A qualitative study exploring stakeholders' perceptions of using digital health technologies to improve conservative treatment of adolescent idiopathic scoliosis

Kamila Sykorova, Anna Mathew, Nenad Pavel, Parisa Gazerani Gazerani, Trust Saidi, Marianne Bakke Johnsen, June Ullevoldsæter Lystad, Helen Christine Bull, Mette Fløystad Kvammen, Hong-Gu He, Julia Jacoby

Submitted to: Journal of Medical Internet Research
on: November 21, 2024

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Kamila Sykorova[1]; Anna Mathew[1]; Nenad Pavel[2]; Parisa Gazerani Gazerani[3]; Trust Saidi[2]; Marianne Bakke Johnsen[4]; June Ullevoldsæter Lystad[5]; Helen Christine Bull[6]; Mette Fløystad Kvammen[7]; Hong-Gu He[8]; Julia Jacoby[2]

[1]OsloMet – Oslo Metropolitan University Faculty of Health Sciences, Department of Rehabilitation Science and Health Technology Oslo NO
[2]OsloMet – Oslo Metropolitan University Faculty of Technology, Art and Design, Department of Product Design Oslo NO
[3]OsloMet – Oslo Metropolitan University Faculty of Health Sciences, Department of Life Sciences and Health Oslo NO
[4]OsloMet – Oslo Metropolitan University Department of Rehabilitation Science and Health Technology Oslo NO
[5]Oslo University Hospital Department of Psychology Oslo NO
[6]OsloMet – Oslo Metropolitan University Oslo NO
[7]University of Agder Department of Sociology and Social Network, Kristiansand NO
[8]Yong Loo Lin School of Medicine, National University of Singapore, Singapore, Singapore, Alice Lee Centre for Nursing Studies SIngapore SG

Abstract

Background: Adolescent idiopathic scoliosis (AIS) affects 2-3% of adolescents, with conservative treatments like bracing and physiotherapeutic scoliosis-specific exercises (PSSE) recommended for mild to moderate cases. However, patient compliance with these treatments is often low. Digital tools, such as smartphone apps and web applications, can help monitor spinal curvature, facilitate remote consultations, and reduce healthcare professionals' workload. These tools may also improve adherence by offering motivation and real-time feedback, particularly for patients facing challenges like brace discomfort or self-esteem issues. Despite the potential benefits, there is a significant gap in research regarding how digital health technologies can specifically enhance the conservative treatment of AIS and improve patient outcomes.

Objective: This study aimed to explore stakeholders’ perceptions of using digital health technologies to improve conservative treatment of AIS.

Methods: This qualitative research study was conducted in Norway involving 17 participants, including one medical doctor, two physiotherapists, eight patients, four family caregivers, and two IT specialists. Following approvals from the authorities and adherence to Norwegian regulations, as well as approval of the study protocol, patients were recruited through The Norwegian Spine and Back Pain Organization. A portion of the sample was recruited through direct communication from one of the researchers. Five focus group interviews were conducted between April and June 2023, after obtaining written informed consent from all participants. Data were transcribed, translated, and analyzed using thematic analysis, with the analysis reviewed by two independent researchers.

Results: The analysis highlighted the need for better education on AIS among health personnel, community support for patients, and improved healthcare services. Participants valued multilingual information, peer connections, and digital communication with health professionals to enhance treatment compliance and reduce the burden on healthcare systems.

Conclusions: Key findings highlighted the need for accessible information, peer support, and better communication with healthcare providers, with gamification enhancing treatment adherence. The findings from this study highlight the potential of digital health technologies to enhance the management of AIS, improve patient outcomes, and elevate the overall quality of care, providing a foundation for future practice and research in this area. Clinical Trial: no

(JMIR Preprints 21/11/2024:69089)
DOI: https://doi.org/10.2196/preprints.69089

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Abstract

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Aim

This study aimed to explore stakeholders’ perceptions of using digital health technologies to improve conservative treatment of AIS.

Methods

This qualitative research study was conducted in Norway involving 17 participants, including one medical doctor, two physiotherapists, eight patients, four family caregivers, and two IT specialists. Following approvals from the authorities and adherence to Norwegian regulations, as well as approval of the study protocol, patients were recruited through The Norwegian Spine and Back Pain Organization. A portion of the sample was recruited through direct communication from one of the researchers. Five focus group interviews were conducted between April and June 2023, after obtaining written informed consent from all participants. Data were transcribed, translated, and analyzed using thematic analysis, with the analysis reviewed by two independent researchers.

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The analysis highlighted the need for better education on AIS among health personnel, community support for patients, and improved healthcare services. Participants valued multilingual information, peer connections, and digital communication with health professionals to enhance treatment compliance and reduce the burden on healthcare systems.

Conclusion

Key findings highlighted the need for accessible information, peer support, and better communication with healthcare providers, with gamification enhancing treatment adherence. The findings from this study highlight the potential of digital health technologies to enhance the management of AIS, improve patient outcomes, and elevate the overall quality of care, providing a foundation for future practice and research in this area.

Keywords: Adolescent Idiopathic Scoliosis; brace; conservative treatments; digital; monitoring

Introduction

Scoliosis is defined as the three-dimensional curvature of the spine (Stokes et al., 1987). Adolescent idiopathic scoliosis (AIS) affects 2-3% of adolescents, aged 10 to maturity, with a higher prevalence among females (Bottino et al., 2023). Treatment strategies vary based on risk progression, bone maturity, and the current stage of spinal curvature (Loughenbury & Tsirikos, 2022).

Current Adolescent Idiopathic Scoliosis Treatment

AIS is treated either surgically or conservatively. Surgical intervention is considered for curves between 40-50 degrees (Anthony et al., 2021), while conservative brace treatment is recommended for growing children with curves between 25-40 degrees. Scoliosis-related surgeries often involve high levels of pain and slow return of function, with risks including infections, neurological injuries, and prolonged cardiopulmonary recovery (Murphy & Mooney, 2016). Additionally, surgeries are associated with chronic anxiety or depression (Julien-Marsollier et al., 2020). Enhanced recovery protocols promote early mobilization to shorten hospital stays, but the average length of stay varies (Gadiya et al., 2021; Pico et al., 2022).

Conservative treatment is often recommended for children or young people with mild to moderate deformity (Hannink et al., 2023). This includes bracing and physiotherapeutic scoliosis-specific exercises (PSSE) for patients with a Cobb angle between 20 and 40 degrees (Wibmer et al., 2016). Scoliosis-specific exercise therapy has been shown to improve quality of life (Zhou et al., 2021) and provide effective long-term results (Maruyama, 2008). The success of brace treatment is directly related to the number of hours the brace is worn (Weinstein et al., 2013). Patients recommended for brace treatment typically have spinal curvature between 30-40 degrees or 20-29 degrees with rapid progression (Martínez-Borba et al., 2021). The goal of bracing combined with PSSE is to postpone or avoid surgery (Karavidas & Tzatzaliaris, 2022; Negrini et al., 2014).

While theoretically effective, practical challenges exist in conservative treatment adherence, primarily due to discomfort, pain, irritation, sweating, and self-esteem issues (Martínez-Borba et al., 2021). High demand for movement correction often requires constant physiotherapy supervision, which is not always accessible at home. More feedback results in more precise exercising, especially in children (Wibmer et al., 2016).

Digital Health Technologies in AIS Treatment

Telehealth and telemonitoring are gaining importance in the health sector (Haleem et al., 2021). The potential to use digital health Information Communication Technologies (ICT), such as smartphone apps and web applications, in AIS treatment is feasible with existing technologies (Bottino et al., 2023; Cho et al., 2023). These digital health technologies could bring several advantages to both patients and health professionals (Bottino et al., 2023; Cho et al., 2023). Current literature primarily focuses on digital health technologies for scoliosis screening (Moreira et al., 2020). Mobile apps can provide periodic monitoring of spinal curvature progression, reducing the need for frequent in-person visits, and offering quick consultations and feedback on exercises (Bottino et al., 2023). Digital health technologies can promote self-management and strengthen patient involvement in monitoring their health conditions (Svendsen et al., 2020).

Digital health technologies enable clinicians to oversee a greater number of scoliosis patients while delivering immediate feedback based on exercise outcomes. ICT-based management simplifies inter-professional communication and information exchange securely, enabling remote communication of health issues and overcoming logistical challenges. Apps can help doctors organize and track appointments, meetings, and administrative routines (Crico et al., 2018). Digital health technologies promise to reduce healthcare professionals' workload and improve patient self-management (Bodenheimer et al., 2002) .The usage of technologies need to be properly consider regarding ethics, legislation, fairness and privacy matters especially in medical field (Vellido, 2019).

Digital tools can encourage early self-screening and detection of scoliosis, preventing complications. A scoliosis screening system using standard 2D digital cameras or smartphone sensors can facilitate global detection efforts. Measurements using apps are more stable and precise due to sensors like accelerometers and gyroscopes. Smartphone apps and web applications are appropriate for monitoring and supervision in home-based treatment programs. (Bottino et al., 2023).

Self-monitoring can motivate patients in their treatment journey, offering empowerment, education, and an accessible platform for communication between clinic visits. Monitoring apps can connect patients with health personnel to address discomfort, answer treatment questions, and provide immediate feedback (Martínez-Borba et al., 2021). Retrospective reports at doctor's offices are problematic as they do not allow early detection of issues. In these cases, it is important for patient to talk about the discomfort, which could potentially lead to more continuous brace usage until the next appointment (Martínez-Borba et al., 2021).

There is a notable research gap in conservative AIS treatment. While some studies describe digital tools in surgical scoliosis treatment (Bottino et al., 2023), few empirical studies explain how to use digital health technologies to improve conservative AIS treatment (Martínez-Borba et al., 2021). Furthermore, there is limited understanding of the digital health functionalities and features required by patients, their caregivers, and therapists. Thus, this qualitative interview study aims to identify how to use digital health technologies to improve conservative AIS treatment in Norway and critically assess whether the promises of digital health are meaningful and desirable for users.

Methods

Design strategy

The qualitative research detailed in this paper was conducted in Norway (2023-2024) and involved 17 participants, including one medical doctor, two physiotherapists, eight patients, four family caregivers, and two IT specialists. The study employed a combination of physical and hybrid participation formats across 5 focus group interviews conducted between April and June 2023. The composition of the focus group participants is summarized in Appendix 1.

Participants were recruited through a combination of methods. A portion of the participants (IT experts and health personnel) was directly contacted by one of the researchers via to invite them to participate in our research. Patient recruitment for this study was facilitated in collaboration with The Norwegian Spine and Back Pain Organization, utilizing their extensive network. The project was advertised on the organization's website and at various events, with individuals expressing interest in participation directed to contact the research team. The organization serves as a patient organization dedicated to ensuring individuals receive appropriate treatment and represents patients’ rights within the Norwegian healthcare system. Ultimately, five representatives, accompanied by their caregivers (one parent each), and three trained user representatives (adults who had scoliosis and received training to help others in similar situations) from The Norwegian Spine and Back Pain Organization were successfully enrolled in the project. Adolescents from diverse cultural and socioeconomic backgrounds were included in the recruitment process. Eligible participants were individuals diagnosed with AIS who had undergone either conservative treatment or surgical intervention, with one participant under observation only.

Data collection

Data were collected by conducting focus group interviews as workshops in English and Norwegian in the spring and summer of 2023. The interview and workshop guide (in Appendix 2) was generated and validated together with the clinical scoliosis experts from Norway. Each workshop extended for approximately 3 hours, with a short break included. All sessions were recorded with the explicit consent of the participants. Adolescents under the age of 18 attended alongside their parents, and all participants provided written consent prior to participation. An interview guide, featuring semi-structured questions, was collaboratively developed by the research team in conjunction with medical experts specializing in scoliosis treatment from Norwegian hospitals and user organization (refer to Appendix 2 for details). Two researchers acted as facilitators during the workshops. Participants were afforded the option to attend either physically or virtually, through a hybrid format.

Ethical consideration

The study received approval from Sikt, the Norwegian Agency for Shared Services in Education and Research, with reference number 743837. Written consent was obtained from all participants prior to their involvement in the study. Ethical approval was deemed unnecessary for this research, as per the decision of the Regional Committees for Medical and Health Research Ethics in Norway (REK).

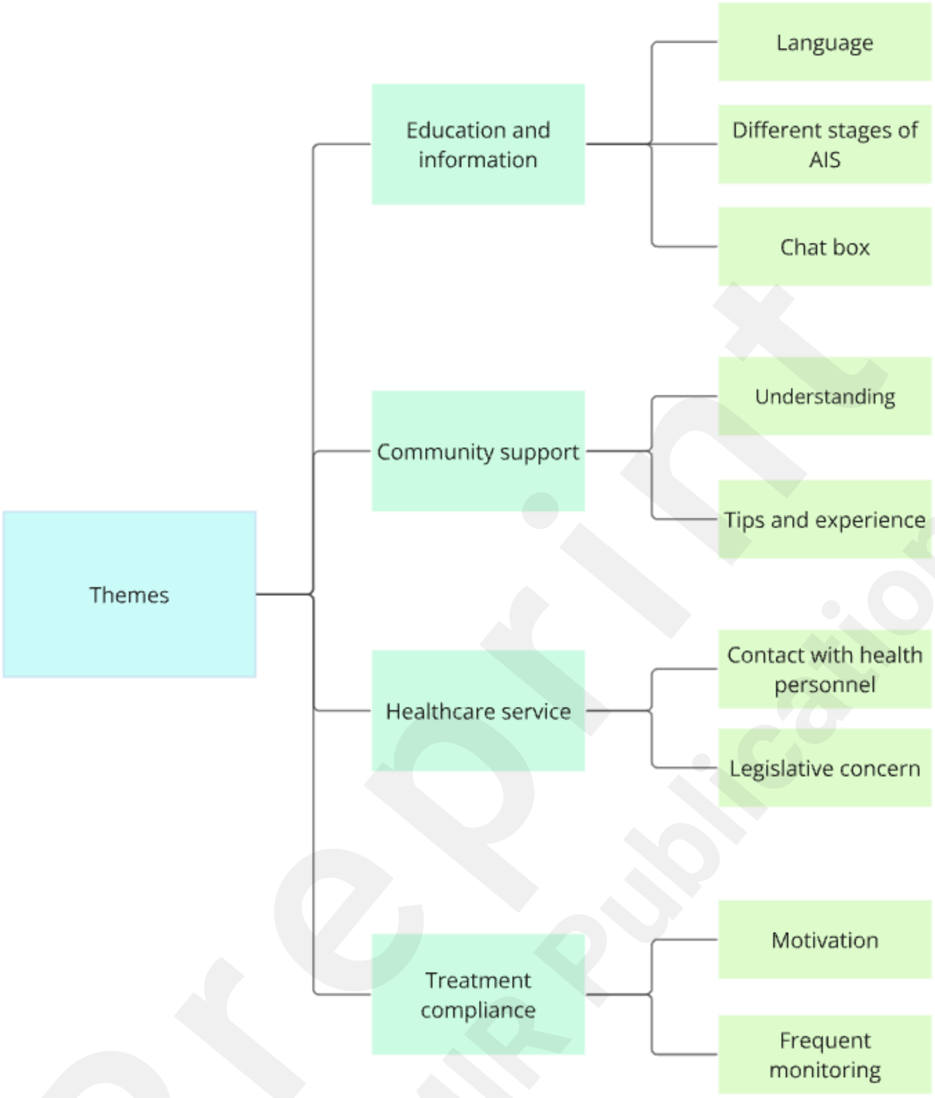
Data analysis

Collected data were transcribed verbatim and translated into English when needed. The content analysis was conducted by the first author of the paper. Systematically evaluation of qualitative data to identify meaning, patterns and themes that manifested from the interviews (Devi Prasad, 2019). A systematic coding procedure was followed to categorize and interpret the data, which emerged in themes and subthemes. Some of the codes were used multiple times. Coding process was completed when the saturation was achieved by the researcher keeping neutral approach. The NVivo R1 program (2020) and Excel from Microsoft Office 365 were used. Subsequently, the analysis underwent independent review by co-authors, who provided their respective feedback and insights. Creating a comfortable environment during focus group interviews enhanced the validity of the collected data.

Results

The analysis was undertaken to obtain final themes and subcategories. Based on data analysis following themes were generated (Figure 1): (1) education and information, (2) community support, (3) healthcare service, (4) treatment compliance. Some of the participants’ quotations are presented to describe closely individual themes.

Figure 1. Themes and subthemes that emerged from data analysis.



Two versions of different prototypes of a potential smartphone application and related content (Appendix 3 and Appendix 4) were created and presented to the participants in the workshops. First prototype was discussed in the fourth focus group interviews. Based on participants' feedback, edited version of the prototype was presented during the fifth focus group interview and new comments were obtained. No usability testing was performed. Overall, the feedback of the prototype was positive as it corresponds to a portable, flexible, and accessible solution.

Theme 1: Education and Information

Patients and their caregivers shared their experiences when receiving an AIS diagnosis, noting that health personnel often lacked sufficient knowledge about the disease to provide proper information. One patient shared a less recognized situation where her general practitioner didn't know anything about scoliosis. Understanding the patient's situation when receiving an AIS diagnosis is essential, not only for further cooperation but also because prepared patients are recognized to have better outcomes, which decreases the cost of healthcare services.

Physiotherapist: *"I think a well-prepared patient will have better outcome, will get home much earlier and in a safer way."*

The aim of implementing the potential app is also to allow access to information at any time. Patients after surgery usually don't remember the given instructions properly. Parents admitted they felt overwhelmed when receiving the diagnosis of their children and were not able to listen to the information.

Subtheme 1.1: Language

Health personnel acknowledged that they encounter situations where they lack a common language with patients. In such cases, effectively communicating information and preparing patients for their new life circumstances related to their diagnosis becomes nearly impossible. Therefore, they were very pleased with the solution providing information in different languages, with Urdu, Arabic, and Polish being the most frequent.

Physiotherapist: *"But you also maybe need to do something in a lot of languages then… And then you can have Urdu, you can have Arabic. Yeah, you can have… You have a lot of Polish, earlier Russian or the Balkan languages."*

Subtheme 1.2: Different Stages of AIS

Patients seek help throughout their journey, and information should be tailored to their current needs.

IT Expert: *"I think that's important when you can… you can kind of build those different phases or that that they would, would… the programme also would change in in what kind of situation you are in and you can have some when you have the information exactly for your situation."*

The app should offer different information for various stages of a patient's journey – for those who just received a diagnosis, those undergoing surgeries, and those following brace treatment, etc.

Family caregiver*: "Well, really, I think … that if it could be divided up … whether you need softening, pain relieving exercises for … in the shoulders, or the pelvis, back … Yes, it could be divided a bit according to different types of needs. It's a bit as if, whether it is training or whether it is just painful muscles and softening exercises … Yes, like specific exercises or, yes, for the program, some exercises for the program."*

Subtheme 1.3: Chat Box

Patients represent the adolescent generation well adapted to digital technology usage. Therefore, when discussing the form of providing information, a chat box was suggested, as the young generation is very familiar with that. Talking to health personnel may be difficult as it would require a report in the patient’s health care journal, and there are other legislative obstacles regarding this implementation.

Patient*: “Well, I think in a way to get an answer to what you're wondering about. There can be so many different... Yes, from where it hurts or what... Yes, one or the other. That one can search up own questions. If it’s possible to add some information? Some concrete information that I can search up. For example in Helsenorge I can ask questions my GP. Is that possible?*

Researcher: “*Yes, it is. Absolutely.“*

Patient: “*Yes. Otherwise, I can't think of anything else right now.. Maybe tips about activities that can be okay, or... Or training, possibilities, or... “*

Researcher: *“Once we started using chat bots, they were very happy because… They’re quite used to talking to chat box, right? They’re very used to that, so this is a very known way of interacting.”*

Another Patient*: “This is a very good suggestion. That you can... That activities can, in a way, become tips from other users. Where you write... So, for example, as XXX has suggested, swimming and stretching is something that maybe not everyone think of ..”*

Theme 2: Community Support

The biggest theme that emerged from the group discussion was the need for support. This could be facilitated by a smartphone app dedicated to AIS, where patients could connect and create their own community. According to reports from our research participants, they would have appreciated communication with others suffering from scoliosis, especially their peers. It would be valuable for them to listen to patients after surgery or those undergoing brace treatment for several years to understand the severity of their own situations and eventually increase treatment compliance. Patients have questions they may be too shy to ask at the doctor’s office.

Patient: “*So what I missed. was someone to be with. Who had gone through the same thing. It did not have to be specific. But someone who could understand me to a certain extent.”*

Subtheme 2.1: Understanding

Receiving an AIS diagnosis may result in the patient experiencing detachment and isolation from their existing social network. Patients often report feelings of alienation, expressing a lack of available confidants. Through the app, connecting with fellow patients offers a higher opportunity for empathy, understanding, and exchange of emotions and perspectives. Participants expressed their wish to have this app connected with “Ryggforeningen i Norge,” is The Norwegian Spine and Back

Pain Organization for scoliosis that has a very active approach. The association organizes events that allow patients to meet, connect, and create their own community.

Family caregiver: “*Connect the app with the patient association.”*

Patient: *“I got that understanding when I went to xxx and met others who had experienced the same as me. A group of people with scoliosis in different ways.”*

Subtheme 2.2: Tips and Experience

According to the patients and their parents, it would be beneficial to be provided with tips and experiences from patients who have been or are in the same situation. Participants mentioned areas like school (e.g., having two sets of books to avoid carrying heavy backpacks, getting extra time for exams, rights to be driven to school by taxi) or types of aids that don’t come to mind.

Family caregiver*: “Like for example, two sets of books and not have to carry a heavy bag to and from school, and others, like chairs to sit on, and yes, and stuff like that.”*

They would also appreciate recommendations for physiotherapists experienced with AIS or tips for general physical activity suitable for AIS. Sharing exercises and workout tips that are safe for a patient’s back when suffering from scoliosis.

Patient: “*And I also think that what you mentioned about yoga, I think many have benefited from it. I have not done it myself, but I have heard that it is nice if you have scoliosis*.”

Some patients revealed their daily struggles after surgeries – e.g., they couldn’t comfortably lay down or sit, so advice in this direction would be gladly appreciated too. What type of chair/mattress do they use? What tips do they have for lowering the pain?

Patient: “*When I got surgery, I found very useful tips for such a little thing for example how to lay comfortably in a bed again. One has to find out how to sit at the dinner table. Just the practical tips one may think are not needed.”*

Theme 3: Healthcare Service

The implementation of this app aims to lower the worldwide burden on the overloaded healthcare system and facilitate smoother connections between patients and health personnel. This is expected to reduce the frequency of personal visits to the doctor.

IT Expert: *“You can take the app with you into the consultation room and share it should you want to. And I think that's kind of important also is… That it clearly communicates this is a patient choice.”*

Subtheme 3.1: Contact with Health Personnel

Especially with AIS, the period between checkups is sometimes 6 months. During this period, patients can experience discomfort when wearing a brace and need detailed guidance from health personnel. Long waiting times to resolve a patient’s problem lower the effectiveness of treatment. According to the participants, it would be beneficial to have the opportunity to ask their doctors or physiotherapists about a current problem so they could continue to follow up on the treatment plan. Patients sometimes have simple questions that could be easily communicated through an app.

Family caregiver: *“If I could have a wish, it would be in relation to the interaction with the health care system.”*

Patients and their caregivers also wish to receive information digitally, no longer as a piece of paper. The app could serve as storage for their rehabilitation exercises, which would be easily accessible at any time.

Subtheme 3.2: Legislative Concerns

Nevertheless, there are legislative concerns requiring further examination, particularly regarding the conversation between patient and medical staff, which must always be documented in the patient’s journal.

IT Expert: *“They said no completely to everything because you cannot have an app that’s owned by the hospitals where you don’t have 100% control everything.”*

A similar obstacle emerged when providing quality information to the patients through an app, which would require control of all shared content by health personnel. This, for now, seems too time-consuming.

Physiotherapist: *“Very important for… for good and safe treatment is that we all give answers to questions, so it will be kind of heavy work for the health personnel to follow this.”*

Another concern is integrating the DIPS – a robust, reliable electronic patient record system used in Norwegian hospitals – into the app.

Physiotherapist: *“You know anything that doesn’t match with the DIPS doesn’t match. DIPS isn’t a… DIPS, is a big problem. So, if this should be used by us, it must be on the patient’s own platform as the tools to as you help yourself.”*

Theme 4: Treatment Compliance

An AIS diagnosis often marks the start of a long-term condition, making it challenging for patients to follow a treatment plan. Bracing requires several years, and physiotherapy sometimes a lifetime regime.

IT Expert: *“This is so important to have a tool set like yours to be able to keep the communications up with the patient for a long time and… It‘s scoliosis. I see that it's not months, it's years. It's maybe for the rest of their lives.”*

Subtheme 4.1: Motivation

Introducing an app to the patients is expected to increase treatment compliance and enhance their motivation through gamification. The patient sample in our research is exclusively female (the prevalence of AIS is significantly higher in females (Bottino et al., 2023)) and the participants reported not being interested in playing games.

Researcher: *"They said that no, we don't use games like that at all."*

Consequently, other gamified features were presented, such as creating their own avatars.

Physiotherapist: *"I think the avatar sounds pretty… I… I think my patient would like that, because they are very into designing like how the braces look like, the pattern.*"

Gamification can be approached by receiving points from workouts or alternative activities and saving their results in the app. By sharing activities, patients can get inspired and develop interest in different activities they might not think of as safe choices (yoga, swimming, skiing, meditation). If the app allows tracking progression and provides feedback to the patients, it could also serve as a motivating feature.

Some caregivers pointed out it is important not to exaggerate the role of exercises within the app. There are patients for whom it's difficult to move, so this could potentially lead to demotivation rather than encouragement.

Family caregiver: *"So, if it's: Now you have managed this much when you exercise, I understand because then you can manage it. But it can be demotivating, and it can be counterproductive when the person can't manage to do it."*

Subtheme 4.2: Frequent Monitoring

This app is meant to allow patients to monitor their situation over a longer period. Among suggested elements was a diary, which would be available to store information regarding their pain, sleep, treatment, mood, feelings, or any other aspect. This results in an overview which makes it easier to detect any changes in pain, problems, etc.

Physiotherapist: *"But what I think emotionally and psychologically about this diary is that I believe that if they have a place to put all their thoughts and feelings and write it down, we have that… And I think if we… if we have a system that organised in that way that you can put all the, that's that one place. That could be therapy in itself."*

This is expected to not only increase adherence to treatment but also provide more accurate information about the patient's history. Recall of events appears to be uncertain. This feature may be helpful regarding the balance between pain and exercising.

Patient: *"So there are also a lot of things I don't remember from the hospital stay. Because of my* *pain meds..”*

Physiotherapist: *“So, so in that stage, when they are laying there in the hospital and they are waking up, they they would need this kind of basic information like what, what can I do now and and how to how to. And and they they lay in bed and they have this devices, they can go back or what did she say? I don't remember. And maybe my parents are coming here. Have the doctor been here? Have had the physio being here? Yes, but I don't remember a thing.”*

Discussion

This study explored patients’ and caregivers’ perspectives on a potential digital solution for managing AIS and identified four key themes based on participants’ perspectives. The themes of education and information, community support, healthcare service, and treatment compliance, emerging from the conducted interviews, highlight how such an app could significantly enhance the treatment process for patients. These themes reflect common concerns in chronic disease management, such as the need for accessible information, peer support, and tools that enhance treatment adherence. The results of the study support findings from other studies on the potential for digital health technologies to improve conservative treatment for AIS, specifically through a smartphone application (Bottino et al., 2023; Minge et al., 2018; Palermo et al., 2020; Zhu et al., 2021). Similarly, other study describes wish of patients with chronic diseases to use the app to increase treatment adherence (Peng et al., 2020) .

Education and Information

Our study shows the challenges AIS patients and their caregivers face in receiving adequate information, particularly at the time of diagnosis. One participant reported how her general practitioner was unfamiliar with scoliosis, leaving the family without proper guidance. This highlights a critical gap in patient education, which can undermine the entire treatment journey. Understanding the disease itself is essential for successful further treatment. Patients who are well-informed tend to have better health outcomes and require fewer healthcare services, leading to reduced costs. Previous research has similarly highlighted that patient education significantly influences treatment outcomes and quality of life (Bray et al., 2023). The app would also allow patients to access AIS information at any time, as it was conveyed that patients and their caregivers were often overwhelmed when receiving the diagnosis and unable to take in more information. Health personnel also shared the need to have the app accessible in several languages, as there is sometimes no common language between them and the patients, resulting in a lack of information provided by health personnel. The proposed app addresses this by offering reliable, accurate information available in multiple languages (such as Urdu, Arabic, and Polish), ensuring that patients from diverse backgrounds can access essential information. As AIS patients represent the young generation, a chat box was suggested as an adequate form of providing information through the app.

Additionally, both patients and their caregivers, as well as health personnel, believe the app should be tailored to individuals' needs and the patients' current stage of AIS treatment. By providing tailored content specific to different stages of treatment—whether patients are newly diagnosed, undergoing surgery, or following brace treatment—the app ensures that information remains relevant and actionable throughout the patient journey. The importance of language and tailoring information to different stages of the patient's journey aligns with studies that suggest personalized patient education can improve adherence to treatment plans(Wittink & Oosterhaven, 2018).

Community Support

Beyond education, the study also underscores the emotional isolation many patients feel after receiving an AIS diagnosis. This sense of detachment from their social circles can worsen the psychological toll of the condition. Participants expressed a strong desire for peer-to-peer support, where patients could connect with others facing similar challenges. The app seems to be an appropriate way of communication for young patients and could provide a vital community-building platform, offering a space for patients to share experiences, offer practical advice, and support one another through difficult phases of treatment. For instance, patients suggested linking the app with patient associations, which already foster scoliosis communities, organize events, and are positively received among the AIS patient group. The connection with such organizations further highlights the value of structured peer support systems in chronic disease management.

This could enhance the sense of belonging and support that many participants identified as essential. Sharing personal tips, such as strategies for managing pain after surgery, adequate physical activity/sport, or in school settings (e.g., extra time for exams or two sets of textbooks to avoid carrying heavy bags), could also alleviate some of the day-to-day struggles patients and their caregivers face, promoting better treatment compliance. The need for community support indeed echoes findings from chronic disease literature, where peer interaction has been shown to reduce feelings of isolation and improve psychological well-being (Macculloch et al., 2009; Motyer et al., 2021). Our findings support the potential for an app that fosters community interaction, allowing patients to share experiences and advice, which can empower them in managing their condition.

Healthcare Services

Another crucial aspect is how the app could ease the strain on healthcare services. Patients with AIS often go months between check-ups, and during this time, they may experience discomfort or require guidance on wearing braces or performing exercises, as shared by our focus group. This app could allow patients to contact healthcare professionals for quick answers to minor issues regarding their current treatment method, reducing the need for unnecessary in-person visits. Participants’ desire for improved communication with healthcare professionals is a recurring theme in healthcare literature. The long intervals between appointments for AIS patients often leave them seeking more frequent guidance, which has been noted in other chronic conditions such as diabetes (Lynch et al., 2008; Toga-Sato et al., 2021). Detailed features of the app need to be discussed in the future to meet the needs of patients, their caregivers, and healthcare professionals.

The app also offers a modern communication tool, replacing outdated paper flyers. However, there are legislative concerns regarding documentation, integration with electronic health records (such as Norwegian DIPS system), GDPR regulations, ethics, fairness and the general safety of using digital applications in healthcare practice (Vellido, 2019). These challenges need to be resolved to ensure secure and legally compliant interactions between patients and healthcare providers, as all the provided information by healthcare professionals needs to be documented in patients’ journals. Updating relevant information in patients' medical records seems to be excessively time-consuming for health personnel. Nonetheless, streamlining patient-provider communication through the app could likely enhance the effectiveness of the treatment plan and reduce patient anxiety during long periods between appointments.

Treatment Compliance and Motivation

The issue of treatment compliance is central to the management of AIS, as long-term adherence to bracing and physiotherapy is often required. To address this, the app incorporates gamification features to encourage compliance. Findings from our study align with the growing body of research on the role of digital tools in enhancing treatment compliance (Cordani et al., 2023; Venkatraman et al., 2024). While some participants expressed disinterest in gaming, others were intrigued by features like creating avatars and other gamification elements, such as earning points for completing exercises or engaging in activities like yoga or swimming. In current literature, features such as avatars or point-based systems have been shown to increase patient engagement in other health-related apps (LeRouge et al., 2015). Additionally, the app could include a diary feature to help patients track their pain, sleep, and overall progress, fostering consistent adherence to the treatment plan. However, the need for balance is critical to ensure the app remains motivating. Overly focusing the app on exercise tracking could potentially discourage patients with physical limitations (e.g., in the post-operative period), a concern noted by caregivers in our study.

An important component of the app seems to be a diary feature, which allows users to monitor their situation over a long period. This results in easier detection and explanation of any changes (pain, sleep, treatment, etc.). This is anticipated to not only enhance treatment adherence but also yield more accurate information about the patient’s history, as the recall of events seems to be uncertain (Rullander et al., 2017). This feature may prove beneficial in balancing pain and exercise.

Implications for Theory

The findings from this study have several theoretical implications that extend beyond the immediate context of AIS management. Firstly, the study contributes to the broader understanding of how digital health technologies can be effectively integrated into chronic disease management. By identifying the specific needs and preferences of AIS patients and their caregivers, the study provides an information that can also be adapted to other chronic conditions (Bashi et al., 2020; Palermo et al., 2020).

Moreover, the study highlights the critical role of cultural and linguistic inclusivity in health technology design. The inclusion of multilingual support in the app underscores the necessity of developing health technologies that are accessible to diverse patient populations. This finding aligns with the growing body of literature advocating for culturally competent healthcare practices and suggests that future research should continue to explore how digital health tools can be designed to meet the needs of diverse user groups (Betancourt, 2003).

The study also advances the theoretical understanding of gamification in health behavior change. By demonstrating the potential of gamification elements to enhance treatment adherence among AIS patients, the study provides empirical support for the use of game-based strategies in health interventions. This insight can support future theoretical models of health behavior change, particularly in the context of chronic disease management, where long-term adherence to treatment plans is crucial (such as (Johnson et al., 2016; Sardi et al., 2017)).

Implications for Practice

The integration of digital health technologies into AIS treatment presents a promising avenue for improving patient education, community support, healthcare services, and treatment compliance. The findings from this study underscore the importance of addressing the specific needs of AIS patients and their caregivers through tailored, accessible, and culturally appropriate digital solutions. While significant challenges remain, particularly regarding legislative and logistical barriers, the potential benefits of such technologies are substantial.

Practically, the study offers several actionable insights for healthcare providers, technology developers, and policymakers. For healthcare providers, the study underscores the importance of comprehensive patient education and the need for continuous support throughout the treatment journey. The development of a digital app that provides reliable, accessible information can help bridge the knowledge gap identified in the study, ensuring that patients and their caregivers are well-informed and better prepared to manage AIS (Bodenheimer et al., 2002).

For technology developers, the study provides a clear roadmap for designing effective health apps. The emphasis on patient-centered design, multilingual support, and gamification features offers practical guidelines for creating digital health tools that are both engaging and effective. Developers should prioritize these elements to enhance user engagement and treatment adherence, ultimately improving health outcomes (Kvedar et al., 2014; Pagliari et al., 2007).

Policymakers can also draw valuable lessons from this study. The legislative and logistical challenges highlighted in the research point to the need for clear regulations and streamlined processes to facilitate the integration of digital health technologies into existing healthcare systems. Policymakers should work towards creating an enabling environment that supports the adoption of digital health tools, ensuring that they are secure, legally compliant, and seamlessly integrated with electronic health records (Blumenthal, 2010).

Additionally, the study's findings on the importance of community support suggest that healthcare systems should incorporate peer support mechanisms into their service delivery models. By fostering connections between patients through digital platforms, healthcare providers can enhance the psychological well-being of patients and improve treatment adherence. This approach can be particularly beneficial in managing chronic conditions, where long-term support and motivation are essential (Dennis, 2003).

In conclusion, this study provides valuable theoretical and practical insights into the integration of digital health technologies in AIS management. By addressing the specific needs of AIS patients and their caregivers, the study offers a comprehensive framework that can inform future research and practice in the field of digital health. The implications for theory and practice underscore the potential of digital health tools to transform chronic disease management, improving patient outcomes and enhancing the overall quality of care.

Limitations

Several limitations of this study should be acknowledged. First, the data collection relied on focus group interviews, which may introduce bias due to group dynamics, where participants may feel pressured to conform to dominant opinions rather than express their true experiences. Individual interviews might have provided additional depth to the data by allowing more personal reflections. Second, the study was conducted using a small sample size, which limits the generalizability of the findings. While the focus groups provided valuable insights into the perspectives of AIS patients and caregivers, a larger and more diverse sample, including a larger group of participants may yield more comprehensive results. Third, the digital solution was only presented as a prototype, and participants' feedback was based on a conceptual understanding of the app rather than actual long-term use. Without actual feasibility study and real-world testing of the app, it is difficult to assess how effective it would be in practice or the extent to which it would address the needs identified in this study. Fourth, the study focused primarily on patients and caregivers from Norwegian healthcare settings, which may not reflect the experiences of individuals in larger and different healthcare systems. For instance, participants' views on access to information or healthcare support may vary depending on the specific resources available in other countries, hence the generalizability of the study finding is low. Lastly, although legislative and regulatory concerns related to healthcare apps were mentioned, this study did not explore these issues in depth.

Future research should focus on developing and testing these digital solutions in real-world settings to evaluate their effectiveness and feasibility. Additionally, efforts should be made to address the identified barriers, ensuring that digital health technologies can be seamlessly integrated into existing healthcare systems. By doing so, we can enhance the quality of care for AIS patients and support them in managing their condition more effectively.

Conclusion

This study highlights the significant challenges faced by AIS patients and their caregivers in terms of access to education, community support, healthcare services, and treatment compliance. The findings emphasize the need for improved communication and information-sharing platforms that can offer timely, personalized guidance to patients at various stages of their treatment journey. A smartphone application designed to address these needs was positively received by participants, who valued the potential for better access to information, peer support, and closer interaction with healthcare professionals.

The identified themes suggest that digital tools, if properly implemented, can play a critical role in alleviating the emotional burden associated with AIS and enhancing treatment compliance through personalized support and motivational features. However, the study also highlights potential legislative and logistical barriers that need to be addressed before such solutions can be fully integrated into healthcare systems.

It emerged from the results that the development of the digital solution holds significant potential to enhance the conservative treatment of AIS. By addressing key issues such as education, community support, and healthcare communication, and by encouraging compliance through innovative features, the app could improve patient outcomes while reducing healthcare costs. However, it is vital that the app continues to evolve based on users’ feedback to ensure it remains relevant, effective and inclusive. The addition of a chat box, as suggested by participants, could further enhance communication, particularly for younger users accustomed to digital interfaces, making the app a comprehensive tool for managing AIS in a modern healthcare landscape.

While this study provides valuable insights into the needs of AIS patients, further research is needed to address the ethical and legal concerns raised regarding app-based healthcare solutions. Additionally, future studies could explore the effectiveness of such digital tools in improving patient outcomes, especially in long-term treatment adherence.

Future research should focus on testing the effectiveness of digital health solutions in real-world settings and exploring how they can be tailored to meet the diverse needs of AIS patients. By addressing these gaps, healthcare providers may be able to offer more comprehensive, patient-centred care that improves both the physical and emotional outcomes for individuals living with AIS.

Acknowledgements

Thank you for the Norwegian Research Council funding for our Pilot Scoliosis project, project number: 341859 to give funding for the study. Thank you also for the research team “Design for Health” at OsloMet, all patients and their parents as well as healthcare professionals about their time and efforts for data collection of this study.

Co-Pilot AI tool was used to do the language correction for this paper.

Conflict of Interest

I confirm that there are no conflicts of interest related to the publication of this paper. I have no personal relationships that could influence the reporting of this work. The research was conducted independently, and no organization stands to benefit from its results.

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Abbreviations

AIS: Adolescent Idiopathic Scoliosis
DIPS: Distributed Information and Patient Data System in Hospitals (Distribuert Informasjons- og Pasientdatasystem i Sykehus)
GDPR: General Data Protection Regulation
ICT: Information Communication Technologies
PSSE: Physiotherapeutic scoliosis-specific exercises
Sikt: Norwegian Agency for Shared Services in Education and Research (Kunnskapssektorens tenesteleverandør)
SRS: Scoliosis Research Society

Appendix 1

Appendix 1. Focus group interviews and participants

Focus Group 1: Needs and Pain Points in Scoliosis Journey, 18-04-2023:

Patient representatives:

Ref nro		Gender	Time from scoliosis treatment
1	Patient 1	Female	10-20 years
2	Patient 2	Female	5-10 years
3	Patient 3	Female	5-10 years

Experts & Company representatives

Ref nro	Title	Role
4	Physiotherapi	Working with scoliosis patients currently in Norwegian hospital 1

	st	
5	Physiotherapist	Leading physiotherapist, responsible of the scoliosis treatment in Norwegian hospital 2

Focus group 2: Needs & Current Practice, Physiotherapy Focus, 25-04-2023

Experts & Company representatives

Ref nro	Title	Role
4	Physiotherapist	Working with scoliosis patients currently in Norwegian hospital 1
5	Physiotherapist	Leading physiotherapist, responsible of the scoliosis treatment in Norwegian hospital 2

Focus group 3: Needs & Current Practice – Patient Perspective, 09-05-2023

Patient representatives & family care givers:

Ref nro		Gender	Time from scoliosis treatment
6	Patient 4	Female	3-5 years
7	Patient 5	Female	Ongoing
8	Patient 6	Female	Ongoing
9	Family caregiver 1	Female	3-5 years
10	Family caregiver 2	Female	Ongoing
11	Family care giver 3	Female	Ongoing

Experts & Company representatives

Ref nro	Title	Role
4	Physiotherapist	Working with scoliosis patients currently in Norwegian hospital 1
5	Physiotherapist	Leading physiotherapist, responsible of the scoliosis treatment in Norwegian hospital 2
12	Medical doctor	Currently giving scoliosis treatment for patients in Norwegian hospital 2

Focus group 4: Vision workshop, focusing on the solution content, 06-06-2023

Experts & Company representatives

Ref nro	Title	Role
4	Physiotherapist	Working with scoliosis patients currently in Norwegian hospital 1

5	Physiotherapist	Leading physiotherapist, responsible of the scoliosis treatment in Norwegian hospital 2

Focus group 5: Future Scoliosis Solution, Patient Perspective 29-08-2023

Ref nro		Gender	Time from scoliosis treatment
6	Patient 4	Female	3-5 years
7	Patient 5	Female	Ongoing
13	Patient 7	Female	Ongoing
9	Family caregiver 1	Female	3-5 years
10	Family caregiver 2	Female	Ongoing
14	Family care giver 4	Female	Ongoing

Appendix 2
Focus group interview guide for participants

1. **Need & Pain Points in Scoliosis Journey workshop (participants: experts, researchers, companies, user representatives from the Norwegian Spine and Back Pain Organization "Ryggforenningen I Norge")**

Patients' journey and clinical practice
- Can you share examples of the patient journey for the three different types of patients?
- What happens in the different stages of the patient's journey?
- What is the current clinical practice for scoliosis treatment and what is the best clinical practice?
- What are the improvements needs for today's clinical practice from a patient perspective?

Treatment planning and communication among experts
- How is the treatment planned for the different patient types? What types of experts are involved in different phases (their roles)?
- How does communication occur between the experts in different phases?
- How are decisions made in different phases, what data is used for decision-making for these three different types of patients, and why?

Patient and parental guidance
- What kind of treatment guidelines/guidance does the patient receive in different phases?
- How are treatment guidelines and scoliosis braces given and communicated to the patients and their parents?
- What are the current challenges with the patient guidelines/guidance from the perspective of different types of patients and clinical experts?
- What are today's challenges in communication?

Technological solutions
- What technology and other solutions are used nowadays, and how is the treatment provided in practice?
- What kind of technological possibilities do the experts meet in the different phases and at different patient groups?

Challenges and needs
- What challenges and needs do different types of patients face in different phases of the patient journey? Why?

2. **Future Solutions workshop (participants: experts, researchers, companies, user representatives from the Norwegian Spine and Back Pain Organization "Ryggforenningen I Norge")**

Use of technology in the treatment process/treatment journey

- What technology and solution components can be used to support different patient groups and at different phases of their journey? Why?

Motivation

- What technology and solution components and content will motivate different types of patients and their parents based on the experience of expert teams? (Show some prototype generated ideas based on previous discussions, go through real-life examples)
- What type of technology use will improve the experience of the different types of patients? How?
- What types of patients will benefit most from the use of technology, and why?

Technological touch points, content options, changes, and optimization

- What are technological touchpoints and content?
- How would the use of technology change the treatment practice?
- What can be optimized due to the use of technology?

Use of data

- What data can be used in decision-making?
- How can the data be used in decision-making processes in different phases?

Communication

- What kind of benefits can technology bring to communication between experts?
- What advantages can technology bring to communication between patients, their parents, and experts?
- What kind of advantages and disadvantages would it bring (e.g. cost advantages, etc.)?

3. **Patients' and parents' workshops (participants: experts, researchers, companies, user representatives from the Norwegian Spine and Back Pain Organization "Ryggforenningen I Norge", 3-5 parents/teenagers with scoliosis diagnosis)**

Process / Treatment journey

- You have now been through the scoliosis treatment.
- What stand out for you as major events in this process in your experience? What happened in different phases?
- Can you reflect on these events, why do they stand out to you?

Treatment experience and motivation

- How would you describe your experience of the various phases of the treatment?
- What do you remember as the most demanding situations or pain points in each of these phases?
- How motivated were you to do the treatment? And what motivated you to do it?

Changes

- What would you describe as the biggest difference in your daily routine during treatment?
- How did the hospital's requirements for scoliosis treatment affect your daily routines?
- How did you feel about this?
- What kind of motivational challenges did you face, and why? Is there any way that these could have been overcome with some changes, e.g. better scoliosis, apps, games, etc,

Guidance from the hospital

- How did you get information about scoliosis and treatment in different phases?
- How did you get the treatment guidance in different phases?
- Who did you communicate with about the tasks and what were the challenges in that communication?

Potential for future digital solutions

- Do you use apps daily? Which ones? Do you play games? Which ones? Which games do you find most engaging? How long did you play them? If the exercise was part of the game, what would the game be about?
- What do you think about these possible features: instructional videos, interactive training, messaging

with the therapist, diary, calendar, and anonymous meetings with other users online? Why?
- (After the prototype demonstration) What do you think of this proposed solution? What would you change? What would you add or remove?

Influence at home

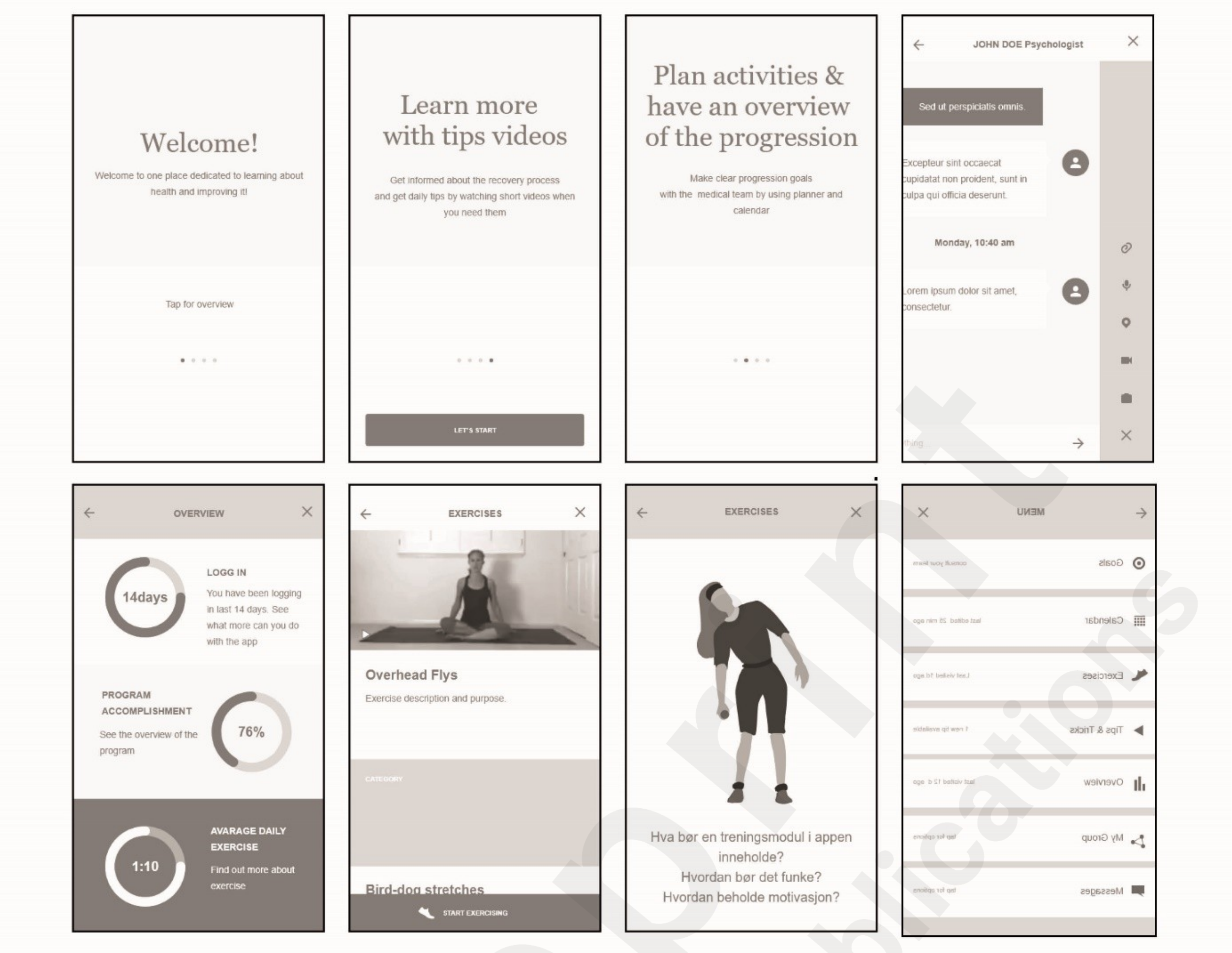
- How would you describe your relationship with your parents, school, friends etc? Does the scoliosis have any influence on these?
- Is there any way that these people could be better involved in the process, how to involve them to motivate you?

4. **Feedback workshop (participants: experts, researchers, companies, user representatives from the Norwegian Spine and Back Pain Organization "Ryggforenningen I Norge", 3-5 parents/teenagers with scoliosis diagnosis)**
    - How can the prototype help patients and parents in the different stages of scoliosis treatment?
    - What works? What doesn't work and why?
    - What makes you feel motivated to use it and why?
    - Do you have any ideas to improve the prototype, so it becomes better, is flexible and motivating to use in a long term?

5. **Vision workshop (participants: experts, researchers, companies, user representatives from the Norwegian Spine and Back Pain Organization "Ryggforenningen I Norge")**
    - What possibilities are there for scoliosis solutions in the future?
    - What is the expected added value it provides?
    - How does this differ from existing solutions/possibilities?
    - What are the funding opportunities for the main project?
    - How can be this scaled up and how to achieve it in practice?

Appendix 3

The first version of prototype presented to the participants at the workshop number 4.



Welcome to one place dedicated to learning about health and improving it!

Get informed about the recovery process and get daily tips by watching short videos when you need them

Make clear progression goals with the medical team by using planner and calendar

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You have been logging in last 14 days. See what more can you do with the app

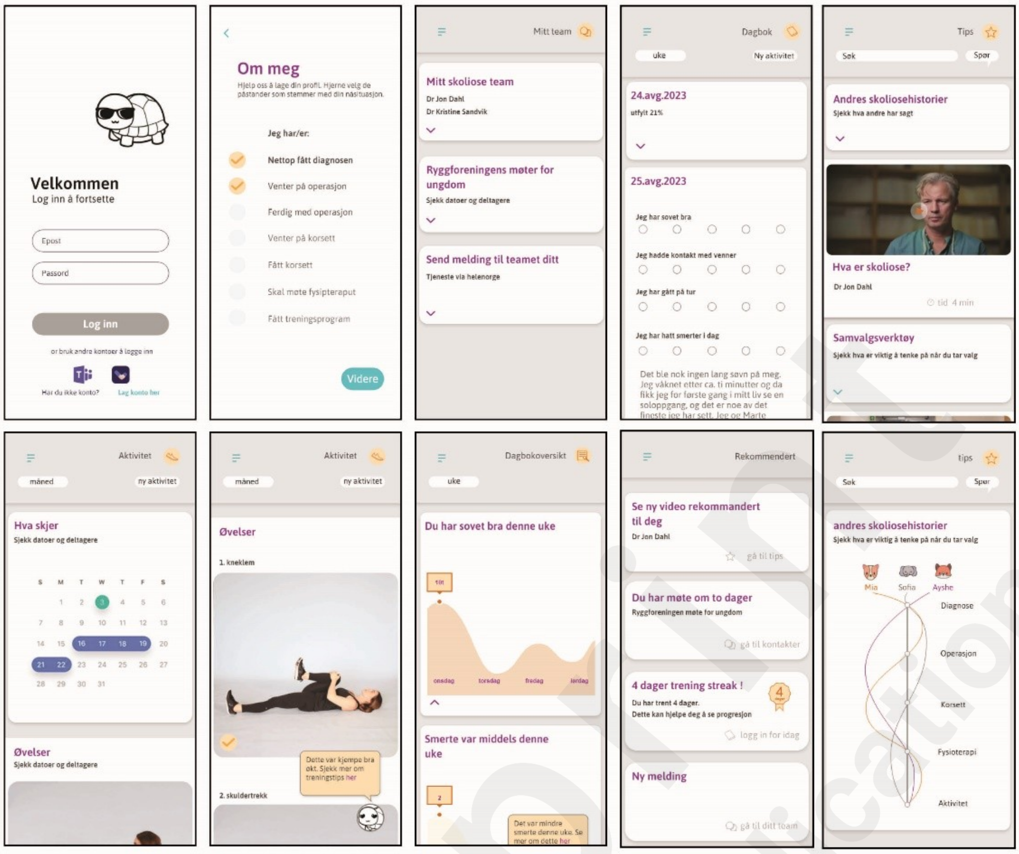
See the overview of the program

Find out more about exercise

Exercise description and purpose.

Hva bør en treningsmodul i appen inneholde?
Hvordan bør det funke?
Hvordan beholde motivasjon?

Appendix 4
Version of prototype presented at workshop number 5. The prototype was edited based on the feedback received from previous workshop.



Det ble nok ingen lang søvn på meg. Jeg våknet etter ca. ti minutter og da fikk jeg for første gang i mitt liv se en soloppgang, og det er noe av det fineste jeg har sett. Jeg og Marte

Supplementary Files

Figures

Themes and subthemes that emerged from data analysis.