

## A Qualitative Study of Parents` Experiences of Information Exchange between the Tertiary Health Service and the Child`s Local Support Team using Videoconference

Merete Kristin Tschamper (MPhil)

Dept. of children and youth, Division for Neuroscience,  
National Center for Epilepsy  
Oslo University Hospital  
Oslo, Norway  
E-mail: meretek@ous-hf.no

Wenche Schrøder Bjorbækmo (PhD)

Dep. of Health Science  
The University of Oslo  
Oslo, Norway  
E-mail: w.s.bjorbakmo@medisin.uio.no

**Abstract** - In this study, four children with rare, epileptic condition including intellectual disability were interdisciplinary assessed in the National Center for Epilepsy (SSE). The results of the assessments were communicated to the children`s local support service using videoconference (VC) with the parents present. *The purpose* for this study was to obtain a deeper insight into parents` experiences with information exchange using VC. *Methods*: In-depth interviews were performed with five parents within a week after the VC. The generated material was analyzed with a thematic hermeneutic research approach. *Results*: The local participation increased from 2-6 in traditional face-to-face meetings to up to 22 participants in the VCs. The parents described how the increased participation ensured a direct, oral information exchange that prevented treatment misunderstandings. The parents were relieved from the responsibility to inform all professionals involved in the local community. In addition the parents suggested this increased the multidisciplinary collaboration and facilitated a comprehensive approach to the children`s complex situations. The parents experienced increased user-involvement in the process of arranging the VC compared to traditional face-to-face consultants. Some parents had started to initiate VC themselves. *Conclusion*: VC was considered a more potent tool for information exchange between providers than face-to-face meetings due to the increased local participation and that everyone was assured to get the same information simultaneously. However a crucial prerequisite seem to be that the professionals from the tertiary health service had clinical knowledge of the child and tailored the information exchanged according to each child and family`s needs.

**Keywords**-Parent; chronic disease/illness; epilepsy; disability; videoconference; patient education.

### I. INTRODUCTION

Epilepsy in combination with disability is a condition that causes various needs for long-term multidisciplinary support. Research show that parents with chronic ill children experiences the lack of information exchange between the child`s providers as one of the main stressors leading to inadequate treatment of the child [1]-[3]. Among other services SSE provides a nationwide and interdisciplinary

assessment- and treatment service for people with rare epileptic conditions. A disease is defined rare in Europe when it affects less than 1 in 2000 of the general population [4]. Each condition affects the patient individually and there is a need for tailored treatment. SSE, together with The National Center for rare, epilepsy related disorders (NK-SE), are legally required to educate the patients, their relatives, and the patient`s local support service in order to ensure optimal treatment [5][6]. Norway is aerially a relatively large country with a widely distributed population. Communication between patients and providers using VC bridge geographical distances and thus holds the potential to be cost-efficient with a broader multidisciplinary scope for information exchange than traditional face-to-face consultants [7]-[10]. Although SSE and NK-SE increasingly use VC to exchange information as an alternative to traditional face-to-face meetings, scant attention has been paid to the parents` experiences with VC as an arena to exchange information about their child`s condition and care [11]-[13]. There is a need for a deeper understanding of how parents of chronic ill children experiences information exchange using VC. A deeper insight into the parents` experiences may have implications for adjusting standard practice to better meet their needs. The findings are likely to be transferable beyond the current context.

### II. INTERDISCIPLINARY ASSESSMENT

An interdisciplinary assessment in SSE normally contains 17 days of hospitalization. According to each child`s individual need, this might include a medical assessment performed by a pediatrician and a nurse specialist in epilepsy, a cognitive assessment performed by a psychologist and a special educator, a motor assessment performed by a physiotherapist and an occupational therapist. The parents also have the opportunity to consult a social worker while hospitalized for advice concerning legal rights for benefits and support. At the end of the hospitalization the results of the assessment, along with recommendations for treatment and educational interventions are communicated to the parents and the child`s local support service either in a meeting face-to-face at SSE or using VC.

### III. VIDEOCONFERENCE

VC is a virtual way of meeting that can be used to exchange information, and provide support and care. The security of sensitive information is ensured through the Norwegian Health Net [14]. In this study the local participants met in VC rooms at the municipal Labour- and Welfare departments. The professionals from SSE or NK-SE participated from a VC-room at Oslo university Hospital. The VCs lasted from 1, 5 to 2, 5 hours.

#### A. Participants in the VCs

The parents participated in the VC concerning their child. They had the choice whether to participate while hospitalized at SSE or at home after discharge. The multidisciplinary professionals responsible for assessing each child participated from a VC-room at SSE.

The special educators responsible for the educational assessment were responsible for arranging the VC in cooperation with the parents. The parents decided whom to invite locally. The local participants were multidisciplinary supporters from the children's local support service. According to each child's individual need, that might include teachers and assistants, municipal physiotherapists, health visitors, representatives from the municipal educational and psychological counseling service, social educators and assistants from respite care-homes. In one VC a grown up sibling, an aunt together with representatives from the municipal Labour-and Welfare department participated.

#### B. Content of the VCs

The results from the interdisciplinary assessments, together with treatment options, were presented and discussed with the local participants in the VC. Another goal for the information exchange was to discuss possible facilitation of the child's environment to prevent seizures, contribute to optimal development and quality of life. The parents were present in the VC. According to practice they were informed about the results of the assessments in advance of the VC.

### IV. METHODS

The empirical material stems from in-depth interviews exploring the parents' experiences of the VC. The thematic hermeneutic analyses of the interview identified several themes of which three is presented in this article.

#### A. Inclusion criterions

The parents participating in the study have a child aged 5-12 with a rare epileptic condition that include moderate to severe intellectual disability. The study included 5 parents who's child had recently undergone an interdisciplinary assessment at SSE followed by an information exchange with the local support service using VC. In order to provide a nuanced description of specific cases, the parents fitting the inclusion criterions were strategically chosen consecutively

as they were admitted to SSE. Only one parent had experienced information exchange using VC at SSE before. Three of the parents had experienced multiple traditional face-to-face meetings in SSE exchanging information with the child's local support service. One of the children had been hospitalized in SSE for the first time.

#### B. Collecting of data and analyses

In-depth interviews were performed with four mothers and a father within a week after the VC. The interviewer did not attend the VCs. The interview guide had few and open questions that aimed to explore how the parents experienced the use of VC for information exchange. The interviews were transcribed verbatim and analyzed with a thematic hermeneutic research approach [15]. Three of the initial themes identified were: A) VC an efficient tool to exchange information between multidisciplinary providers B) Increased parental control and involvement C) The impact of the relationship with the professional arranging the VC.

### V. FINDINGS

In the following, the results from three of the identified themes will be presented.

#### A. VC an efficient tool to exchange information between multidisciplinary providers

In the VC there were from 10 to 22 local participants compared to 2-6 in former face-to-face meetings at SSE. According to the parents, the direct information exchange and discussions between the professionals prevented treatment misunderstandings that occurred when the local support service only received written reports. In addition, the parents experienced an increased multidisciplinary collaboration that facilitated a comprehensive approach to the child's complex situation. Finally the parents saved time not having to attend meetings explaining the reports from SSE to the local providers.

#### B. Increased parental control and involvement

The parents experienced increased control and user-involvement in the process of arranging the VC. As almost all the invited local professionals participated, the scope for the information exchange widened. Some of the parents actively used the VC as an arena to inform not only the providers of care and education, but also other providers like social workers, family members or the principal on the local school. Some parents had started to initiate VC themselves by contacting personnel at SSE or NK-SE.

#### C. The impact of the relationship with the professional arranging the VC

The parents suggested that the positive and trusting relationship they had established with the professional arranging the VC was important for the quality of the information exchange. They also considered it crucial that the professional from SSE and NK-SE had clinical knowledge of their child in addition to special scientific

knowledge of the rare, epileptic conditions in order to tailor the information to the child and family's needs.

## VI. DISCUSSION

For the parents in this study the most important issue was that the VC increases the local participation. The increased local participation enabled a direct information exchange between providers from different levels of the health service, school and social services in a way that would not have been possible without this technology. Thus The VC offers an arena for the participants to relate, share experiences and co-shape their knowledge of the child's situation and needs. The possibility for the local providers to ask clarifying questions directly to the professionals prevented misunderstandings in the follow-up treatment.

However, this outcome seemed to depend upon the quality of the interaction created between the participants in each VC. As the interactions in the VC are dynamic, the parents experienced the quality of the interaction differently from each other. To ensure that misunderstandings in the follow up treatment are prevented, the participants need to contribute and ask question – this requires a dialogue. Without dialogue the VC becomes an arena simply for information transfer – not for information exchange.

Whereas some of the VCs in this study seem to have a relaxed ambiance where the local participants asked questions and contributed, others seem to have been tense, with less interaction. The parents suggest the local participants might feel insecure talking in the virtual space in front of a camera with the whole local support team present. The VCs with the most dialogue seemed to be the ones where the participant communicated at regular basis using VC. The communication in the VC where the participant met for the first time a mother described as “a monologue.” In this VC the local participants listened without responding. If the local providers do not provide any feedback, it is impossible for the participants from SSE or NK-SE to correct potentially incorrect impressions. Thus, it is possible that the VC might create, not prevent, misunderstandings.

The parents' relationship with the providers seemed important for their experiences of the quality of the information exchange. It seemed crucial for the parents to have a trusting relationship with the professional arranging the VC, and for them to share the same opinion regarding the child's condition. According to the parents, the professionals organizing the VC recognized and used the parents' experiential knowledge of the child as a basis for the information exchange. The parents' opinion and the professionals' clinical understanding of the child's situation seem to have united during the hospitalization in SSE/SS.

The parents explained that they trusted the professionals at SSE or NK-SE to describe the child's needs in a tailored way. They also appreciated the way they were included in all stages of organizing the VC. This, and the fact that they

decided whom to invite locally, seemed to increase the parents' sense of control of the information being exchanged in the VC.

The parents also appreciated that the child was interdisciplinary assessed during one hospitalization. This facilitated a comprehensive approach to the child and family's needs.

## VII. CONCLUSION AND FURTHER WORK

The parents considered the VC a more potent tool for information exchange between providers than face-to-face meetings due to the increased local participation. However a crucial prerequisite seem to be that the professionals from SSE and NK-SE had clinical knowledge of the child and tailored the information exchange according to the child and family's needs. In this qualitative study the sample was not designed to be statistically representative. However the findings are consistent with other research concerning the use of VC in information exchange for patient with long-term conditions [7]-[10], [16]. The importance of a trusting relationship between the patients and the providers for the interaction to be successful is also consistent with previous research [17][18]. There is a need for further studies of the conditions that needs to be present in order to ensure the quality of the information exchange using VC. The long-term effect on the treatment of the child and whether the use of VC reduces hospitalizations also needs to be investigated.

## ACKNOWLEDGMENT

We would like to thank the parents and the providers who participated in this study. The study was conducted in collaboration with The National center for rare, epilepsy related disorders, Oslo University Hospital and Solberg School, Norway.

## REFERENCES

- [1] Gundersen T. 'One wants to know what a chromosome is': the internet as a coping resource when adjusting to life parenting a child with a rare genetic disorder. *Sociology of health & illness*. 2011;33(1):81
- [2] Grut L, and Kvam M. Facing ignorance: people with rare disorders and their experiences with public health and welfare services. *Scandinavian Journal of Disability Research*. 2013;15(1):20-32
- [3] Pelentsov LJ, Fielder AL, Laws TA, and Esterman AJ. The supportive care needs of parents with a child with a rare disease: results of an online survey.(Report). *BMC Family Practice*. 2016;17(1)
- [4] What is a rare disease? [Available from: <http://www.rarediseaseday.org/article/what-is-a-rare-disease>]
- [5] Pasient-brukerrettighetsloven. Pasient- og brukerrettighetsloven. LOV-1999-07-02-63: Helse- og omsorgsdepartementet; 1999 [Sist endret: LOV-2014-06-20-41 fra 01.01.2015; [Available from: <https://lovdata.no/dokument/NL/lov/1999-07-02-63>]

- [6] Spesialisthelsetjenesteloven. Spesialisthelsetjenesteloven. LOV-1999-07-02-61 Oslo: Helse- og omsorgsdepartementet; 1999 [Available from: <https://lovdata.no/dokument/NL/lov/1999-07-02-61>]
- [7] Cameron MPL, Ray R, and Sabesan S. Physicians' perceptions of clinical supervision and educational support via videoconference: a systematic review. *Journal of telemedicine and Telecare*. 2014, Vol. 20(5) 272–281
- [8] Lindberg B, Nilsson C, Zotterman D, Soderberg S, and Skar L. Using information communication technology in home care for communication between patients, family members, and healthcare professionals: a systematic review. *International journal of telemedicine and applications*. 2013;2013:31
- [9] Hagen K. Users' Experiences with Clinical Video Conferencing at a Resource Centre for Rare Disorders [Master]: University of Tromsø, Norway; 2010
- [10] Gentles SJ, Lokker C, and McKibbin KA. Health information technology to facilitate communication involving health care providers, caregivers, and pediatric patients: a scoping review. *Journal of Medical Internet Research*. 2010;12(2):e22
- [11] Chi NC, and Demiris G. A systematic review of telehealth tools and interventions to support family caregivers. *Journal of Telemedicine and Telecare*. 2015;21(1):37-44
- [12] McLean S, Protti D, and Sheikh A. Telehealthcare for long term conditions. *BMJ: British Medical Journal*. 2011;342(7793):374-8
- [13] Åkesson K, Saveman BI, and Nilsson G. Health care consumers' experiences of information communication technology: A summary of literature. *International Journal of Medical Informatics*. 2007;76(9):633-45
- [14] Norsk Helsenett SF. [Available from: <https://www.nhn.no/helsenettet/video/Sider/default.aspx>]
- [15] Braun V, and Clark V. *Successful qualitative research: a practical guide for beginners*. LA: SAGE. 2013
- [16] Steel K, Cox D, and Garry H. Therapeutic videoconferencing interventions for the treatment of long-term conditions. *Journal of Telemedicine and Telecare* 2011;17(3) 109-117
- [17] Wade V, and Elliott J. The role of the champion in telehealth service development: a qualitative analysis. *J Telemed Telecare* 2012;18:490–492
- [18] Carlisle K, and Warren R. A qualitative case study of telehealth for in-home monitoring to support the management of type 2 diabetes. *Journal of Telemedicine and Telecare* 2013;19(7) 372–375

