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"T@ngled Up in Blue": Views of Parents and Professionals on Internet Use for Sexual Purposes Among Young People with Intellectual Disabilities

Lotta Löfgren-Mårtenson[1] · Emma Sorbring[2] ·
Martin Molin[2]

Abstract This study aim to examine parents' and professionals' views on the usage of Internet for love and sexual purposes among young people with intellectual disabilities (18–20 years) in Sweden. Five semi-structured focus group interviews were conducted with professionals (n = 8) working on special programmes in upper secondary schools and with parents (n = 5). The interviews were analysed with thematic analysis and the theory of sexual scripts were guiding the process. The results show that the Internet is seen as a social arena with complex challenges; for love and sexuality, for sexual conduct, and for sexual risk and opportunities. Young people with intellectual disabilities are looked upon as more vulnerable than other youth. However, the result also show that parents view the risk of their adolescent of being lonely as greater than the risk of being abused or mislead. A Net-script consisting of rules is geared towards the young people with intellectual disability. Nevertheless, a change to a more flexible and nuanced Net-script is shown while the group of young persons with intellectual disabilities are seen as more heterogeneous than earlier. In-depth knowledge about parents' and professionals' perspectives on the Internet and sexuality is important since the young people live in a dependency situation towards their surroundings. In addition, the surroundings' attitudes and behaviour are essential for the young peoples' access of support and opportunities to develop their own capacity and to experience love and sexuality.

Keywords Intellectual disability · Internet · Sexuality · Parents · Professionals · Sweden

✉ Lotta Löfgren-Mårtenson
charlotta.lofgren-martenson@mah.se

1 Centre for Sexology and Sexuality Studies, Malmö University, Nordenskiöldsgatan 8, 205 06 Malmö, Sweden

2 Centre for Child and Youth Studies, University West, Trollhättan, Sweden

Introduction

Many people with intellectual disabilities live socially isolated lives and are in need of more community contact [1, 2]; therefore, the Internet can be an important arena for finding friends and partners [3–6]. Due to current advances in new technology, such as laptops and smart phones, social media has become an integral part of daily life for most young people [7]. Given that people with intellectual disabilities require support from those around them, it is often the case that family members and care staff provide the primary support for their use of new technology [8]. This study aims to examine the views of parents and professionals in regard to this new technology and how it affects the young people in their care.

For over two decades, the Internet has been used as a social arena for love and sexual purposes; for example, to flirt, to get in contact with others in anonymous and more personal ways, and for pornography consumption [9, 10]. Previous research shows that people with intellectual disabilities use the Internet for similar social reasons, especially those linked to love [4, 5]. In addition, they strive for societal participation in order to be like "everyone else" [11, 12], for example, by seeking a partner on the Internet [4, 5]. Conversely, former studies highlight the restrictive views on how young people use the internet by those in their surroundings [ibid.]. Parents and professionals worry about the risk of sexual abuse or that young people with intellectual disabilities might be sexually misled on the Internet. On the other hand, the young people are worried about the risk of disappointment by not being allowed to find friends and partners on the Internet.

Recent research shows that family members and care staff are often the primary support for the Internet use [8] of the young people they care for. In conjunction with this, an overall feeling of distress may arise over the negative aspects of using the Internet [13]. Media attention focuses heavily on the risk of being deceived on the Internet and on how it gives easy access to pornography. The biggest concern raised by the media has been in relation to the use of Internet by children and young people in particular [14–17].

In regard to young people with intellectual disabilities, a general concern and ambivalence about them and sexuality already exists [3, 18]. Many parents want their children to experience the positive aspects of love and sexuality; however, at the same time, they see them as particularly exposed, vulnerable and running the risk of sexual abuse or unwanted pregnancy. Therefore, those who care for young people with intellectual disabilities have a strong sense of responsibility—one often manifested through various forms of control [ibid.].

The views and perceptions of parents and professionals towards sexuality and the use of the Internet are vital due to the young people's lifelong dependency on them [3]. While the activities of young people on the Internet are a growing research field; in general, only a few studies have focused on the Internet use of persons with intellectual disabilities. In *EU Kids Online*—the largest study in Europe on these issues, Livingstone et al. [7] stresses the importance of studies that focus on young people who are particularly vulnerable to what the Internet offers and contains. The objective of this article is to fill that gap.

Aim and Objectives

The aim of this article is to investigate the perceptions of parents and professionals regarding the Internet as a social arena for love and sexuality among young people with intellectual disabilities (18–20 years). The following research questions guide the process:

- How do the parents and professionals describe the young people with intellectual disabilities' use of the Internet for love and sexual purposes?
- What are the parents' and professionals' experiences and opinions on the use of the Internet by young people with intellectual disabilities for love and sexual purposes?
- How can the parents' and professionals' prevailing rules and guidelines (however loose or fixed they may be) regarding the young person's Internet use be described?

Theoretical Framework

We employ Gagnon and Simon's [19] classical sexual script theory in our analysis of society's views toward sexuality, the Internet and intellectual disabilities. The term "script" is used as a metaphor—a manuscript that answers questions concerning how, when, with whom and why to act sexually. According to this theory, sexual patterns, norms and behaviour should be learned through social and cultural processes. Further, what is considered to be "normal sexual behaviour" is something that changes over time and in diverse cultures. Moreover, the scripts differ due to aspects such as gender, disability, age, et cetera. The scripts are never static, nor immutable. The Internet is one example of a factor that can act as a catalyst for steadily increasing changes of sexual patterns, cultures and behaviour norms [10]. By using script theory, the results from the interviews with parents and professionals may be placed in a cultural, social and temporal context.

Methods

We choose qualitative methods in order to answer the research questions [20, 21]. Altogether, 13 parents and professionals between 38 and 58 years were interviewed in this pilot study. Both interview groups were selected by means of strategic sampling [22] in order to generate initial data that would cover and deepen the research questions. The professionals (seven females and one male) were all part of a special teacher programme at an advanced level for professionally active teachers. The interviews were completed in focus groups with five professionals in one group and three professionals in the other. The duration of each interview lasted about 45–60 min and was conducted at the university by one of the authors.

The parents (three females and two males) were all parents of pupils in their last year of the upper secondary special programme for pupils with intellectual disabilities. The pupils went to the same upper secondary special programme class, but varied in age between 18 and 20 years. The parents were contacted by a letter informing them about the aim, research questions, and level of expected participation, and also provided an explanation that participation was voluntary. Their ages ranged from 47 to 57 years. Four of the parents were interviewed in gender homogeneous pairs, except one woman who was interviewed individually (due the sudden sickness of the other parent who was unable to join the interview). The interviews each took about 60–90 min and were conducted by one of the authors, either at the university or at the local clubhouse of an interest group for persons with intellectual disabilities (FUB, The Swedish National Association for Persons with Intellectual Disability).

Research Approach and Analysis

Interviews in smaller groups or in pairs have the advantage that the participants are able to engage in a discussion about the subject of interest with each other [21]. In addition, another motive for creating the smaller parent groups was ethical, given that the pupils referred to in the interview were all enrolled in the same class. The interviews were semi-structured with a set of pre-designed questions following designated themes. This allowed the participants to express their own thoughts and experiences during the interview while, at the same time, providing the interviewer with the possibility to steer the topics and content being discussed. The themes for the interview guide were the same for both the professionals and parents. This article focuses on the following themes: (1) The Internet as an arena for love and sexuality, (2) the attitudes and behaviour of parents and professionals concerning the use of the Internet by young people with intellectual disabilities.

The interviews were recorded (in total 5 h and 29 min) and then transcribed (in total 73 pages). The transcribed interviews were analysed with a qualitative approach and a thematic analysis was used, which is a method of identifying, analysing and reporting patterns within data sets [23]. The first step of the thematic analysis was to get to know the data through transcribing, reading and re-reading the interviews. Thereafter, statements were highlighted in order to systematically code interesting features in relation to the research questions. The codes were later organised into potential themes, designed to encapsulate the content of the dataset. To ensure this, data were systematically reviewed and refined. Finally, the themes were named in order to reflect the content of each theme. Willig [24] highlights the importance of reflexivity in the data analysing process, such as personal 'biases' of relevance to interpreting data (that is, gender, ethnicity, age, personal experiences of the subject matter of the research and so on). In this study, one researcher had vast experience of conducting parental interviews, while the other researcher had correlative experience of doing interviews with professionals. The two researchers conducted the interviews with its respective category of informants. In order to counteract interpretations based on preconceptions of the two informant groups, the transcribed materials, the codes and themes were continuously reflected and discussed within the research group as a whole.

Ethical Considerations

The study followed the Swedish ethical rules regarding the requirements of information, consent, usage of data and confidentiality [25]. To maintain confidentiality, no names, ages or other identifying information will be given in relation to the quotations of the professionals and parents in the presentation of the result.

Results

The analysis of the data presented in this article resulted in the following themes, exemplified by questions to show the complexities of each area: (1) Arena for love and sexuality—hopes or sorrows? (2) Arena for sexual conduct—doing right or wrong? And (3) Arena for sexual risk or opportunity—who's responsibility?

When presenting the results, we have selected anonymous citations from the interviews in order to maintain confidentiality. We use *R* as a shortened form of Researcher and *P* for Parents, accordingly, *T* for Teachers.

Arena for Love and Sexuality: Hopes or Sorrows?

In their interviews, the professionals emphasise the Internet as an important arena for love and sexuality. They state that many young people with intellectual disabilities are "a bit isolated in real life (IRL)" and the Internet is sometimes their only contact network. However, both the professionals and the parents notice a gender difference in the Internet use among youth with intellectual disabilities. Overall, the girls seem to be more contact and relationship-seeking, while the boys more often use the Internet for checking results and facts. The parents talk about their adolescents:

> P1: He is on the Internet a lot…googling and yes…[…]…seeking information… He understands.
> P2: […] The Internet is as obvious as air for them…[…]. My daughter uses it for social causes, music, Facebook and a few games.

Having a presence on the Internet seems to be a significant way of getting confirmation from others. Therefore, it is important for the young people to visit the same sites that "everyone else" visits, for example, Facebook. In addition, to display that they are able to find partners is also a way for young people with intellectual disabilities to show that they are "normal", according to the interviews with the professionals. A teacher remarks that his pupils manage to find boyfriends and girlfriends throughout Sweden. He explains:

> It seems to be a way of feeling recognition somehow…to show who you are and…how many girls and boys you have met…how much sex you have. Again, it is this thing about being "normal"!

The parents agree that the Internet is an arena for love and sexuality. However, in general, they talk more about the positive social aspects of the Internet. They confirm that many young people with intellectual disability are lonely and that the Internet plays an important role in their contact arenas. However, the parents also tell of their children's difficulties to communicate on the Internet without the help of body language. One mother tells of her daughter:

> P: I wish that she would go out and meet people face to face…
> R: Why do you wish that?
> P: Because I think it is better! (laugh)
> R: Why?
> P: Because you are supposed to interpret…interpret faces…and feelings… feelings of warmth…or…well, you get so much more information when you talk to people (in real life) instead of wondering…"Is this what she meant?"

Only a few of the parents think that their children's use the Internet specifically for sexual purposes. In these cases, they often speak of accidental visits to sites with sexually explicit material. Instead, most parents explain that their children are not as mature as other young people of the same age and, therefore, not yet interested. However, the young people with intellectual disabilities do have hopes and dreams concerning love and relationships. One parent describes their daughter:

It is not that easy…she is not there. She talks very much about her hopes about having a boyfriend and stuff like that. But, I think that is more about just having someone…not the physical aspects…

The interviews with the professionals show that several of the young people with intellectual disabilities do have boyfriends and girlfriends on the Internet. These so-called net relationships usually only exist on the Internet, and the partners seldom meet in real life. However, net relationships are experienced equally real as any other relationship. The professionals also describe the young people's difficulties in understanding the other person's feelings and needs in the net relationship. Therefore, the Internet is seen as an arena for disappointment and conflict. One teacher gives an example of a heartbroken pupil:

I have pupils who…only have net relationships…and they write to each other… and then suddenly…they are sitting by the computer crying…and in despair… because now it is over…the other partner broke up…and… really, they have never met outside of cyberspace!

Another complication, according to the interviews with the professionals, is that it is common to have several partners at the same time on the Internet. The professionals speak with disdain about these parallel net relationships. One teacher talks about one male pupil with intellectual disability in particular:

This guy…he has girlfriends in different places…and they meet online…He writes "I love you" to them even though they have never met! He writes to more than one…at the same time…and sometimes this becomes obvious and then there are huge quarrels (on the Internet)!

Arena for Sexual Conduct: Doing Right or Wrong?

According to the interviews with both the professionals and the parents, young people with intellectual disabilities have a hard time understanding what is considered proper behaviour on the Internet. This seems to be especially difficult when it comes to love and sexuality. Several of the teachers tell of situations where their pupils cannot understand, for example, the consequences of writing things with sexual meanings or to brag—or even lie—about sexual experiences. Likewise, they tell about pupils who publish pictures of themselves in the shower without understanding the boundaries of what is the right or wrong behaviour on the Internet. As a result, the professionals have to tell the young people what to do or not do. One teacher gives an example of a male pupil who expresses his feelings of love to people he has never met outside of cyberspace:

Well, it is difficult (for them) to have some kind of sense of what is proper to write or not. For example, this thing with "I love you" ….[…]. They express anything in some kind of…well, other youngsters can do that also…but these kids, they write anything without thinking…

More than a few professionals point out problems that are consequences of their pupils' naivety. For example, they state that their pupils do not understand the importance of presenting themselves on the Internet in proper ways. In addition, according to the interviews, they sometimes do not even understand that they are being used. One teacher explains:

They probably use the Internet like everyone else, but are much more naive […] My experience is that girls often meet boys and are being used – but then they talk and chat with classmates far and wide, they say, "you know, I met a guy the other weekend in this or that town…"

The interviews with the parents show that some of them are worried about their children visiting the "wrong" sites, for example, those with easy access to pornography. One parent tells of their son who is both curious and afraid of these sites. Another consequence of their children's immaturity compared to other young people of the same age is that it makes it difficult to talk about sex and sexuality on the Internet. A parent states:

He is so embarrassed when we try to talk to him…[…]. But they have talked about this at school…[…]. I think it is very good that (professionals) at school can support them in these issues.

Some of the parents are afraid that watching pornography might destroy a lot for their children, given that they do not understand those kinds of sexual expressions. Therefore, one parent says that they try to prevent their son from visiting these sites. The parent describes a situation where a fake police message came up on their son's computer screen:

We have the computer on the upper floor […] and we saw the reaction in his eyes: "It is not to do with any weird sites now, is it? You know that can lead to something really wrong…it can be very, very tangled!" Suddenly, a (fake) warning came up claiming to be from the police and he panicked […]. We were lucky, you can say [laugh]! Now he understands how dangerous it can be!

Several of the parents state that they can accept their children's expressions of sexual feelings or interest as long as it is "healthy" or "normal" sexuality. One parent explains his view on the possibility that their daughter might use the Internet for sexual purposes:

P: I guess I would consider it strange at first. That it would feel a little bit scary…and I would be a little bit afraid…but as long as it is healthy, what I consider healthy…
R: What you consider healthy?
P: Yes, then I guess I would not mind…I would probably not know about it any-way…because she might not tell…

Arena of Sexual Risk or Opportunity: Whose Responsibility?

Even though the professionals regard the Internet as an important social arena, they are at the same time worried about the risks. One teacher explains that the Internet can be a positive arena for some youngsters with intellectual disabilities, but for others, it has resulted in tragic or unwanted consequences such as the effects of humiliating or clumsy statements or even experiences of being forced into unwanted sex. Several professionals describe dangerous situations where young people with intellectual disabilities have travelled to another town to meet someone they do not know outside the Internet. A teacher confirms these situations at his school:

Yes, I recognize it. They meet…pupils, youth from other cities…It does not always work out well.

But it is not only the risk of being abused or cheated that the professionals talk about. It is also the risk of abusing others or putting other people in dangerous situations because of

the pupil's inability to understand the consequences of their actions. One professional tells of a pupil that published a picture of a teacher on the Internet and stated that he was gay. This resulted in a dramatic and huge crisis in their school. However, the teachers have been able to use this as an example of the consequences of irresponsible Internet use and also to show the pupils what kind of information that, for example, a company like Google collects about its users. The question about who is responsible for preventing risks on the Internet is obvious in the interviews. One teacher describes a situation where a parent wanted the school to check her daughter's communication on the Internet. The teacher continues:

> Then her mother called and said that her daughter had a boyfriend on the Internet…and she wanted me to check up on it!

Nevertheless, the interviews also show that not everyone is acting in dangerous ways on the Internet. On the contrary, some young persons with intellectual disabilities are too cautious to try any contact-seeking activities on the Internet. A reason for this could be all the talk about the risks of the Internet, according to one teacher. This limits their opportunities to make new friends and maybe even find partners. One teacher says:

> […] I am especially thinking of one guy who really…"No, this is too dangerous!"…and you can somehow hear the adult arguments…that one should not meet anyone, it's too dangerous and adventurous. He would never cross that boundary.

In general, the parents who were interviewed do not focus as much on the risks of the Internet as the professionals. They say that they are not that worried because their children seem to stick to what and whom they know on the Internet. Furthermore, they frequently share information about what is happening on the Internet and who they have contact with. Instead, the parents seem to weigh the risk of their child living a lonely life as more important than the risk of sexual abuse. One parent tells of their son who only occasionally meets a friend outside the Internet. The parent continues:

> They don't have a life, so to say. In my eyes, it is no life. This is the social isolation that we are talking about.

At the same time, their parents state that is hard for their children to predict the results of their actions on the Internet and to detect what is true about other people's intentions. Therefore, they have to help them understand what is going on in cyberspace. However, some youngsters with intellectual disabilities are able to take responsibility for their behaviour and also to set boundaries towards unwanted contacts. One parent gives an example of their daughter who showed that she could handle a situation where a guy was sexually abusing her on Facebook. The parent says:

> Well, there was this guy…and first it was nice…and she wanted them to be friends. But after a while it was very much talk about sex and stuff like that…Then she blocked him immediately and said that she didn't want him there.

Discussion: A Changing Net Script?

In summary, Internet use is seen as an integral part of our community today, compared to 10 or 15 years ago when only a few adults were using it [c.f. 4, 5]. Both parents and professionals view the Internet as a commonly used social arena for young people with

intellectual disabilities; however, the Internet use of these young people is tied to their identity as having complex challenges, whereas other youth who use the internet in the same way do not have this burden. The professionals describe situations where the young people anticipate and hope to find friends and partners. At the same time, they view the Internet as an arena for disappointments, broken relationships and conflicts. Sharabi and Margalit [26] studied the relation between virtual friendship and social distress among Israeli young people with and without intellectual disabilities. They found that young people with intellectual disabilities report higher levels of loneliness and negative affect compared to young people without intellectual disabilities. However, when looking at the relation between virtual friendship and loneliness as well as negative affect, there were no differences between the groups. This indicates that young people with intellectual disabilities make up a heterogeneous group (like adolescents in general) and that relations on the Internet have different effects on different individuals.

Further, our result show that the professionals are more certain than the parents that young people with intellectual disabilities use the Internet for sexual purposes. The parents state that their children are more inexperienced than other young people of the same age and not that interested in sexuality. This is in line with Sorbring [15] who shows how the parents' views of their adolescent's sexual activities on the Internet in general are connected to feelings of uncertainty and to their children's age and gender. However, this might be a naïve perspective supposition by the parent. In the UK, for example, adolescents with intellectual disability and with harmful sexual behaviour are over-represented both as victims and as perpetrators [27]. If patterns offline are similar online, this indicates that young people with intellectual disabilities is a vulnerably group.

In addition, the result shows gender differences as the girls with intellectual disabilities are looked upon as more contact-seeking than the boys. Previous research demonstrates that boys with intellectual disabilities are more insecure about who to contact and when to do it, and for these reasons, they let the girls take the initiative [18]. Johansson and Hammarén [28] show similar results in their study on youth and sexuality in Sweden and talk about "the vulnerable masculinity". However, it is the girls with intellectual disabilities in this study who are considered vulnerable. Dating unknown persons on the Internet is also connected to girls' behaviour and is viewed as risky. Additionally, gender differences are illuminated concerning pornography sites discussed only when it comes to the behaviour of boys. This differs from other studies that show increasingly more gender fluidity in the younger generation when it comes to patterns of sexual behaviour and norms [e.g. 10, 29].

Both the professionals and parents consider the Internet an arena for positive opportunities as well as sexual risks. Nevertheless, the professionals seemed to be more worried about the risks than the parents who state that the opportunities outweigh the disadvantages. For them, the real risk is described as the risk of loneliness and social isolation. Stendahl et al. [30] suggest that the Internet, in general, but virtual worlds, more specifically, can be present opportunities for people with intellectual disability to develop new friendships and relationships and to maintain these. In virtual worlds, one can either "hang out" at a bar for the sole use of people with, for example, autism or one can choose another place to hang out that is not specified for the use of any specific disability. Virtual worlds can open up the opportunity to travel the around world visits concerts and spend time with friends that you otherwise would never have meet [ibid.].

That parents consider the Internet to be an arena for relationships is an interesting change compared to previous research where both parents and professionals worried about the risks of abuse, and so on. [c.f. 4, 5]. In addition, previous research shows that the young

persons with intellectual disability viewed the risk of not finding a partner on the Internet as more obvious than being abused [ibid.]. One way of understanding these different views on risk is to look at it as a social process that consists of negotiations [31]. It is the social and cultural context which defines and pervades the view. Our study shows that teachers express their professional point of view, while the parents see it from their adolescents' social situation. A third perspective is shown in a previous interview study where the point of view of the young people stems from their longing for partners and friends [4, 5].

On the whole, the young people with intellectual disabilities are described as a more heterogeneous group by both parents and professionals compared to previous research [e.g. 4, 5]. Some persons are able to handle the complex communication on the Internet, but others are not. In other words, the net script seems to have developed into a more flexible and nuanced script towards each individual's need for guidance [c.f. 4, 5, 19]. In addition, the parents' net script is less restrictive than the professionals'. These results shed light on the role of staff and family support [8], in general, and on 'positive risk-taking' in particular [32]. Positive risk-taking allows the focus to be on managing risks not avoiding or ignoring them; "Taking positive risks because the potential benefits outweigh the potential harm" (ibid. p. 228). The tendencies of a changed net script can be linked to Seale's [32] conclusion that "technologies are frequently conceived and talked about as revolutionary tools capable of transforming the lives of people with learning disabilities. They might indeed have this potential, but this potential can be mediated by powerful others: supporters (professionals and parents)" (p. 231). In line with this research, Bunning et al. [33] studied the culture of information communication technology (ICT) in the lives of young people with intellectual disabilities and found that ICT was frequently used by the young people to maintain but also to form new relationships. However, several of the young people pointed out difficulties with the technology, and the authors point to the need for knowing more about the nature of these difficulties and how technology can be easier to manage or/and how the use of technology among young people with intellectual disabilities can be supported by others.

Several parents have stated that it is the professionals' foremost responsibility to teach young people with intellectual disabilities how to act on the Internet in order to prevent sexual abuse, assault or being misled. Similarly, the result shows a continuous restrictive net script where young people with intellectual disabilities as a group are looked upon as more vulnerable than other youth. As a result, they are in need of more rules, and sometimes threats, than other young people. These more strict rules foremost consist of defining inappropriate behaviour, such as consuming pornography and dating unknown persons on the Internet. The opposite, what actually is considered proper behaviour, is relayed more diffusely. In summary, it seems as though the net script is both fixed and in a process of continuous change. However, none of the informants talk about giving more responsibility to the young people through information and education, even though a successful example of a female's strategy to cope with a situation of sexual assault occurs in one focus group.

To conclude, in-depth knowledge of the perspectives of parents and professionals about the Internet and sexuality are important given that these young people are dependent upon their surroundings. Therefore, these results are useful as part of education strategies that focus the use of internet among pupils with intellectual disabilities, as well as while designing potential interventions geared towards the youth. In addition, knowledge about the attitudes and behaviour of those around young people are essential for access to support and opportunities to develop their own capacity to experience love and sexuality.

Limitations of the Study

The study has several limitations. First, the data is limited and consists mostly of females (ten females and three males). We know that views on sexuality are influenced by gender due to the socialization process [19]. That means that the result might have shown other perspectives with another allocation. Second, the sample of the professionals originate from a special teacher programme on an advanced level for professionally active teachers. This might reveal bias while these informants are actively seeking new knowledge. Therefore, they might be more open-minded towards the research subject than other professionals. Third, because the parent informants were recruited from the same upper-secondary special school, this might limit the variation of experiences by their children's use of the Internet for sexual purposes. Therefore, the result cannot be generalized to other populations. However, it gives in-depth knowledge of perspectives and experiences that are relevant for the research area and for changing practices on education context. While updated research on the field so far is limited, this pilot study contributes to the field and can serve as a base for further research.

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