Experiences of Sex Education among Health Professionals, Parents and Adolescents with Physical Disabilities in Southwestern Ontario	<ol style="list-style-type: none"> Both parents and professionals believed it was someone else's responsibility to convey information about sexual health Sexuality did not feel like a relevant topic because of the complex medial challenges 	<ol style="list-style-type: none"> Some parents felt that talking about sexuality could be damaging Parents feel that even for professionals it is a taboo subject Patients are (unconsciously) seen as asexual 	<ol style="list-style-type: none"> Parents state a need for more accessible and relevant resources Parents feel inadequately prepared to provide sexual education 	<ol style="list-style-type: none"> Parents felt more comfortable talking about it than their teens Parents felt inadequately and felt fear about how to approach and discuss sexuality Parents prefer one on one time with professional to ask questions 	The importance of improved sex education resources and services tailored to youth with disabilities was highlighted, as well as for parents, educators and professionals
Pownall [37]: Sexuality and sex education of adolescents with intellectual disability: mothers' attitudes, experiences, and support needs.	<ol style="list-style-type: none"> Mothers of young people with intellectual disability believed the school to have the responsibility in delivering sex education to their child 	<ol style="list-style-type: none"> Mothers of children with intellectual disability discussed sexual matters at a later age, about less topics and in less detail (than mothers of children without intellectual disability) 	<ol style="list-style-type: none"> Mothers had doubts whether sexual issues were already relevant: they do not want to confuse or frighten their child by talking about sex to soon 	<ol style="list-style-type: none"> Support for mothers in being more proactive Having a partner who also takes an active role in discussing sexual health Mothers preferred talking to their daughters, fathers to their sons 	The research highlighted that mother-adolescent communication about sex is a challenging and complex undertaking, regardless of whether the adolescent has a disability

Table 3 (continued)

First author (year)	Determinant: attitude	Determinant: beliefs	Determinant: knowledge	Determinant: self-efficacy	Conclusion
Stein [36]: The Importance of Sexuality Education for Children With and Without Intellectual Disabilities: What Parents Think	<p>1. 58.1% (n = 36) of the parents approved of comprehensive sexuality education</p> <p>2. 16.1% (n = 10) approved of “other” sexuality education</p> <p>3. 12.90% (n = 8) preferred an approach of biology-based education.</p> <p>4. 11.3% (n = 7) did not approve of any sexuality education</p> <p>5. 1.6% (n = 1) approved of abstinence only sexuality education</p>	<p>1. Parents believed their child would benefit from sexual education</p> <p>2. Most parents of children with IDD (89.3%) acknowledged the utility of sexuality education for their child</p>			Most parents were in favor of sexuality education for their child, however, there were some differences in terms of the curriculum covered in this educational activity

Table 4 Description of the results from included articles concerning healthcare professionals (n = 11)

First author (year)	Determinant: attitude	Determinant: beliefs	Determinant: knowledge	Determinant: self-efficacy	Conclusion
Bray [39]: Discussing sexual and relationship health with young people in an acute children's hospital	1. Professionals feel that talking about sexual health should be carried out by nurses	1. Own beliefs and assumptions avoided about sexual health 2. Context and cultural factors effect the discussion about sexual health 3. Professionals have a personal idea that sexuality does not belong in a children's hospital	1. Lack of knowledge and information (professionals) 2. Professionals weren't sure how to handle confidentiality about sensitive topics and discussing this with parents 3. Professionals were hesitant to talk about sexual health because they did not know what the best approach was	1. A trusting and ongoing relationship makes professionals more confident in talking about sexual health 2. Professionals felt uncomfortable and embarrassed to talk about sexual health 3. Professionals felt more confident in talking about sexuality when sexual health was related to concrete aspects of the person's condition 4. Practical issues: Lack of privacy in the hospital; Time and space	Professionals can often feel reluctant to talk about sexual health because of lack of knowledge and information
Bray [42]: discussing sexual and relationship health with young people in a children's hospital: evaluation of a computer-based resource			1. The video aspects of a computer-based resource were seen as most useful in increasing knowledge	1. More professionals feel able to talk about sexual or relationship health after accessing the computer-based resource	A computer-based resource can positively influence the reported knowledge and skills of healthcare professionals

Table 4 (continued)

First author (year)	Determinant: attitude	Determinant: beliefs	Determinant: knowledge	Determinant: self-efficacy	Conclusion
East [34]: somebody Else's Job: Experiences of Sex Education among Health Professionals, Parents and Adolescents with Physical Disabilities in Southwestern Ontario	<ol style="list-style-type: none"> 1. Lack of acknowledgment about the youth's need for information and advice 2. Both parents and professionals believed it was someone else's responsibility to convey the information 	<ol style="list-style-type: none"> 1. Patients are (unconsciously) seen as asexual 	<ol style="list-style-type: none"> 1. Professionals feel inadequately prepared to provide sexual education 	<ol style="list-style-type: none"> 1. Professionals felt inadequately and felt fear and anxiety about how to approach and discuss sexuality 2. Professionals fear for negative reactions from parents and colleagues when discussing sexuality issues 3. Professionals prefer one on one time patients 	The importance of improved sex education resources and services tailored to youth with disabilities was highlighted, as well as for parents, educators and professionals
Kazmerski [31]: provider and patient attitudes regarding sexual health in young women with cystic fibrosis	<ol style="list-style-type: none"> 1. Providers agreed sexual health issues were highly important to discuss 2. All program directors stated that cystic fibrosis care providers have a fundamental role in the responsibility for discussing and managing sexual health in female patients 	<ol style="list-style-type: none"> 1. Almost all program directors felt that age-appropriate patient sexual health education resources would be helpful for young women with cystic fibrosis and their families 2. Many providers felt that creation of "formalized" assessments or "a routine approach" directed by universally accepted guidelines would be helpful 			Both cystic fibrosis providers and patients agree that the fibrosis provider has a fundamental role in providing fibrosis specific sexual healthcare. Educational resources coupled with individualized sexual health discussions may facilitate improved sexual health care for young women with cystic fibrosis

Table 4 (continued)

First author (year)	Determinant: attitude	Determinant: beliefs	Determinant: knowledge	Determinant: self-efficacy	Conclusion
McCabe [33]: Nursing, sexual health and youth with disabilities: a critical ethnography	1. Sexuality was often approached from a medical perspective	1. Sexuality is approached as a taboo topic, not to be discussed	1. Education and resources on supporting sexual health for youth are needed 2. Professionals experience a challenge in balancing sensitive topics, such as sexual health 3. Professionals experienced that sexual behavior was more often feared or misunderstood in patients with a disability	1. Familiarity with a patient or family makes it easier to address sexual health 2. Being able to discuss it with colleagues and have a family-centered approach 3. Time and physical space	Aspects of the clinical, institutional and broader social environments undermine the ability of nurses to promote sexual health
Murphy [35]: sex education and intellectual disability: practices and insight from pediatric genetic counselors	1. Most counselors thought that it wasn't their role to give sex education, but physicians, nurses, educators and social workers should be prepared to do it	1. The feeling they did not want to assume that the caregiver or patient was interested in sex education	1. Lack of training on how to provide sex education counseling 2. Professionals were least interested in receiving training, but most interested in receiving a printed sex education resource guide	1. Professionals were more comfortable to provide sex education when it was directly related to a genetic condition 2. Unfamiliarity with patient and patients culture makes it harder 3. Not having enough time	Patients and families are bringing topics of sexual health forward during genetic counseling sessions and genetic counselors do have a role to play in this

Table 4 (continued)

First author (year)	Determinant: attitude	Determinant: beliefs	Determinant: knowledge	Determinant: self-efficacy	Conclusion
Rana [41]: Nurses' approaches towards sexuality of adolescent patients in Turkey	1. Most nurses believe it's the parents job to talk about it, so they do not feel responsible		1. Lack of training on (discussing) sexuality 2. Nurses should be supported through basic and continuous education programs and institutional policies	1. Discomfort because of own sexuality or the impact of cultural values 2. Comfortable if the patient started the discussion 3. Uncomfortable initiating a discussion about sexuality	Nurses were aware of the importance, but they were not comfortable talking about sexuality with adolescents. Nurses approaches are rather conservative
Rueda [38]: social workers' roles in supporting the sexual and relational health of children with disabilities				1. Normalizing sexuality for children was seen as important 2. Providing a safe environment, helping children with underlying issues and working in groups	Services are needed that promote positive sexuality and relational health among children with disabilities. It is important that social workers be proactive advocates ("treat with love and respect") for the full inclusion of people with disabilities as equal citizens
Van der Stege [40]: Using a Board Game About Sexual Health with Young People with Chronic Conditions in Daily Practice: a Research into Facilitating and Impeding Factors	1. Lack of effort and lack of motivation in using the board game to improve sexual health communication	1. Lack of (conversational) skills for discussing sexual health			Special schools and rehabilitation centers seemed to provide better opportunities to talk about sex than hospitals. Motivation, skills and correspondence with work were facilitating factors

Table 4 (continued)

First author (year)	Determinant: attitude	Determinant: beliefs	Determinant: knowledge	Determinant: self-efficacy	Conclusion
Van der Stege [29]: Using the new board game SeCZ TaLK to stimulate the communication on sexual health for adolescents with chronic conditions	1. Professionals reported discussing sexuality as an important part of their work	1. Professionals reflected positive feelings about using the board game			SeCZ Talk is a promising tool to encourage discussion about sexuality and intimate relations with adolescents with chronic conditions and disabilities
Wilson [32]: Transition staff discuss sex education and support for young men and women with intellectual and developmental disability		1. Staff had the feeling that young people did not get the education elsewhere			A better way for providing sex education and support to young adults with IDD is needed

Attitude

Adolescents with chronic conditions expressed a need to discuss sexual health with their healthcare professionals [28–31]. However, preferences in the ways sexual health should be discussed differed between adolescents. In a questionnaire study, the majority of young people preferred to be asked about sexual and relationship issues [28]. As a follow up, a focus group study was conducted to explain the results.

Adolescent patients in this focus group explained that patients wanted to know that ‘the door is always open’ to discuss sexual health with their healthcare professional [28]. Patients saw nurses as the most approachable professional to discuss sexuality. Patients with spina bifida explicitly requested healthcare professionals to talk about sexual health, but they did not want their parents to know about their sexual and romantic life [30]. Patients with cystic fibrosis emphasized that healthcare professionals should start sexual health discussions with the first signs of expected puberty [31].

Parents are less convinced that sexual health is an important topic in the life of their child with a chronic condition [32–34]. Parents experienced sexuality as a taboo topic, which should not be discussed [33]. Some parents reported the disease and medical challenges as priority above sexual health [34]. They might even feel scared to think about it [32] and felt only comfortable talking about sexuality when the child is not present [35]. On the other hand, in a questionnaire study the majority of parents (58.1%) approved of sexuality education [36]. According to some parents, it is the healthcare professionals’ responsibility to provide information on sexual health and counseling [34]. Mothers of young people with intellectual disabilities believed that it is the school’s responsibility to educate in sexual health [37].

Healthcare professionals acknowledged that discussing and normalizing the discussion about sexual health is important for young patients [29, 35, 38]. However, they are not convinced that it is their responsibility to start this discussion. In some studies healthcare professionals stated that discussing sexual health is an important part of their work [29, 31, 38, 39]. Counselors thought that other professionals, like medical doctors and nurses, should be prepared as well to discuss sexual health [35]. Nevertheless, some healthcare professionals showed poor attitudes and motivation when it comes to discussing sexual health [40]. Others believe that it is parents’ responsibility to discuss sexual issues with their children [34, 41]. The few times that sexual health was discussed, it was often approached from a medical perspective [33], such as side-effects of medication or problems with the menstrual cycle.

Beliefs

Adolescents with chronic conditions experienced a social stigma on sexuality and disability [34]. Sexuality was approached as a taboo topic (by themselves and their families), which should not be discussed with healthcare professionals [33]. They also felt that healthcare professionals see sexuality as a forbidden thing to talk about [30]. However, adolescents with chronic conditions believed that talking about sexuality and disability in main stream classes and with healthcare professionals could be beneficial to get any myths and confusions out of the way [31, 34].

Patients’ belief that parents and healthcare professionals approach sexual health as a taboo topic, seems to be accurate. Parents reported experienced sexuality as a taboo topic for themselves as well as for healthcare professionals [33, 34]. Parents were afraid that

discussing sexual health could be damaging for their children's development, especially when they were already struggling with social isolation or bullying [34]. However, a questionnaire study showed that most parents believed their children would benefit from sexual education [36].

Parents and healthcare professionals tended to (unconsciously) see adolescents with chronic conditions as asexual [34]. While some healthcare professionals were afraid to make inaccurate assumptions by starting up the conversation [35], others felt sexuality does not belong in a children's hospital [33, 39]. Healthcare professionals own beliefs, values, or assumptions seemed to influence this taboo feeling and might have avoided them to talk about sexual health [39, 41]. It is striking that, just as adolescents and parents, healthcare professionals reported that sexual education could be beneficial [31].

Knowledge

Information on sexual health for adolescents with chronic conditions, their parents, and healthcare professionals was lacking [30, 33, 34]. Adolescent with chronic conditions experienced a lack of information on sexual intercourse and fertility [30], disability specific information [34], and easy-to-understand information [33]. This sexual health education should be individualized, start early, and continue in adolescence [30]. Adolescents with physical conditions in the study of East and Orchard [34] preferred to receive this information from anonymous sources such as the internet. But they could also benefit from better quality sexual education from trusted resources, like parents, healthcare professionals, or educators [31, 34].

Parents reported a need for more accessible and relevant resources [34], information on sexual development, and specific disease information [33]. They preferred one on one time with professionals to ask for information [34]. Mothers of patients with intellectual disabilities needed more information on when it is appropriate to discuss which topics on sexual health [37].

The healthcare professionals also experienced a lack of information and resources on supporting sexual health for adolescents with chronic conditions [33, 35, 39]. Healthcare professionals preferred to receive printed information to increase their knowledge, for example a sex education resource guide [35].

Self-Efficacy

Several factors or circumstances can help adolescents, parents, and healthcare professionals to feel more or less confident to communicate about sexual health. For adolescents with chronic conditions, trust in a healthcare professional and a strong connection were important to feel comfortable in discussing sexual health issues [28]. Adolescents reported that the following factors made it harder to initiate sexual health discussions: not enough time with the healthcare professional [28], presence of other people (especially parents) in consultations [28, 30], and experiencing an unsafe and insecure environment [28, 38]. Patients with cystic fibrosis explicitly recommended in-person discussions with their healthcare professional [31].

Parents felt inadequate in discussing sexual health, fear on how to approach and discuss sexual health, and were afraid their intentions would be misunderstood [34]. Parents should be supported and empowered to be more proactive in discussing sexual health [37, 38].

Parents stated that they felt more comfortable asking healthcare professionals questions about sexual health when their child was not present [35]. The barrier to discuss sexual health decreased when their partner takes an active role in the discussion [37] and a safe environment is experienced [38]. Mothers felt it is easier to talk to their daughter, while fathers talk to their sons. Cultural issues were reported as influencing in the perspective of families about the sexuality of their child [32]. Parents suggested more education, training, and support to support them in providing sexual education [30, 34].

Healthcare professionals reported not feeling comfortable or confident to discuss sexuality with young patients [34, 35, 39, 41]. Reasons for feeling uncomfortable were uncertainty of the best approach, embarrassment [39], fear that intentions would be misunderstood [34], fear for negative reactions from parents or colleagues [34], unfamiliarity with the patients culture [35], and meeting a patient for the first time [35]. Facilitating factors were the patient initiating the discussion [35], a trusting and ongoing relationship [39], sexual health being related to concrete aspects of the (genetic) condition [35, 39], familiarity with a patient or family [33], and being able to discuss concerns with colleagues [33]. Practical factors also supported healthcare professionals to initiate sexual health talk. Not being able to talk in private, for example due to lack of space or presence of parents, was seen as a major barrier [28, 32–34, 39]. Lack of time was mentioned as a problem in hospitals, especially in outpatient clinics [28, 33, 39, 40]. Healthcare professionals requested training to provide sex education counseling and to increase (conversational) skills [35, 40, 41]. For example, a computer-based resource could help healthcare professionals to feel more able to communicate about sexual and relationship health [42].

Discussion

This review established four determinants (attitude, beliefs, knowledge, and self-efficacy) in the communication about sexual health, from the perspectives of three groups: adolescents with chronic conditions, their parents, and healthcare professionals. Adolescents and healthcare professionals agree that sexual health needs to be discussed, but neither of them initiate the discussion. First, because patients expect professionals to initiate the discussion and professionals expect colleagues or parents to initiate the discussion. Parents have a different perspective: they rarely see sexual health as a relevant topic and are mainly concerned with the physical state of their child. Second, sexual health is perceived as a taboo topic, not only for adolescents with chronic conditions and their parents, but also for healthcare professionals. Most of them seem to believe that others experience the same taboo. Parents and healthcare professionals are afraid to encourage sexual activity or damage sexual development by initiating the discussion about sexual health. Third, majorities of all three groups report a lack of knowledge, accessible information, and disease specific consequences. Both adolescents and healthcare professionals report that a trusting and strong bond between patient and healthcare professional increases self-efficacy in discussing sexual health. Healthcare professionals report that familiarity with the patient and his culture and discussing the medical aspects of sexual health are facilitating. For parents, empowerment from healthcare professionals, one-on-one time with professional, and an active marital partner would be facilitating. All three groups report practical barriers such as lack of time and presence of others (especially parents) in consultation.

The results of this review show an impasse with on the one hand the need to discuss sexual health and on the other hand the feeling that it is a taboo topic. Because of the

feeling that sexual health is a taboo topic, adolescents with chronic conditions, their parents, and healthcare professionals withhold from initiating the conversation. Consequently, the belief that “sexual health should not be talked about” is confirmed. A reluctance to act is often seen as the basis of these barriers that withhold patients and healthcare professionals from initiating the conversation.

Our results are in accordance with studies on adult patients and their healthcare professionals. A systematic review of healthcare professionals’ experiences in discussing sexuality demonstrates three main factors with great similarities to our review: organizational (lack of time, resources, policy, and training), structural (worry about causing offense and lack of awareness), and personal (discomfort, knowledge, motivation, and personal attitudes) [43]. More specific, cancer patients also show the need to talk about sexual health, however professionals experienced barriers like patient characteristics (assumptions about the patients desire), provider characteristics (knowledge, skills), and practical issues (time) [44]. Nurses assumed that adult patients do not have sexual concerns or expect them to start the conversation [45].

Sexual health promotion is important for all adolescents, with or without a chronic condition [16]. The determinants in communication about sexual health are very similar in both groups. For example, parents of adolescents without chronic conditions also need the appropriate knowledge and skills to keep them from avoiding the topic [46]. Professionals working with adolescents without chronic conditions feel the same barriers. Adolescents without chronic conditions also do not want to talk about sexuality in front of their parents. However, adolescents with chronic conditions experience additional negative consequences because of their disease, like negative self-image and higher body dissatisfaction [11–13]. Adolescents with chronic conditions are often overprotected and miss out on chances to experience with their sexuality [3]. Due to these factors, adolescents with chronic conditions need more disease specific knowledge. In our view, healthcare professionals are the most appropriate persons to provide this information because they have the medical background to explain the consequences for diseases.

Limitations

To our best knowledge, this is the first review aiming to overview the determinants in communication about sexual health between adolescents with chronic conditions, parents, and healthcare professionals. Although we used a broad and inclusive range of search terms, we may have unintentionally omitted relevant studies from our review. For example, our search string was focused on chronic/long-term diseases, which might have excluded studies that do not mention these terms. Second, the included studies contained different study qualities. An integrative review allows to include all study designs. This results in an extended oversight of the current knowledge on determinants in communication about sexual health in healthcare settings. However, it also results in including studies of lesser quality.

Practical and Theoretical Implications

Healthcare professionals are aware of the importance of discussing sexual health, however barriers withhold them from initiating the discussion. The Sexual Rehabilitation Framework is a way to support healthcare professionals in addressing biopsychosocial areas of sexuality in adults with spinal cord injury [47]. An adjusted framework for adolescents with chronic conditions could be beneficial for healthcare professionals in child and

adolescent care. The PLISSIT (Permission, Limited Information, Specific Suggestions, Intensive Therapy) model is an instructive guide for the healthcare professional which is already studied and used in adolescents with chronic conditions [48].

Implementing a model to support healthcare professionals can be effective, but also awareness of the importance of discussing sexual health with adolescents with chronic conditions should be increased. Future research should focus on adolescents' own perspective on (discussing) sexual health conducted into adolescents. The consequences of (chronic) disease on sexual health and thereby quality of life should be emphasized. Broadening this knowledge could help to convince healthcare professionals of the importance of sexual health talk in healthcare.

Adolescents, parents, and healthcare professionals need training to increase knowledge. Most adolescents with chronic conditions and parents seem to expect this information from healthcare professionals. Knowledge of disease specific consequences in healthcare professionals should be increased by future research and implementation in practical situations. Thereby, healthcare professionals should be empowered by increasing knowledge and skills, for example through regular training possibilities. As an addition from knowledge of healthcare professionals, existing websites and brochures of patient associations can be supplied.

The ultimate aim is to normalize sexual health discussions in healthcare. To achieve this aim, communication about sexual health should become an integrated component in educational programs and hospital policies to support and empower healthcare professionals. For example, sexual health should be a standard component in (electronic) patient files. Lastly, the practical barriers, like lack of time or space, should be acknowledged. In the current hospital policies, it may be hard to overcome these factors. Future research should study the possibilities of other interventions, like e-health, to provide patients the care they deserve. It could be beneficial to give sexual health a more prominent position in sites like Cyberpoli, which is an online platform for adolescents with chronic conditions [49].

Conclusion

This review of fifteen included studies provided an in-depth insight in four determinants in the communication about sexual health between adolescents with chronic conditions, their parents, and their healthcare professionals. Attitude, beliefs, knowledge, and self-efficacy contain barriers and facilitators in the communication about sexual health. However, both adolescents with chronic conditions and healthcare professionals expressed a need to discuss sexual health, sexual health is still seen as a taboo topic. Adolescents with chronic conditions, parents, and healthcare professionals do not feel comfortable talking about it and none of them initiate the discussion. This is partly due to practical barriers, like lack of time and space. Personal barriers are also determined, for example lack of knowledge, skills, motivation, and responsibility. The following implications were made to improve communication about sexual health in healthcare settings. First, healthcare professionals should be provided with more information about (disease specific) sexual health and the importance to address it. Second, sexual health should be integrated in patient files, educational programs, and hospital policies. Every hospital should employ a professional (for example psychologist or sexologist) to accompany and support healthcare professionals in sexual health issues. Third, practical barriers should be minimized and future research

should look into other possibilities to support patients. In the long term, discussing sexual health should become normalized by providing knowledge, training, and support for healthcare professionals and integrating sexual health in education and hospital policies. After all, sexual health is part of holistic care for patients.

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Compliance with Ethical Standards

Conflict interest The authors declares that there is no conflict of interest.

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