Sammendrag/Summary

Gi et kort sammendrag av prosjektet med vekt på å beskrive formål, forskningsdesign, de mest sentrale utfordringene og mulig anvendelse av prosjektresultatene.

A craniofacial anomaly (CFA) affects the function and appearance of the head and face. In Norway, centralised and multidisciplinary care has been implemented for this patient group. Despite a long-term and complex treatment pathway, few national and international studies have explored patients’ or parents’ treatment experiences, emotional support needs, or the impact of appearance-altering surgery on self-perceptions. We also lack knowledge about how health professionals experience the process of shared decision making and main challenges in treatment-related communication.

The project will employ a mixed methods design, consisting of both qualitative interviews (thematic analyses) and quantitative patient-reported questionnaires (quality of life and other treatment outcomes). Sample size: ±80 patients or parents; ±15 intervention study; ±10 health professionals. The main challenge will be a large amount of qualitative data, which is well-known to be time-consuming work. As a solution, patient and parent interviews were collected during the pilot study (with no available funding for analyses), and students in psychology will be recruited for transcriptions and help with analyses.

The project will potentially improve health services for those affected by CFAs, integrating the patient perspective into care, through a close collaboration between the patient organisation and the treatment team. Results may also inform other treatment settings with extensive treatment pathways.

Hoved- og delmål (750 tegn)

Gi et kort sammendrag av hvilke resultater som forventes oppnådd i løpet av prosjektperioden.

The primary aim will be to explore treatment-related experiences from three perspectives: patients born with a CFA, parents, and specialised health care professionals.

More specifically, the aims are to:

1) Investigate the emotional impact of appearance-altering surgery on the development of self-perceptions, in order to advance knowledge about treatment-related aspects of CFAs
2) Examine physician-patient communication from three perspectives (patients, parents, specialised health professionals), in order to promote shared decision making and knowledge about the processes involved in treatment-related decisions
3) Explore whether an intervention tool could facilitate shared decision making between patients with CFAs and health professionals
A number of benefits are anticipated for participants (patients, parents, and health care professionals). Qualitative research is particularly able to identify key issues and research priorities according to users’ perspectives. Direct input from users provides a unique potential to improve existing health services by integrating the patient perspective into care. Our pilot study (2016) showed that patients and their parents had not previously had any opportunities to speak about their treatment-related experiences and therefore valued the chance to tell their story. Results also indicated that multidisciplinary consultations could be emotionally overwhelming, and that patients and parents could feel a lack of autonomy in relation to treatment decisions.

The present project may therefore provide an essential opportunity to feed patients’ and parents’ views back into the healthcare service directly, and guide and improve provision of care for this patient group. Adding health professionals’ perspective and experience into the project is also thought to strengthen the potential benefits of the present study.

Shared decision making, the process of involving patients in the treatment process, is now enshrined in Norwegian policy documents (Helsedirektoratet, 2014). Ideally, treatment decisions should combine the physician’s medical expertise and the patient’s personal priority expertise. Nevertheless, research has shown that even experienced and specialised health professionals may be unaware of patients’ expectations and priorities. Therefore, an “advocacy” type of intervention may be needed to improve treatment-related communication. The National Unit for Craniofacial Surgery is well aware of the challenges involved in achieving shared decision making, and supports the testing of a simple intervention tool (PEGASUS - Patient’s Expectations and Goals: Assisting Shared Understanding of Surgery; Harcourt et al., 2015) that have been proven to enhance physician-patient communication in similar surgical treatment settings. The present project will therefore provide indications of whether implementing a simple intervention tool such as the PEGASUS could enhance treatment-related communication for patients with CFA and their families.

Including the perspectives of health professionals involved in the treatment of CFAs into the project is expected to strengthen the possibilities of implementing results and findings, and also hopefully improve health professionals’ experienced challenges regarding treatment-related communication. Hence, benefits are anticipated also for health care professionals.

The study will be run in close collaboration with the patient association, Norsk Craniofacial Forening. The project’s Advisory Group will ensure that research questions are of central importance to patients and their families, and is driven by patient-reported priorities.