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Using a Participatory Action Research design to develop an application together with young adults with Spina Bifida

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Abstract

Introduction: Young adults with spina bifida often have cognitive difficulties. As a result, young adults with disabilities are facing challenges with respect to housing, education, relationships and vocation which increases risk of unemployment

Aim: The aim is to describe a method to develop a smartphone application together with young adults with spina bifida as an assistive technology for cognition.
Method: In a Participatory Action Research approach, young adults (n = 5) with spina bifida were individually interviewed with Canadian Occupational Performance Measure (COPM). The participants´ restrictions in everyday life activities, identified by COPM, were discussed in a focus group formed by the young adults and the result was analyzed using qualitative content analysis. Developing the application the principles of Human-Centered-Design and Universal Design was followed.
Result: An application made for iOS with a focus on usability and worthiness, done by creating a clear and intuitive interface, with a calendar function useful for example to initiate and plan social activities was developed.
Conclusion: The method seems useful when the outcome from the project, a beta version of an application for iOS Smartphone, was achieved in agreement with the participants. The study highlight the importance of involving individuals with disabilities when developing smartphone applications.

Keywords. Assistive technology for cognition, COPM, spina bifida, Universal design

1. Introduction

The diagnosis spina bifida can result in a variety of problems, amongst them incontinence, restrictions of mobility and cognitive functioning, particularly regarding executive ability and working memory (1, 2). As a result, young adults with disabilities are facing challenges with respect to housing, education, relationships and vocation which increases risk of unemployment (3). Today, participation in education, work and society is largely built on the notion that everyone can initiate, plan and structure their daily activities (ADL). Once a young adult has difficulties e.g. in time orientation (following schedule) they often need support in their daily activities, which affects the rest of the family.

However, previous research shows that new technologies have the potential to facilitate the activities of daily living for people with cognitive difficulties (4-7). Smartphone with applications is one example of useful assistive technology for cognitive impairment. There is a plethora of different applications in the label market to support memory, planning etc., but these device are usually not designed to fit the needs of persons with disabilities e.g. with perceptual and cognitive difficulties in terms of design and function.

An application for smartphones with a variety of features may provide people with cognitive difficulties increased ability to perform their ADL activities, reach their educational goals and thus have greater opportunity to gain access to work. There are few studies, where people with cognitive difficulties are included in the development process of smartphone applications regarding design and functionality (4). The assumption is that an application would be made more useworthiness and functional when people with cognitive difficulties are involved in the process (8). They have experiences and knowledge of needs of support for reducing participation restrictions, which would be useful in the development of an application.

2. Aim

The aim of this on-going study is to describe a method to develop a smartphone application together with young adults with spina bifida as an assistive technology for cognition.

- What brought the individual interview with the instrument COPM to the group discussions?
- In what way did design and function influence the application of the everyday experiences of young adults with spina bifida?

3. Method

A Participatory Action Research approach (9) was used to develop a smartphone application in cooperation with young adults with the diagnosis spina bifida. While developing the application the approach of Human-centered-design was used and principles of Human-Centered-Design and Universal Design were followed.

3.1 Participants

The sample consists of 14 young adults with spina bifida aged 15 to 30 years enrolled in an habilitation centre in Sweden. Written information and a formal invitation to participate in the study was sent out. Five young men with spina bifida, 17 – 27 years of age, agreed to participate. Two of the participants had an additional diagnosis that meant extra regular medical procedures. Three participants lived at home with parents and two in independent living in the vicinity of their parents.

3.2 Procedure and data collection

The study consists of three phases; a pre-phase, a semi-structured individual interview with the Canadian Occupational Performance Measure (COPM) (10) and a focus group (11).

3.2.1. Pre-phase

Because the research team considered it was important to have a paper prototype to discuss in the first focus group session, a literature review in the area was done. In addition, health professionals (n=6) with experiences of young adults with spina bifida obstacles in everyday activities been asked for advice in beneficial functions in the application. The literature review, health professionals' views and the compilation of individual interviews with the participants made it possible to start up the development of the application.

3.2.2. Interview

The instrument Canadian Occupational Performance Measure (COPM) is an outcome measure designed by using a client-centered approach to enable clients to identify, prioritize, and evaluate important issues in order to obtain a description of activity limitations in everyday activities (10). In the individual semi-structured interview, lasted about 60 minutes, the participant been asked about the daily activities they want, need or are expected to do and asked to identify those that are problematic. For each activity area there are two self-report scoring domains of performance and satisfaction. At the end of each interview, the author summed up the problem areas that the participant had brought up and made sure it was correctly understood.

3.2.3. Focus group

Central in the method Participatory Action Research (PAR) is the participants' involvement in the process, both discussions and observation in practical exercises was used to collect data (9). In each session the participants discussed a given topic, led by a discussion leader EA in cooperation with the second author M L-W. The four focus group meetings were spread out from October 2013 to March 2014, and each session lasted for 90 minutes. Interview questions and working materials to each sessions were based on the development process of the application and the discussions in the group at the previous meeting. The technical development of the application has been made by the information technology manager in between the focus groups sessions (see Table 1). A proposal for what functions the application should contain and how it should be designed was prepared in collaboration with the participants and documented during the group sessions.

3.3 Data analysis

Processing and analysis of data has been made in several steps. The individual interviews were analyzed and summarized in order to describe the participants' needs at group level. Subsequently, a compilation based on the COPM-interviews was done and the transcribed data from the focus groups interviews been analyzed by qualitative content analysis (12). The data gathered by the usability testing were analyzed using a qualitative approach. Observation notes what functions worked well and which did not, were linked together with the data from the transcript discussions. This was then interpreted to draw conclusions about the design.

4. RESULT

4.1 Individual interviews

The individual interview with participants showed that they had a good insight and awareness of their difficulties. They related their disabilities to consequences in their everyday activities, consequences based on difficulties to initiate, plan and remember activities and knowing what needed to be prepared for an activity. The result show restriction in participating in both indoor and outdoor activities. For example to remember the scheduled visits to the bathroom, order medical supplies on time, order transportation service, to maintain an overview of the private economy, to take initiative to contact friends and doing leisure activities

4.2 Focus group

Table 1 showed an overview of the whole process where the results from the COPM-interviews were compiled to form the basis for the interview guide, used at the first focus group session. In the first occasion the compilation made by the resulting activity problems in the individual interview was discussed.

The participants had both gain and negative experiences of using technology support. In general, participants had difficulty learning new things and they were all aware that they needed to practice to learn to use new technologies.

The participants found it easier to annotate and confirm the proposed features and design than coming up with new ones. A couple of suggestions for new features were observed during the discussion in the focus group. Participants' comments affected the basic structure for the continued development of design in the application. This meant that the design was based more on gestures than using buttons to interact with the interface press buttons to get it faster to find right functionality in the application and be easier to navigate the phone.

Table 1. Overview of the process in the focus group in the development of the application

Procedure	Activities
Pre-phase	Literature review and a meeting with health professionals (n=6) with long experiences of everyday activity limitations in young adults with spina bifida. Meeting did consists of group discussions regarding what kind of functionality the application should have and paper prototyping. A note was that social interaction and taking initiative came as most suggested functionalities in an application.
Interview	Individual interviews with the participants who had own experiences of participation restrictions at school, work and leisure.
First Focus group meeting	The participants began to get to know each other. A high recognition was recorded when the results from the compilation of the difficulties of everyday activities from COPM was described by the focus group leader. An introduction of the paper prototype application regarding design and functionality was done. First, participants prioritized problem areas independently and then discussed in the group. A key comment was that altered the design completely, from a more standard interface to a gesture driven one. Since both groups had social interaction highly prioritized we added social media to the wish list.
Second meeting	Reflections upon the new gesture driven design and general consensus were positive, with fewer steps to perform different functions, such as edit/create/delete etc. as requested. A continued discussion on preliminary features and design. The participants got help with sub-questions to identify strengths and weaknesses in the application regarding design and functionality. A limitation at this stage of the project was the lack of a real prototype making it hard for the group to visualize the impact of certain design and functionality decisions.
Third meeting	They took turns to practically test the prototype of the application. Participants were active and interaction in the group had increased compared with the previous group sessions. They could now, by them self, create and edit an activity, which for some of the participants had been very difficult, for some it was even the first time they could do so by themselves.
Fourth meeting	Now the first beta version was finished for testing. A notion was that participants remembered how they could create and enable functions, learned from last session. Which is one of their difficulties handling applications like this. Noticed were also while testing, that two of the gestures were similar in their animations which made it difficult to distinguish between these two functionalities.

5. Discussion

The overall aim of the project was to develop an application that would facilitate the performance of everyday activities for young adults with cognitive difficulties. The question was whether PAR was a good method for working with young adults in developing the application and what benefit the individual interviews had for the process.

The method seems useful when the outcome from the project, a beta version of an application for iOS Smartphone, was achieved in agreement with the participants. An application made for iOS with a focus on usability and worthiness, done by creating a clear and intuitive interface, with a calendar function useful for example to initiate and plan social activities. Based on the individual and the focus group interviews a need of an assistive technology (AT) to increase the participants' social activities was highlighted. This is in agreement with findings in two reviews (6, 7) where the result show a potential for AT in areas such as memory, planning and organization but AT to enable participating in social activities is missing.

Smartphones can be used in many contexts to facilitate everyday life (4, 7) but can be complicated to learn to use, especially if the user has cognitive difficulties. The young adults with spina bifida, were well aware of their difficulties and how it affected their daily lives. Based on their experiences a proposal for new features and design functions was developed. Their participation meant that the design was based more on gestures to quickly get into the application and to get more space for easier navigating the screen. These gestures, e.g., pinch, pan and pull, has been converted to create, edit, and maneuver themselves within the application. This provides more benefits than a straightforward interface, buttons for many functions are very abstract, "this is pressed, and something happens there," with gestures, we can let the user interact directly with the interface which gives a clearer link between cause and effect. Some users even have difficulties to manage to hit small buttons, which will not be a big problem in a gesture-driven interface. This highlights the importance that people with disabilities will be included in the design of applications (4).

This is an on-going project and the next step is to let young adults with cognitive difficulties try the usability of the beta version of the application in their everyday activities.

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