

Children with chronic complex conditions: Preferences for digital and in persons support and involvement in their own care-a qualitative interview study

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Margaretha Jenholt Nolbris^{1,2} , Stefan Nilsson^{1,2,3} ,
Diana Swolin-Eide^{4,5} and Malin Berghammer^{2,6}

Abstract

Children living with chronic complex conditions (CCC) face challenges that affect their daily lives, often negatively impacting their perception of life, health, and overall well-being. A person-centered approach by healthcare professionals can facilitate better support tailored to each child's individual needs. This approach can be applied both digitally and in person within healthcare settings; however, there is limited knowledge regarding the type of support children prefer. This study aims to describe how children with complex chronic conditions (CCC) experience digital and in-person support, their information needs, and their perceived participation in their own healthcare. Twelve children aged 10 to 17 years were individually interviewed, using a qualitative descriptive method. The data were analyzed with manifest content analysis, where two categories were identified: "Support and involvement in one's own healthcare" and "Receiving information in different ways." Findings indicate that children with CCC require personalized information and support addressing their specific needs, incorporating both professional and peer-to-peer support. This study highlights a person-centered care in healthcare, which enhances children's rights and encourages their active participation in their own care.

¹Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

²The Queen Silvia Children's Hospital, Sahlgrenska University Hospital, Gothenburg, Sweden

³Centre for Person-Centred Care, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

⁴Department of Paediatrics, Institute for Clinical Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

⁵Department of Pediatrics, Sahlgrenska University Hospital, Gothenburg, Region Västra Götaland, Sweden

⁶Department of Health Sciences, University West, Trollhättan, Sweden

Corresponding author:

Margaretha Jenholt Nolbris, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Box 457, Gothenburg 405 30, Sweden.

Email: margaretha.nolbris@fhs.gu.se

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Introduction

For many children living with chronic complex conditions (CCC), their condition could have a huge impact on their daily life (Perrin et al., 2007; WHO, 2023). It includes a wide range of conditions, from life-threatening to incurable diseases, from neonatal period up to adolescents (De Bock et al., 2019; Feudtner et al., 2014; Van der Lee et al., 2007). It includes diseases with no possibility of spontaneous recovery and which are rarely completely cured, which could also be associated with negative effects on the affected children's medical care, as well as on their health and well-being (De Bock et al., 2019). The children are situated in an environment marked by uncertainty, medical interventions, and prolonged treatment. This vulnerability becomes the starting point for the family's emotional and practical adjustments. When the diagnosis is made, a first loss occurs, and the future they had imagined changes (De Souza et al., 2025).

In this study, the definition of CCC is based on two criteria. Firstly, it should have lasted 3 months or longer, sometimes lasting up to several years (Van der Lee et al., 2007); secondly, the disease should have an impact of some kind on the child's or adolescent's health (Perrin et al., 1993). A CCC entails a long-lasting care relationship with the healthcare professionals with recurrent contact (Nuutila and Salanterä, 2006), unlike those who present as emergency cases and require temporary hospital care (Doman et al., 2004). When a child is born with a serious condition or contracts a disease, this poses a major challenge and could become a long-term medical condition for the child that affects the whole family (Ekra and Gjengedal, 2012). Research shows that children with CCC frequently experience greater emotional, developmental, and behavioral challenges than their peers without these conditions (Blackwell et al., 2019).

Pediatric care for children with CCC challenges healthcare staff, requiring extensive knowledge of diagnoses and nursing practices. Staff must provide comprehensive care to prevent condition deterioration and develop competence in managing stress, anxiety, self-care, sleep, nutrition, and future planning. Understanding each child's adaptation process is crucial as providers guide patients through managing their conditions (Imogen, 2023). Development and improvement in treatment and diagnostic with children who have a CCC during the last decades, have contributed to a higher survival rate, but this increased survival rate could sometimes involve also negative side effects that lower their quality of life (Turkel and Pao, 2007). The healthcare staff therefore need to be updated on treatment methods and the possible side effects for children and adolescents with CCC.

Coronavirus disease 2019 (COVID-19) affected pediatric care settings in many ways, and flexible regulations during the pandemic increased the use of telemedicine with video consultations (Edwards, 2024). This technique was subsequently reported to enhance feasibility, accessibility, and positive family experiences (Contreras et al., 2020). Telemedicine consultations allowed the identification of issues enquiring required hospital readmission (Mejia et al., 2022). COVID-19 pandemic highlighted the need for digital information and further development of the use of to be informed about their illness and medications and to be able to be involved and prepare for procedures (Coyne, 2006). One method could be used, Bear cards, cartoon drawings, that shows and express different emotions of feelings, verbally, non-verbally or just pointing at a bear card (Deal, 2010). Exploring digital telemedicine in pediatric settings is crucial, particularly from children's perspectives. Telemedicine can complement traditional face-to-face healthcare, supporting children

with CCC in managing their health, developing self-care independence, and participating in treatment decisions. However, it's essential to balance digital solutions with children's needs for in-person healthcare, ensuring a comprehensive approach to pediatric care.

Aim

To describe how children with complex chronic conditions experience digital and in-person support, their information needs and their perceived participation in their own healthcare.

Method

A qualitative descriptive method was used, and children were interviewed individually, some children have back up with a parent. A descriptive qualitative method is used to gain a deeper understanding of participants' experiences, feelings, and perspectives within a specific context (Polit and Beck, 2021). This method is particularly useful when exploring complex phenomena and allows for a detailed and nuanced understanding of participants' experiences.

A semi-structured interview guide with a range of topics and open-ended questions was used, along with follow-up questions when needed. An interview guide was developed by the research team and was aligned with study aim.

Population

Staff at the pediatric outpatient clinics of Queen Silvia Children's Hospital contacted potential participants by phone. Families could choose either a video interview or an in-person interview at the hospital. Eligibility required having lived with a CCC for more than 3 months and being able to speak and understand Swedish. Written study information was mailed before informed consent was obtained, followed by a confirmation letter for those who agreed to participate. To ensure confidentiality, all participants were assigned pseudonyms and coded as "boy" or "girl" with their age.

Data collection

Data collections were performed from October 2019 to June 2020, three interviews before COVID-19 and nine interviews during COVID-19). The interview started with background questions including name, age, diagnosis, and date of diagnosis. An interview guide consisted of 10 questions with follow-up questions (Table 1), and all interviews were performed by two of the authors (1 and 4). All interviews were transcribed by the same two authors. All authors have extensive experience within the field and many years of pediatric research experience. About 2 months after the interviews, participants were contacted by phone; none reported negative reactions, and all valued the chance to discuss their experiences.

Data analysis

A qualitative manifest content analysis was conducted, enabling a systematic, reliable, replicable, and valid examination of the textual data (Krippendorff, 2018). By focusing on explicit content, this approach minimizes interpretative bias and ensures that findings remain grounded in participants expressed experiences. All authors participated in the analytic process. First, the text was read to gain an overall understanding. Second, meaning units relevant to the study aim were identified; the

Table 1. Interview guide.

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1. Do you receive continuous support from your clinic today?
 2. How do you receive support today?
 3. If you get support today, what do you think about it?
 4. Would you like digital support?
 5. What, by whom, how and when would you like digital support?
 6. How could you be involved?
 7. Would you like to meet/chat/Skype online with children/young people in the same situation?
 8. What do you think about the future of digital support?
 9. Could a list of frequently asked questions with answers be included?
 10. Are you told about your rights as a child?
-

first author (MJN) initiated this step in close collaboration with the last author (MB). Third, the meaning units were condensed and coded. In the final step, codes were organized into subcategories and categories through an iterative comparison between parts and the whole, consistent with established content analysis procedures (Elo and Kyngäs, 2008). All authors discussed the analysis and agreed on the final categories and subcategories to achieve trustworthiness. Credibility was strengthened by supporting findings with quotations, while dependability was ensured through documentation of each analytic step and continuous discussions within the research team, which also contributed to confirmability by reducing preconceptions.

Ethical considerations

Before starting this study, an analysis of the risks and benefits was performed by researchers, with a backup plan if a participant should need psychological support after being interviewed. This study was approved by the Swedish Ethical Review Authority board (approval number: 2019-04,356) on approval date 9 September 2019. The study was conducted in line with the Declaration of Helsinki (WMA, 2013). Children and parents received age-specific oral and written information and were informed that their participation was voluntary and could be withdrawn any time without prejudicial consequences.

Findings

Twelve children with CCC (7 boys, 5 girls) aged 10–17 participated in this study (Table 2). Three mothers assisted in interpreting communication, and one father was present as backup support during one interview. Digital interviews were performed with 8 children and in person interviews with 4 children. Participating children had various conditions including obesity, diabetes, neuropsychiatric disorders, and multi-disabilities. Interviews were audio-recorded and lasted 12–30 minutes. Two main categories and five subcategories are illustrated in text below with quotations from participants.

Support and involvement in their own healthcare

The children talked about ways of receiving support and reported that they felt satisfied with the support provided, regardless of whether it was in real life or accessed via their smartphones or

Table 2. Participants.

Participants	Type of interview	When
1 Boy 14 y	Digital interview	Before Covid 19
2 Girl 12 y	Digital interview	Before Covid 19
3 Girl 10 y + mother	Digital interview	Before Covid 19
4 Boy 15 y	Digital interview	During Covid 19
5 Girl 10 y + mother	In person interview	During Covid 19
6 Boy 15 y	Digital interview	During Covid 19
7 Boy 12 y	Digital interview	During Covid 19
8 Boy 13 y	In person interview	During Covid 19
9 Boy 14 y	In person interview	During Covid 19
10 Boy 16 y + mother	In person interview	During Covid 19
11 Girl 17 y	Digital interview	During Covid 19
12 Girl 16 y	Digital interview	During Covid 19

tablets. The children had been receiving healthcare for many years and pointed out that they knew what to expect, which made them feel secure and involved in their own care. They also talked about the support they experienced when meeting others in the same situation.

Feeling satisfied with support

Children experienced support from both nurses and doctors. Children in this study described needing support for almost everything when it was new to them. Support needed changed over time, and they described being encouraged to take more and more responsibility for managing their CCC during the years after they started receiving treatment at the clinic.

“I think they have been quite supportive in that, that you should take your own responsibility, that you should be part of it... at least the doctors I’ve had” (Peter-14 years).

Nurses in particular helped me a lot... They kind of keep an eye on things...” (Sara-17 years).

Children commented that they knew how they wanted things to be performed, which strengthened their feeling of participation. It did not mean that they needed to be involved in all aspects of their care, and they did not want to decide everything themselves; they trusted their doctor very much to know what was best for them. Being satisfied with support also included being involved in their own care, which meant that they could also prepare themselves before the procedures they had to go through.

“I know how I want it, yes... now I’ve been here for so long so now I don’t even have to ask... Yes, in that way I feel that I am involved but not otherwise...” (Dennis-12 years).

“So ... I wouldn’t want to decide what the doctor should do or anything because the doctor probably knows better than me...” (Margret-12 years).

“Yes, every time they do something, they tell me beforehand what’s going to happen, like now it will sting, now I will take this ... and now I’m going to stick this needle in and now I will ...they tell me all the time what they are going to do and they are good, then you can prepare for it...” (Dennis 12-years).

Support was provided directly during the visit at the hospital by a doctor or a nurse, otherwise it was received through a phone call. The children stated that it was easy to receive support and get questions answered if they needed to, it was just a matter of calling the staff to get answers to their questions. Children had different experiences of receiving digital support and different feelings about what kind of support they needed, but they wanted it to be flexible, and they also wanted to be involved in the planning and to get answers to questions or get advice from available staff through digital channels.

“Private conversation and also being able to text (the staff) it would be great, a bit more and that they expanded more digitally (Georg-15 years).

“Yes, it can be good for others... I have no use of it (digital information) right now anyway... In the future, I may have it or I see that others have it... (Dennis-12 years).

Being able to make decisions and participate in healthcare

All the children were encouraged to take responsibility for managing their everyday healthcare, to become experts on their own illnesses. Being able to be involved and to make decisions meant a lot to the children. Even if it sometimes meant that they had to go through some examination or procedure they would prefer to avoid, they understood that it was part of their treatment. Children reported being involved in coordinating their medical tests and monitoring so as not to disrupt their schooling too much.

“I get to decide a little, without the blood tests (Anne-10 years with mother).

“I’m free to decide what I can do, very much. I can eat what I want but in small portions. It may not be so good, that you get to eat this instead. I have the right to eat what I want” (Kevin-14 years).

“They answer questions, they listen to me, what I think (Anne-10 years with mother).

“Would like to be able to coordinate more so it doesn’t turn out that I don’t come one day and then after two days and one day again I come again, it doesn’t work for me to be away from school. Take tests at home and be in the hospital every other month. Some planning could certainly be done digitally” (Georgs-15 years).

“It would have been good and ... I don’t know more what special rights you have in hospitals more than you can say no to things you don’t want to do....but if there are things that you have to do because if you don’t do it you’ll die..., then that’s another matter... then you mustn’t say no to it....you can say no to it but it probably won’t be accepted....” (Dennis-12 years).

Wanting to meet others in the same situation

Another way of receiving support was through meeting other children in the same situation, a wish that the children felt was not fulfilled. They talked about sharing experiences with others and highlighted how much it would mean for others. They also mentioned that a good way for this to be achieved would be through digital channels, such as Facebook and online forums.

“Yes, it becomes like, it becomes a kind of community because then there are people who are going through the same thing as you....(Sara-17 years).

“I have a friend with diabetes in my German class. Then there is a Facebook group called ‘Share thoughts about diabetes’, maybe 5000 who are in it and it’s great. You only have to post a question and there are lots of people there who kindly answer. It’s based on experience if someone has had the same problem. They are mostly young people and adults there. It would probably be if you got something similar for, like, children only and maybe even staff in such a group. Then you could read questions and answers” (Peter-14 years).

“I don’t know.... I also think it would have been good if different diabetes patients had been able to write their own experiences and stuff...” (Sara-17 years).

Receiving information in different ways

The children wanted to receive information, and they did so at the clinic but also before the visit in order to prepare them for what would happen. Older children talked about alternative ways of receiving information and described their needs and wishes regarding this. As a result of the ongoing Covid-19 pandemic, when the study was conducted, they received more information through online consultations, email, chat and phone calls to avoid physical contact. In this study, children talked about other ways of presenting information, such as the use of different pictures to explain illness and examinations, and Bear cards (cartoon drawings of bears that show different emotions) to help children to express their feelings (e.g., anger, sadness, happiness) non-verbally.

Use of digital tools

Children talked about how their contact with the clinic involved the use of various digital tools. At the beginning of the COVID-19 pandemic the clinic began to use a lot of digital contact as a complement to the previous care where the visits were always in real life. Video meetings via the FaceTime app allowed the healthcare staff to illustrate and evaluate pain treatments and different metrics like blood sugar testing. Nurses or doctors gave feedback on test results and discussed with the child further strategies for coping with their diabetes. The children saw this way of meeting health care professionals mostly in a positive light.

“In this year 2019, there was maybe a lot of pain, many contacts with questions, leaving measurements, leaving messages, asking questions, feedback from healthcare staff, seeing test results when you want and not having to come at a particular time, having a relationship with the staff... (Peter-14 years).

“Yes... if you are just going to have a meeting... and talk about blood tests with the staff... then I think it’s much easier to meet the way we have done... so it won’t be so complicated in the hospital with the staff...” (Margret-16 years)

Children did not all use the same digital tools in their contact with their clinic. It could be contact through apps such as FaceTime or Google Meet using cell phone or iPad. They described how to handle them, how they wanted to use them if they could decide for themselves, and what other contacts channels they also wished for. Some children suggested a website as a good source of information, where you could have the possibility to ask questions and get them answered.

“It would have been good digitally instead of having to call a person. If I had forgotten the medication then I could have searched the app then, what to do and how to proceed. I think that would have been good for most people... (Georg-15 years).

“Ask a medical question and I can ask it with my name and just ask it centrally and someone could answer the question, that would be great. You would like to ask a question and then a month passes before you get an appointment and then it was now again you should ask and you have not written it down.....next time you have to ask ... (Peter-14 years).

“If you have a question, you could quickly FaceTime with the doctor or something. Like with a plate with a normal portion as a picture to show the staff and they could say more or less about it, it would help and be great... (Kevin-14 years).

Using images for information about the condition

The children talked about the importance of getting to know more about their health condition. They had ideas of ways to do so, such as being shown authentic or drawn images about their illness or situation. Bear cards were helpful for expressing feelings, and the children also talked about combining explanations with both images and text, for example, before a certain procedure was performed. They also felt this would be good not only for themselves but also for their family and friends.

“Yes... But it can still be good for people who have diabetes, but also for relatives... Because after all I have friends and family who want to know about and what to do with my diabetes... So I still think it’s good if there is basic information about it... (Sara-17 years).

“Talked and showed pictures and some text, good combination (Didrik-13 years).

“With pictures of bears that describe feelings and in the mobile the bears are best (Anne 10-years with mother).

Discussion

The aim of this study was achieved by examining how children with CCC in Sweden experienced the received support from healthcare and how they wished their care had been provided. Some of the interviews were performed during the COVID-19 pandemic and some before. The findings reflect the children’s experience of information via digital technology or face-to-face support and the nature of their contact with the healthcare system. When the World Health Organization classified outbreak of the coronavirus disease COVID-19 as a pandemic on 11 March 2020, it affected health care in various ways, including health care settings.

Previous studies have pointed out that children with a CCC need regular return visits. Still despite this, psychological support is often absent, which could contribute to negative consequences in their everyday life due to lack of resources in their everyday life environment (Groothoff et al., 2005; Meijer et al., 2000; Taylor et al., 2008). Children with CCC reported feeling secure due to regular hospital contact and wanted to learn more about their conditions (Imogen, 2023). They preferred clear, age-appropriate information and visual aids, which helped them understand complex medical information, potentially reducing anxiety and increasing their sense of control. Children expressed satisfaction with both in-person and digital care, indicating successful adaptation of the healthcare system to modern communication forms. Their sense of security and

participation in care is viewed positively and the children felt well-supported by their healthcare team and in their interactions with doctors and nurses, which potentially could lead to improved treatment outcomes and a higher quality of life (Britten et al., 2020; Thunberg et al., 2022; UNICEF, 2019).

These promoting factors with supported, reassuring and adapted information of health professionals for children with CCC are supported by several studies (Wogden et al., 2019). Every child and young person has the right to tailored professional support to improve quality of life, good health, and well-being; but more focus needs to be placed on support for the child's coming everyday life and future adult life. Healthcare professionals must be mindful of using communication methods tailored to each child's needs and the specific situation (UNICEF, 2019). Supporting a child's preferred way of communicating can enhance their understanding of instructions and better prepare them for various healthcare situations (Thunberg et al., 2022).

The children with described three possible ways to get information: through in-person meetings with healthcare professionals, through digital support channels or through a mix of both. Instead of in-person clinic visits, an online consultation could be arranged, in which the doctor or nurse meet the child and parents through a video conferencing app such as Google Meet. Additionally, the suggestion of a website as an information hub where children can ask questions and receive answers highlights the need for more interactive and easily accessible digital resources. This reflects a desire for continuous support beyond traditional in-person or virtual appointments, emphasizing the need for healthcare systems to evolve with children's expectations for instant and reliable information. Ideas of combining text with images before a procedure reflects children's need for clear, comprehensive explanations. A step-by-step visual guide, supplemented with simple text, can demystify medical processes and help children know what to expect. This not only prepares them mentally but also allows them to ask questions and voice concerns, enhancing their participation in their care. Similar results indicate that nurses utilized various methods, both individually, digitally and in combination, but with a great responsibility for children's participation, rights, protections, and threats in line with the Convention of the right of the Child (UNICEF, 2019).

Present study showed that the use of digital technology increased (Berry et al., 2022), and many of the consultations were held online instead of a face-to-face visit. That COVID 19 has driven digital innovation within pediatric care is also confirmed in another study (Gerli et al., 2021) which reported changes in the type of visits for children with CCC at the children's hospital. Today's children belong to a generation that has grown up with digital technology as an integral part of everyday life (Hysten et al., 2022); for them, the switch to digital communication was smooth. Many eHealth interventions are now used to support children in pediatric care (Brigden et al., 2020; Costa et al., 2021). Children's diverse use of digital tools in healthcare communication highlights the need for flexibility. While they navigate apps like FaceTime and Google Meet skillfully, their varied preferences indicate that a one-size-fits-all approach is inadequate. Healthcare providers should offer multiple digital communication options to meet individual needs effectively. Rise of eHealth, driven by digitalization, has improved communication between sick children, families, and healthcare professionals (Costa et al., 2021). Thanks to these online information channels, children with CCC were able to get more accessible information about their condition during the consultation. Children also commented that the available contact channels depended on which outpatient clinic they belonged to, how experienced that health care setting was with the digital technology and what the clinic preferred.

Child's best interests in healthcare involves addressing both health and well-being, while also upholding children's rights (Afua Quaye et al., 2021; Bester, 2019; Carter et al., 2014; Coyne et al., 2014). Getting information that suits each child is the goal, as supported by the UN Convention on

the Rights of the Child, which states that all children have the right to participate in their own care, maintain health, and prevent ill health (UNICEF, 2019). Care should be tailored to meet individual wishes and expectations, whether online or in-person. Healthcare professionals must possess child competence, show respect, and prioritize the child's best interests, incorporating examinations and treatments into a well-documented care plan (Britten et al., 2020; Thunberg et al., 2022; UNICEF, 2019). The family perspective also needs to be included when making care delivery or policy decisions for children with CCC (Sidra et al., 2024). Younger siblings of children with CCC are affected by their care, as other family members take care of them. This situation impacts child's with CCC siblings' health and leading to anxiety, stress, anger, and depression (Kelada et al., 2022).

E-health support from nurses can enhance parental empowerment and improve care coordination for children with CCC (Shouldice et al., 2023). Parents' involvement is essential in complementing the child's narrative and facilitating a structured transition to adult care (Bratt et al., 2023; Seung Hong and Jin Im, 2024). Tailored interventions for transitioning children with chronic conditions should balance reduced parental overprotection with maintained engagement, increased autonomy support from healthcare providers, and a comprehensive transition plan to enhance adolescents' well-being (Sidra et al., 2024).

Although not found in the present study, compared to healthy peers, children with CCCs have a higher incidence of mental illness, anxiety, and depression, persisting into adulthood (Brenninkmeijer et al., 2009; Pao and Bosk, 2011; Rapley and Davidson, 2010). Therefore, a CCC can be seen to have a negative impact on the quality of life for these children and adolescents, which further strengthens the benefit of carefully planned support for these children (Carter et al., 2017).

Another source of support, apart from that provided by healthcare professionals, was support from peers. Peer support was mentioned by the children in our study as an important strategy for finding meaningful and valid healthcare information. The use of peer support has been identified as beneficial in previous research (Nilsson et al., 2022) and is an activity that should be highlighted and developed further within the healthcare organization. Digital and personal healthcare tools are essential for addressing emotional needs and educating children with CCC (Regions, 2025). A person-centered care improves the overall healthcare experience. Children appreciate sharing information with family and friends, recognizing their condition's impact on loved ones. Educating both children and their support networks enhances the child's sense of security, fosters mutual understanding, and improves CCC management. Person-centered care is essential for children with complex chronic conditions CCC, considering their age, maturity, needs, and abilities (Britten et al., 2020; Thunberg et al., 2022). Methods involving images can help children to expressed themselves non-verbally, to express emotions underlines the importance of addressing the emotional aspects of healthcare (Deal, 2010; Kreichberg et al., 2022).

Limitations

Interviews were conducted at the onset of COVID-19, potentially influencing participants' responses. While the small number of interviews may seem limiting, in qualitative research, depth is prioritized over quantity, and this smaller sample allows for a deeper exploration of experiences. A follow-up interview after the end of COVID-19, may have provided more information about how information has been. Another limitation is that only one hospital was involved, but since it is one of the largest pediatric hospitals in Europe, it covers diverse disciplines, providing access to a broad range of children with CCC.

Implications for practice

Promoting participation of children with CCC in healthcare requires secure care relationships and support. Understanding children's perspectives in pediatric care is crucial. Digital and personal communication tools help children express feelings, experiences, and questions, enabling healthcare professionals to listen and respond effectively. Specific tools, such as bear cards, offer unique opportunities for children with CCC to discuss and express their emotions regarding their condition. These tools are designed to be child-friendly and engaging, making it easier for children to open up about their feelings. By using these tools, healthcare providers can enhance children's involvement in their own care, fostering a sense of empowerment and control over their health journey. Overall, integrating these communication strategies and tools into pediatric care can significantly improve the quality of care for children with CCC, ensuring they feel heard, supported, and actively involved in their treatment plans.

Conclusions

This study highlights a person-centered care approach that promotes children's rights and participation. Children valued both digital and in-person support and wanted involvement tailored to their needs. Future research should explore sustainable integration of these approaches and ensure equitable access and participation for children with CCC.

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ORCID iDs

Margaretha Jenholt Nolbris  <https://orcid.org/0000-0002-6911-1484>

Stefan Nilsson  <https://orcid.org/0000-0002-8847-9559>

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