

**Study : Quebec's deaf youth (16-30 years) faced
with HIV/aids and STBBIs : between confidence
and a lack of knowledge, a collective issue**



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Titre

Les jeunes sourds (16-30 ans) du Québec au regard du VIH/sida et des ITSS : entre confiance et manque de connaissances, un enjeu collectif / Quebec's Deaf youth (16-30 years) faced with HIV and STBBIs : between confidence and a lack of knowledge, a collective issue.

Résumé

Le Québec fait piètre figure quant aux services et d'éducation en santé sexuelle pour les personnes sourdes utilisant une langue signée. L'article présente les résultats d'une recherche à devis mixte, unique au Québec, comprenant 14 entrevues en langue des signes québécoise (LSQ) et 56 questionnaires bilingues (français ou LSQ) complétés par des jeunes sourds. Confiants de trouver une information adéquate via leurs pairs ou Internet, les jeunes présentent toutefois un score moyen de 63 % se rapportant aux connaissances documentées par le questionnaire au sujet des ITSS¹ dont le VIH/sida. Ce constat nous porte à croire qu'il est nécessaire de faire davantage de promotion auprès des intervenants en santé ainsi qu'auprès des jeunes sourds pour un site Internet adapté. L'étude exploratoire menée permet également de conclure qu'il importe de former les jeunes à juger de la fiabilité de l'information récoltée sur Internet.

Abstract

Quebec has a poor record concerning sexual health services and education for Deaf people using a signed language. This article presents results of a mixed method research project, unique in Quebec, including 14 interviews in Quebec sign language (langue des signes québécoise : LSQ) and 56 bilingual questionnaires (LSQ or French) completed by Deaf youth. Even if young people are confident of finding adequate information via their peers or the Internet, they have scored at only 63% for the knowledge documented in the questionnaire about STBBIs², including HIV/AIDS. This suggests that there is a need for more promotion directed toward health care providers and Deaf youth of an already

¹ Infections transmises sexuellement et par le sang

² Sexually Transmitted and Blood-borne Infections

existing adapted website. This exploratory study also concludes that it is important to train young people to judge the reliability of the information collected on the Internet.

Mots clés : S/sourds, jeunes, santé sexuelle, VIH/sida, ITSS

Keywords: D/deaf, young people, sexual health, HIV/AIDS, STBBIs

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Sexual health of Deaf youth

Quebec's Deaf youth constitute a disadvantaged minority group with respect to access to formal sources of appropriate information about sexual health. Generally speaking, and this is true for Quebec as it is probably in other parts of the world, health workers lack cultural sensitivity and competence regarding the Deaf (Pendergrass, 2013; Richardson, 2014; Sheppard, 2014), which hampers the establishment of trust between caregivers and patients (Chong-Hee Lieu, Sadler, Fullerton and Stohlmann, 2007, Hoang, LaHousse, Nakaji and Sadler, 2011). Trust is essential when it comes to addressing sexual health. In Quebec, the *Coalition Sida des Sourds du Québec* (CSSQ), an organization with three employees, is the only one with a provincial mandate to meet the individual sexual health information and support needs of 5,000-6,000 people. The CSSQ is also tasked with regularly providing information to groups of Deaf people, at the invitation of organizations and schools across the province.

However, Deaf people are vulnerable to STBBIs, including HIV / AIDS. In the United States, the number of cases of HIV / AIDS among Deaf people is estimated to be between 8,000 and 40,000 according to Winningham, Gore-Felton, Galletly, Seal and Thornton (2008). According to a profile of the Deaf community in the state of Maryland, 4.3% of Deaf individuals had STBBIs, compared to 0.39% of the general population (Monaghan and Schmaling, 2006). Such data are non-existent in Quebec, so it is currently impossible to obtain a reliable statistical portrait of the situation in Quebec. Nevertheless, it is possible to estimate that the situation in Quebec is similar, if not worse, given the scarcity of sexual health services adapted to the Deaf.

Consequently, no data has ever been collected in Quebec on the level of knowledge of young people or on their experiences in relation to health. Results from US studies indicate that Deaf youth have a lower level of sexual health knowledge than their hearing peers (Bat-Chava, Martin and Kosciw, 2005, Donnelly-Wijting, 2014, Goldstein et al., 2010). Since they are generally from a hearing family with whom they do not share the primary language of communication, Deaf youth are likely to be deprived of essential information related to sexual health that is usually exchanged in an informal context of family discussions. An audio-verbal language such as French is a second language for young Deaf people in Quebec, and its syntax and modalities of expression differ greatly from Quebec Sign Language (LSQ). As a result, the reading level of the Deaf is on average very low. Consequently, their ability to understand written information in health pamphlets and websites is generally limited (McKee et al., 2015). It can therefore be assumed that Deaf youth lack at least some of the information essential to their sexual health. However, recent literature on the subject is rare (Donnelly-Wijting, 2014, Goldstein et al., 2010, Klein, 2011, Winningham et al., 2008, Zodda, 2012). For the reasons mentioned above, young people who are Deaf are undoubtedly vulnerable to contracting STBBIs, including HIV / AIDS. However, the sexual health experiences and knowledge of Deaf youth in Quebec remain unexplored. The needs of this clientele remain unknown and consequently, the same applies to the CSSQ's intervention targets. Thus, this article presents the results of a research study currently underway aimed specifically at assessing the life habits and knowledge about sexual health (STBBI including HIV / AIDS) among young Deaf people throughout Quebec - with the end goal of addressing, in an exploratory way, the issues that this population encounters when it seeks information about sexual health.

What does the literature say about the subject?

Since the 1990s, fewer than fifteen US studies on sex education for Deaf youth have been published (Donnelly-Wijting, 2014, Goldstein et al., 2010), and none have been published in Quebec. For this reason, only a tiny fraction of the literature reviewed considers the internet as a source of information used by young people. Thus, the use of the internet by young people seems to be under-represented by the existing literature, and its importance in the lives of young people seems to be largely underestimated. As a result,

the currently available data is potentially obsolete, which is why this research project is essential to bridging a knowledge gap on sexual health information sources, knowledge and experiences of young Deaf people. The value of exploring the knowledge and experiences of young Deaf people in order to better understand risky sexual behavior is in a context where young people have access to the internet more than ever before as a medium of information. On the other hand, all the participants in the study were in primary or secondary school in the early 2000s and, consequently, sexual education courses were gradually excluded from the school curriculum with the arrival of the reform implemented by the Parti Québécois then in power (Duquet, 2003). In the past, passive learning took place at school; now young people have to actively seek out information that is not available to them in the school setting.

Relationship with parents

At the outset, it is important to recall a reality often ignored by people outside the Deaf community: about 90% of Deaf children have at least one hearing parent (Mitchell and Karchmer, 2002), so that the first language of a Deaf person who uses LSQ is generally not his or her native language. Gabriel and Getch (2001) explain that, in addition to being faced with the same challenges as parents of hearing children, hearing parents of Deaf children face specific issues related to sexual health, starting with communication. Smith, Massey-Stokes, and Lieberth (2012) report that it is challenging for parents to acquire adequate vocabulary in a signed language to be able to discuss health-related topics such as tobacco, drug and alcohol use, as well as puberty and sexuality with their Deaf child. Consequently, impediments to communication between hearing parents and Deaf children remain, causing the young person to be distanced from his / her family, and ultimately resulting in isolation of the Deaf child (Mitchell and Karchmer, 2005). According to Willis (2011), discomfort, lack of knowledge about sexuality and communication difficulties are factors that contribute to the reasons that parents avoid talking about sexuality to their child. This situation is likely to be even more pronounced in the Deaf community. Indeed, the pictorial and explicit nature of signs in connection with sexuality increases the embarrassment of some parents, who perceive that sex education for young people is part of the role of the school. These factors explain the reluctance of parents to transmit

information about sexuality to their young Deaf children (Willis, 2011). Zodda (2015) reports that Deaf people immediately turn to friends and family for sexual health information, while hearing youth refer more to written information (Heuttel and Rothstein, 2001). However, people in their social network who are not knowledgeable about HIV can transmit wrong or inaccurate information, which may increase the risk of HIV transmission among Deaf people (Heuttel & Rothstein, 2001).

Sources of information used

Internet

Goldstein et al. (2010) report that 70% of Deaf students in the US receive HIV-related information from school, 56% from the internet, 52% from friends, 44% from family and 44% from television. According to Francavillo (2009), Deaf youth prefer in order of importance: peers, parents, school and the internet, the latter being the least-known source of information. However, as the most frequently used source of information, peers are likely to hinder the process of decision-making regarding sexual health (Bat-Chava et al., 2005, Osowole and Oladepo, 2000). Francavillo states that the internet has become the fastest-growing health-related educational tool. Unfortunately, a significant proportion of the information found on the internet lacks visual support. A sufficient level of literacy is necessary in order to understand the written content, which disadvantages many Deaf people. The average reading level of a Deaf graduate of an American high school corresponds to the fourth or fifth grade of elementary school (Steinberg, Barnett, Meador, Wiggins and Zazove, 2006). Karras and Rintamaki (2012) report that many participants feel the need to develop their autonomy and independence as they enter adulthood, particularly with regard to their parents. The internet is perceived as a means to exercise independence by allowing the individual to acquire health information without the help of others (Karras and Rintamaki, 2012). Smith et al. (2012) recognize that the internet can be particularly attractive to young Deaf people, since it is perceived as a visual medium. Deaf and hearing participants (n = 67) in the study of Suter, McCracken and Calam (2012), reported that their peers (42%) and their mother (27%) are the most credible sources of information. Only a minority of participants identified the internet and books (16%) and school (12%) as reliable sources. It seems debatable to consider "internet and books" as

one and the same type of information source, since access to visual material is facilitated via the internet, whereas this is not necessarily the case with books, which suggests that if the two media had been judged separately, the internet would have most likely been rated more popular among young people. Among the sources of sexual health information identified, there is no consensus among the authors on the preponderance of the internet. However, its growing importance is unanimously accepted.

Peers

Deaf youth appear to be more vulnerable than their counterparts to misinformation from their peers about sexual health (Bat-Chava et al., 2005, Donnelly-Wijting, 2014, Gabriel and Getch, 2001, Goldstein et al. 2010; Heuttel and Rothstein, 2001; Smith et al., 2012). Despite the fact that adolescents in general and their parents view parent-child communication as the preferred method of sexuality education (Somers & Surmann, 2004), adolescents prefer less formal sources of information, such as their peers and the media (Sprecher, Harris, & Meyers, 2008). This phenomenon seems even more pronounced among young Deaf people. According to Prior (2014), this central role of peers in sexual socialization is even more pronounced among Deaf youth, due in part to their difficulty of accessing information that is available otherwise (Fitz-Gerald & Fitz-Gerald 1978, Swarz, 1993, Joseph et al., 1995, Roberts, 2006). Many studies have highlighted the importance of peers to Deaf youth as a primary source of sexual health information (Heuttel and Rothstein, 2001, Joseph, Sawyer and Desmond, 1995). Esmail, Krupa, MacNeill and MacKenzie (2010) report that sex education for Deaf and hard of hearing youth is done through observation of their peers and siblings, which is called accidental learning. Participants in the Esmail study (2010) nevertheless admit that this type of learning can lead to unsafe sexual behavior.

Exploring the information-seeking needs and strategies of Quebec's Deaf youth: some methodological benchmarks

The research presented in this article aims to explore the knowledge and experiences of Quebec's Deaf youth in relation to sexual health, in order to determine (1) the specific needs of Deaf and hard of hearing youth, with regards to sexual health

education and (2) the sources of information related to HIV / AIDS and STBBIs used by these young people.

In order to achieve this, the research specifications used were mixed, integrating mostly a qualitative paradigm. The quantitative data come from a self-administered online questionnaire, available in French and in LSQ videos, allowing for a better understanding of young Deaf people's knowledge of sexual health. At the same time as questionnaires were administered, interviews were conducted with young Deaf people, thus linking their qualitative description of their sexual health experiences with quantitative data on their knowledge of the subject.

Scientific literature has established the premise that Deaf people are deprived of sexual health information, primarily because their first language of communication, LSQ, is a minority language not shared by the majority of parents of Deaf children, and by sexual health service providers. This would greatly affect how Deaf people seek and obtain information when needed. Therefore, it can be argued that the majority of Deaf youth do not possess adequate knowledge about the modes of transmission of STIs, including HIV / AIDS, or how to protect themselves (Baker-Duncan, Dancer, Gentry, Highly and Gibson, 1997, De Andrade and Baloyi, 2011, Doyle 1995, Joseph 2000, Luckner and Gonzales, 1993, Zodda, 2015).

In order to complete our study, nine elements of the online questionnaire were considered reliable measures of knowledge about the transmission of STBBIs, including HIV / AIDS. Nine other elements concerned the means of protection. For example, the statement "Deaf people can contract HIV or other STBBIs" is about the transmission of STBBIs, whereas the statement "An oral contraceptive protects against STBBIs" is related to the means of protection. Respondents to the online questionnaire were asked to indicate their agreement (TRUE) or their disagreement (FALSE) in relation to the statement. When evaluating the knowledge score via the online questionnaire, the choice of "I do not know" in answer to a question related to STBBIs including HIV / AIDS was considered to be a wrong answer, due to lack of certainty as to the correct response.

Sample and Recruitment

The recruitment of participants for the questionnaire and for the interview was made possible by a general call via the CSSQ's network of contacts: LSQ or ASL video and explanatory text on the organization's Website and Facebook page, as well as via email. It was voluntary, convenient and non-probability sampling. Respondents to the questionnaire were asked to indicate their interest in being contacted for an interview. Furthermore, additional participants were recruited for interviews via the Facebook social network and via AQEPA, the Quebec Association of Parents of Children with Hearing Problems in Saguenay-Lac-St-Jean. During the interviews, participants were asked to complete the questionnaire online. Two independent non-exclusive samples were developed from the same population, with 14 participants in the individual interviews and 56 respondents in the questionnaire as preliminary samples, as data collection is still ongoing. The inclusion criteria for the mixed research specifications were: to be between 16 and 30 years of age, to identify as Deaf or hard of hearing, and to be a resident of Quebec. The exclusion criteria were: having a cognitive deficit making it impossible to complete the study consent form, and communicating in a language other than English, French, LSQ or ASL.

Note that identifying as hard of hearing was added as an exclusion criterion only for qualitative interviews in order to explore the experience of the Deaf sample only, as the latter make up the majority of the quantitative sample. Two-thirds (38/56) of respondents to the online questionnaire self-identified as signing Deaf and 18% (10/56) as oral deaf for a total of 86% of the sample, while the last eight respondents self-identified as hard of hearing. The average age of the 56 respondents to the questionnaire was 25 years [16; 30] with a standard deviation of 3.98 years. It was composed of 24 men, a trans man and 31 women. The 14 participants in the qualitative interviews had an average age of 26. Among them was an equal number of men and women. Twelve participants self-identified as heterosexual, one woman and one man as homosexuals. Half the participants were with a partner ($n = 7$) and the other half were without a partner ($n = 7$).

Questionnaire

A self-administered on-line questionnaire with the SurveyMonkey® platform was used. It included questions related to knowledge and experiences related to sexual health, in addition to a socio-demographic questionnaire. A total of 50 questions made up the quantitative collection tool: 13 questions about sexual life, 7 questions about sexual health, 6 questions about the relationship with a partner (if applicable), 18 knowledge-based questions related to STBBIs including HIV / AIDS and, finally, 6 knowledge-based questions related to the CSSQ. To date, the number of respondents represents close to 1% of Quebec's Deaf population, which suggests that the sample is representative of the population.

Interviews

Qualitative interviews were conducted by two hearing researchers in the preferred language of the participant, French or LSQ, accompanied by a French-LSQ interpreter if necessary, and directly in LSQ in the case of the Deaf research assistant. The interview guide had two components: (1) Sources of Sexual Health Information, and (2) Improving Access to Information on HIV / AIDS and STBBIs, as well as a socio-demographic questionnaire. The meeting between the participant and the researcher lasted between 20 and 90 minutes. Two of the authors of this article conducted interviews to the point of relative data saturation, which made it possible to increase the credibility of the data collected due to the following two factors: the triangulation of researchers as well as a thorough knowledge of the Deaf by the two principal researchers.

Data analysis

SPSS Statistics® version 24 software was used to analyze the quantitative data. Central tendency tests were performed with a p-value of 0.05. Interviews were fully transcribed and then analyzed using the matrix meta-analysis methodology presented by Miles, Huberman and Saldaña (2014), which consists of including all relevant and significant data from each individual case and condensing them into table format, organized according to descriptive codes or in vivo codes. Subsequently, in the course of matrix analysis, the division or regrouping of data makes it possible to refine their

classification into coherent units. In order to try to answer the two research questions mentioned above, central themes emerged from the analysis. During the process, the researcher responsible for matrix analysis ensured that she exchanged views with the other two researchers who conducted the interviews in order to obtain a consensus on the organization of the data, and in doing so, increase the reliability of the analysis and interpretation of the data.

Interpretation of results

The sample of participants in the interviews contained divergent cases, which tends to indicate data saturation and an increase in the credibility of interpretation of the data. For example, regarding the sources of information consulted, one young person said, "Yes, I consult the right places: Facebook and Google. I search a little randomly. I look at the information and I choose the right one" (Interview VN810097). Another participant had a more critical view of information sources: "Anyone can put information on Google. It is important to know where the information comes from. Are they reputable organizations? Who did the research? You can't trust just anyone. For example, we know that anyone can put things in Wikipedia, so it's not a valid site with reliable information" (Interview VN810092).

Ethics

A study focused on the needs of Deaf participants has the advantage of honouring the principle of justice, integration and protection of the interests of vulnerable groups by enabling Deaf people to share their experiences in relation to sexual health, they are frequently excluded from scientific research processes, because, among other reasons, due to communication difficulties with the researcher (McKee, Schlehofer and Thew, 2013). On a more technical level, the researchers who conducted this study followed the ethical guidelines of the Tri-Council Policy Statement produced by the Government of Canada (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2014).

Potential and limitations of the study

It is important to emphasize that, given the lack of preliminary studies and data on which to specifically base the research, the exploratory approach undertaken raises for the first time sensitive and central questions which, of course, merit sometimes more systematic and more thorough attention. The context of data collection and the production of analyses has resulted, for example, in the online questionnaire having been developed by the CSSQ on the basis of the educational material it distributes to its members and which it uses during presentations in schools. Therefore, the questions were not developed by a health professional, resulting in limitations in the validity of the questionnaire. For example, the expected answer to the question of whether the condom is the only means of protecting against STBBIs, was “true.” However, a health professional is required to inform the patient that sexual abstinence is also a valid means of protection (Clinique l'Actuel, n.d.), so “true” is a questionable correct response. On the other hand, the use of a five-point Likert scale in the knowledge section of the questionnaire, as well as the "I do not know" and "Sometimes" option may be debatable and detrimental when interpreting the data. In the case of questions about sexual health knowledge, the presence of a neutral category allowed respondents who did not have a strong opinion on the subject to reply (Fortin and Gagnon, 2016) and remained easily interpreted as an erroneous answer, since these were really dichotomous questions.

Among the other limitations of this mixed research, the absence of interviews with participants from outside the major urban centers limits the possibility of exploring experiences for Deaf youth living in rural areas, where interpreting services are difficult to obtain. In addition, the sample of participants in the interviews is relatively homogeneous in terms of gender identity: there are no transsexual men or women. As for the quantitative part of the mixed estimate, the preliminary sample from which the analyses were presented are still very limited. Therefore, this sample cannot necessarily be generalized to all Deaf Quebec youth.

What do young Deaf people say about their information search process regarding sexual health?

Sources of information about sexuality

At first, Deaf young people indicated that they needed visual support in order to grasp the message presented to them: "Sometimes, by searching on the internet, you find yourself stuck because of the lack of knowledge of French, so sites with images help [...]" (Interview VN810103). The sources preferred by the participants are the internet and their Deaf peers. Young people appreciate the presence of many images on the internet: "Yes, for me it's quite easy. I just have to type words on which I want to have information. There are lots of pictures. For example, there are lots of pictures on pregnancy. There's information about where she can go for a pregnancy test, etc. Also, there are good sites on disease prevention. It's easy for me to find them" (Interview VN810091).

Some participants in the interviews acknowledge the advantages of a source of information specifically for Deaf people in Quebec: "At the CSSQ, they say the word and also make the sign [*which corresponds to the word*]. We're given the definition. That's much clearer. Sometimes there are limits with just writing. Also [*information*] on symptoms, how to define symptoms, how to recognize them ..." (Interview VN810095). However, only a few more than one third (21/56) of respondents to the online questionnaire indicated that they had already visited the CSSQ site, which is unfortunate since it is a real source of accessible and valid information. In an interview, one participant denounces the lack of sexual health services for the Deaf: "Hearing people have much more choice. They have plenty of information while we Deaf people are so limited. [...] People who work in sexual health services don't know how to sign." (Interview VN810106). Despite the absence of health services offered directly in LSQ, the CSSQ nevertheless offers a support service for its members who visit health care professionals. Although this aspect was not addressed in the interview, the support provided by the CSSQ poses challenges in terms of confidentiality, as addressed by Mallinson (2004), linked to the phenomenon of promiscuity between the members of the Deaf community that the author calls the "Deaf

Grapevine.” Being seen in the company of a CSSQ worker can easily be a factor of stigmatization within a restricted community such as the Deaf community.

According to another participant, the CSSQ site remains unknown to many, despite its likely relevance: “[...] You see, you told me about the CSSQ site. I'd never seen it before. That was something I didn't know about. So, there are a lot of young people who don't know about it either. I think there are a lot of people who don't even know where to go for information. Maybe it already exists and we don't know. [...] The CSSQ site seems interesting because there are many young Deaf people who have difficulty with reading, so having it in LSQ makes information accessible. For Deaf people who have good reading comprehension, it's different, but for people who don't have good reading skills, having visual information helps a lot.” (Interview VN810091). The site provides comprehensive and detailed information on the prevention, screening and treatment of STBBIs, including HIV / AIDS. The information is entirely available in LSQ and ASL videos with a French or English text containing the information presented in the video. More than two-thirds of respondents to the questionnaire (36/56) expressed an interest in receiving appropriate information in LSQ regarding sexual health, legal rights and obligations with reference to STBBIs, etc. via social networks, suggesting that it is essential to continue to promote the activities of the CSSQ via social networks.

It goes without saying that not everyone has the ability to discern true versus false when it doing an internet search. Yet, the acquisition of a critical sense of internet sources is rarely prioritized in youth education, as if it were obvious that anyone can determine which of the countless websites containing sexual health information are accurate and reliable. Nevertheless, participants expressed confidence that they could find the information they needed about sexual health. To achieve this, they prefer to consult their peers with whom they share a preferred language of communication, LSQ: “I'm not sure how reliable the sites I visit are [...] So first I look for the information by myself, and then I check with my friends” (Interview VN810103b). Another participant explained that his friends who communicate with him in LSQ are able to clarify information about sexual health: “I'll ask my Deaf friends who use sign language ... about technical vocabulary. like

words used by doctors, for example, words whose meaning I don't understand" (Interview VN810103b). Many young people have identified peers as a source of accessible information because of the common use of sign language, or they refer to the internet since it contains visual support facilitating the acquisition of information. During the interviews, participants frequently indicated that communication with parents was more difficult, and lack of a common language was certainly a factor preventing them from receiving information related to sexuality: "I didn't have a very strong bond with my parents. I prefer to be independent. The fact that I'm the only Deaf person in the family makes me go and look for information from other Deaf people because communication is easier ... No, my father, not at all [*doesn't communicate in LSQ*]" (Interview VN810100).

Eighty-nine percent (89%) of respondents to the questionnaire (50/56) have two hearing parents, a greater proportion than appears in the literature (Mitchell and Karchmer, 2002). However, no fewer than 63% of the respondents' family members know LSQ. It should be noted that the level of fluency and competence in LSQ/ASL was not questioned, which does not allow us to conclude that communication about sexuality takes place in a signed language. In the interview, participants reported negative communication experiences within their family, mainly because of a lack of a common shared language: "My parents communicate with signs like hearing people. Maybe the reason we couldn't communicate comfortably about sexuality was because we didn't have the same mode of communication. When I first got my period, I learned about it at school [...] how the menstrual cycle worked. Not from my parents" (Interview VN810089).

Moreover, young people's lack of understanding of certain French terms sometimes prevents them from understanding the message communicated by their parents: "There were times when my father tried to write, but there were words that I didn't understand. Sometimes I wasn't too sure of the vocabulary. For example, chlamydia or syphilis. There were words I didn't know, like gonorrhoea. My mother wrote those words, but I didn't understand the vocabulary" (Interview VN810095). Another participant stated, "It's harder for Deaf children who have hearing parents, because the communication isn't clear; there's a barrier caused mainly by communication. So often the parents will let it go ... Since the

parents and the child have never had any real communication, they're embarrassed when they try to share information about sexuality. But in my case, my parents were Deaf, so there was no stress related to communication" (Interview VN810090).

The absence of communication in relation to sexuality between parents and their Deaf children deprives them of certain information that, in hindsight, they deem essential. For example, one participant had never had information from her parents about the emergency contraceptive pill: "It seems like my parents didn't want to help me ... It's as if my parents had forgotten that I was Deaf and had put me aside [...] Deaf people like me are often forgotten" (Interview VN810107). This experience about the fear of an unwanted pregnancy is due to a lack of information resulting from unsatisfactory communication between the parent and the Deaf child. In short, it must be remembered that clear and fluent communication is a determining factor in the closeness of a relationship, and thus promotes conversations about sexual health. In fact, young Deaf people seem to be unaware of the challenges they face when consulting and evaluating information sources.

Knowledge about transmission risks

Despite young people's confidence at being able to respond independently to their sexual health questions, the overall average score of 63% (11.25 / 18) for sexual health knowledge questions indicates that their information sources are invalid, or that young people often misunderstand the information obtained. Questioned on the subject in individual interviews, young people stated that it was easy to find information on the internet and from their peers. It should be noted that young people who are Deaf have gaps in knowledge about the risks of contracting an STBBI including HIV / AIDS: a majority of respondents (55% = 31/56) believe that a person in a conjugal relationship cannot be exposed to STBBIs. The same proportion (55% = 31/56) erroneously believe that having one partner protects against STBBIs, which seems consistent with the proportion of respondents (55% = 31/56) who do not consider that limiting the number of sexual partners reduces the risk of contracting HIV and other STBBIs. Nearly one-third of respondents (29% = 16/56) believe that having sex with people they know well will prevent them from contracting HIV or other STBBIs. One-quarter of respondents (25% = 14/56) are not aware

that a pregnant woman living with HIV can pass it on to her child during delivery. Finally, only a minority of respondents (32% = 18/56) acknowledged that a person who consumes alcohol or drugs before sex increases the risk of contracting HIV or other STBBIs. Yet the effect of disinhibition associated with substance use is well documented in the literature (Winningham et al., 2008).

Knowledge about protection methods

More than one in five respondents (21% = 12/56) were of the opinion that a Deaf person is not at risk of contracting HIV or another STBBI. In response to the question of whether condom use is the only way to prevent the transmission of HIV / AIDS or STBBIs, almost half (45% = 25/56) of respondents mistakenly believed that it is not. In fact, more than a quarter of respondents (27% = 15/56) believed that an oral contraceptive protects against STBBIs. Only half of respondents (50% = 28/56) are aware that there is no cure for HIV. An overwhelming majority of respondents (73% = 41/56) did not know about PPE (post-exposure prophylaxis) and a similar proportion (70% = 39/56) did not know about PrEP (pre-exposure prophylaxis). These knowledge gaps appear to be related to the frequency that Deaf youth turn to their peers as a source of information, and/or their inadequate use of the internet. Of course, some of them show a more nuanced judgment on the sources consulted. Thus, one participant explains, "... I don't just consult one website: I validate the information. I go to many sources, and all the information I get from these sources gives me the information I need" (Interview VN810090). Although diversification of sources can be effective in confirming or deepening information, it is still possible that the sites consulted will all disseminate false information if none has been validated by the public health authorities. Indeed, the number of sources consulted on the Internet does not increase the veracity of the information conveyed there.

Discussion: Towards better use of available resources

Based on the results of the online questionnaire, young Deaf people have a lack of knowledge about the modes of transmission of and appropriate means of protection from STBBIs including HIV / AIDS. These are needs to which the CSSQ is unquestionably able to respond. However, few interview participants and respondents to the questionnaire say

they are familiar with this specialized resource. Consequently, Deaf youth remain dependent on written information in a language they do not master well enough to provide them with basic knowledge of sexual health. They rely on their internet research habits and their social networks to find answers to their questions, both of which entail a risk of misinformation. In light of the interpretation of the data, the deficits observed in the literature occur even now in Quebec, when the flow of information should be easier and more efficient. It seems unrealistic to view the internet as a "turnkey" way to compensate for the discrepancies among general health service providers, lack of support from family due to the language barrier, and sexual health needs of Deaf youth. Since the internet is a medium preferred by this population, data from exploratory research demonstrate on the one hand, that use of the CSSQ site should be strengthened using social networks as a means of promotion. On the other hand, a specialized sexual health service such as the CSSQ could implement activities enabling young Deaf people to develop strategies for identifying appropriate information related to sexual health by offering information capsules on the subject, by presenting a list of reliable internet sources and by adding a Glossary section to its existing site. These activities would provide LSQ and ASL support to youth who visit sites in French or English. Finally, the bilingual information available on the site can undoubtedly serve as a support for communication about sexuality between parents and Deaf children.

Conclusion

The methodological limitations mentioned above in this study are far from calling into question the relevance of the exploratory approach outlined in this article. In our opinion, this study is essential in that it contributes to the limited knowledge about the sexual health of Deaf youth. They demonstrate limited knowledge about STBBIs including HIV / AIDS: their average score of 63% on the questionnaire on the risks of transmission and the means of protection is cause for concern. This research project is based on an original international framework, which has never been done before in Quebec. The strengths of the study include the fact that the consent form, the questionnaire and the interviews were all conducted in the language preferred by the Deaf participants, thus limiting the risks of lack of comprehension of French or English, where applicable. In

addition, knowledge about sexual health was assessed only through the self-administered questionnaire, so as to limit any social desirability bias that might have been present if such questions had been asked in an interview. For example, on the question of whether the person knows the PrEP, respondents to the online questionnaire were free to answer in the negative, without fear of an unfavorable judgment on the part of the researcher. The cross-referencing of quantitative and qualitative data is an undeniable strength, in that it raises questions about the confidence expressed by young people during interviews, considering that they show gaps in their knowledge of sexual health. Due to ease of communication, the young people interviewed named peers, the internet and, to a lesser extent, family members as sources of information.

It seems appropriate to question whether these preferences derive more from a profile specific to Deaf youth or from a generation effect. The literature does not recognize the internet as a major source of information, which does not correspond to the data collected through interviews with young Deaf people. There is a good chance that the medium has gained substantial popularity since the early 2000s, a fact which is not reported in the recent literature (Zodda, 2012). As far as peers are concerned, the associated risk of misinformation is clearly mentioned in the scientific literature (Karras and Rintamaki, 2012), which is why it is essential to inform young people about how to exercise critical judgment on the sources of information available to them. One of the elements that remains unknown and which this research project does not answer is the health literacy of Quebec Deaf youth and its impact on the health status and sexual health behaviors of young people. This type of action presents an unavoidable methodological challenge, namely the transcultural validation of a measuring instrument (Fortin and Gagnon, 2016). Of the 51 health literacy tools listed in the literature (Haun, Valerio, McCormack, Sørensen and Paasche-Orlow, 2014), only one has been validated among Deaf people who communicate in ASL, the Newest Vital Sign (McKee et al., 2015). It is also the only instrument to have been validated in French. However, no LSQ version has yet been developed.

Although the sample of participants in the interviews is limited, the results of this study may contribute to the discussion of the sexual health of Quebec's Deaf youth, given

the relative empirical data saturation obtained during the interviews. It is therefore possible to consider that the results are transferable to a group of American or French Deaf youth, since their Quebec peers have similar experiences and realities in connection with deafness, as well as the use of a minority language (Lachance, 2002).

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