Patients as co-designers of the STARR system prototype

Leire Ortiz-Fernández†
Physical Medicine and Rehabilitation
Cruces University Hospital
Barakaldo, Spain
leire.ortizfernandez@osakidetza.eus

Ander Alava-Menica
Physical Medicine and Rehabilitation
Cruces University Hospital
Barakaldo, Spain
juanandres.alavamenica@osakidetza.eus

Jordi Marti-Carrera
Innovation Department
Init Group
Bilbao, Spain
jmarti@theinit.com

Ruben Garcia-Fernández
Innovation Department
Biocruces Health Research Institute
Barakaldo, Spain
ruben.garciafernandez@osakidetza.eus

Janire Orcajo-Lago
Biocruces Health Research Institute
Barakaldo, Spain
janire.orcajolago@osakidetza.eus

Eunate Arana-Arri
Clinical Epidemiology Department
Biocruces Health Research Institute
Barakaldo, Spain
eunate.aranaarri@osakidetza.eus

Javier Escobal-Gonzalo
Innovation Department
Init Group
Bilbao, Spain
jescobal@theinit.com

ABSTRACT

Background: Stroke is the leading cause of severe disability. Modifiable risk factor management is crucial. Effective learning tools to cope with common problems and support active recovery as a standard remain elusive. Health apps are growing and opening opportunities. Listening carefully to patients can help to find gaps that matter. We propose a "Decision SupporT and Self-Management System for StRoke SurvivoRs" (STARR) for self-management and reduction of recurrent stroke.

Objective: To analyse a prototype app on patients' real life incorporating quality criteria in the final pilot acting patients as co-designers.

Methods: Action based study using focus groups. First, detect unmet needs to focus the design on. Next, check the app feasibility with quantitative and qualitative measures. A bioengineer was involved with the patients to offer support with the devices and STARR app. Finally, research on STARR Project is carried out in randomized clinical trial.

Results: Based on 5 patients, detailed technical and non-technical incidences, a list of quality criteria for eHealth app was stablished concerning trust, accessibility, connectivity, safety and functionalities.

Conclusions: Built on design, end users experiences are important in the development of effective eHealth interventions. Stroke patients have specific needs. It is important to create a system matching unmet needs, expectations and technology. Prototype feasibility studies in real world situations are important.

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CCS CONCEPTS

• Life and medical sciences • User characteristics •

KEYWORDS

Stroke survivor, self-management, codesign, prototype, eHealth app

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1 Background

Stroke is the leading cause of severe and long-term disability in developed countries. Around 15 million people suffer from a stroke each year most of them ischemic due to modifiable risk factors [1]. Crucially, secondary stroke prevention is championed as guideline care; as of yet there are no systematic programs offered. Effective and feasible learning tools to teach patients and their family caregivers how to cope with common problems following stroke and/or support active recovery as an international standard of care remains elusive. [2]

However, the category of health-related apps is potentially growing opening opportunities in this field. In 2010, 5820 apps in multiple app stores were focused on health and wellness, in 2013, more than 17000 medical apps existed, most being free to download. [3] Don Berwick suggested that by listening very carefully to patients and families, we could find the gaps that matter. [4]

We propose a "Decision SupporT and Self-MAnagement System for StRoke SurvivoRs" (STARR) which is an integrated self-management solution for people with stroke by bringing together experts in stroke, video analysis, physiological sensor monitoring, lifestyle analysis, data fusion and platform development.

The STARR system will use existing stroke risk predictive models, will develop a modular, affordable, and easy-to-use system to inform stroke survivors about the relation between their daily activities (e.g., medication intake, physical and cognitive exercises, diet, social contacts) and the risk of having a secondary stroke in real time. Self-management does not necessarily mean going alone. Typically, it means providing encouragement and support to a stroke survivor and their family/caregiver to allow them to take the main role in dealing with their chronic condition by making informed decisions about healthcare and by engaging in more healthy behaviours. Therefore, it involves a sharing of expertise between clinician and patient.

If effective, the STARR system will lead to better prevention and a reduction of the number of secondary stroke events, as well as to a more efficient participation of stroke survivors in medical decision-making.

2 Objective

As a multicomponent system, we will analyse the created prototype app from the theoretical studies to the empirical studies on real life with a small sample of patient and caregivers incorporating the end users quality criteria to improve the final pilot study; all this as a proof of concept. Patients and caregivers are co-designers with engineers and health professionals.

3 Material and Methods

We designed an action-based study in different phases using focus groups and individual interviews. The first phase aimed to detect unmet needs in stroke survivors and caregivers. Total of 56 patients were initially recruited. All were subacute and chronic stroke survivors attending rehabilitation outpatient consultations in our Tertiary University Hospital. They suffered mild to severe disability measured by Barthel Index. All were living in the community and able to collaborate with the study. The results helped to focus on the design of the eHealth system.

Once the self-management application was created, we needed to check its feasibility for further development and improvement. 5 chronic stroke survivors suffering from a moderate to severe disability living at home, able to follow the guidelines and devices, without socio-familiar dystocia, were recruited with their caregivers. Disability was measured by Barthel Index while dystocia by Gijon's questionnaire. The follow-up period was 8 days.

The evaluation involved quantitative and qualitative measures, such as the number of incidences and subjective impressions of end users, resulting in a final list of quality criteria.

A bioengineer, specialised in health care, from the hospital visited the patients homes, explained the functioning of the commercial devices orally and with written guidelines developed during the STARR project, showed what, and how, to measure the blood pressure, weight and use of the created eHealth app to add the data and to answer the qualitative measurements (through questionnaires).

Technical support was offered face-to-face and by phone when needed. Access to medical doctor consultations was offered in event of any medical condition or complication.

Commercial devices were a scale, a tensiometer, a mini-bike and a mobile-phone with developed STARR app called VERA which integrated the process of taking these measurements and asked regularly some questions through medical validated questionnaires.

Finally, research into the effectiveness of the STARR Project is carried out by a randomised clinical trial (NCT03580642), which started in February 2019.

4 Results

We recruited 5 participants; unfortunately, patient 4 dropout due to hospital admission. The patients´ characteristics are shown in table.

Table 1. Patient descriptions

Table 1	Genre	Age	Side	Technical aids
Patient 1	F	55	Left hemiparesis	Ankle foot orthosis, cane
Patient 2	F	43	Right hemiparesis	-
Patient 3	M	41	Right hemiparesis	DAFO orthosis cane
Patient 4	M	62	Left hemiparesis	Cane
Patient 5	M	67	Right hemiparesis	Cane in exteriors

4.1 Incidences

Technical and non-technical problems were observed. All patients required assistance from the technician almost every day. Luckily, they felt comfortable asking for help when necessary showing great

involvement and interest in the program. There were no medical complications. Table 2 shows the different technical issues observed in every patient each day.

Table 2. Technical incidences

Day	Technical incidences	Description of the problem
1	Patient 5	In low battery conditions, the VERA app was not working
1	Patient 1	Program login issues
5	Patient 1	Program login issues
5	Patient 5	Program login issues
5	Patient 2	Faulty tensiometer. Scale lost connectivity.
6	Patient 3	In low battery conditions, the VERA app was not working
6	Patient 3	There's no internet coverage in the bathroom. He thought the data was not registered. Once connection was re-established, all the measurements were automatically sent.

4.2 Quality criteria

Based on the detailed incidences, a list of quality criteria for eHealth application was established. These quality criteria concern trust, accessibility, connectivity, safety and functionalities of VERA app as following:

4.2.1. Trust: When visiting patients at their home because of the technical support help, we realised that it was very important to incorporate a health professional as eHealth technician. To allow the health professional come into their homes gives them more confidence, since they perceived that non-health care professional could misuse their personal data or try to make economical profit from them.

4.2.2. Accessibility: The created app should be easy to log in to, have simple access requirements. The experience should be completed and integrated with both the app and devices. For example, the app should explain how to use the devices instead of having a separate user manual for each device.

Patients and caregivers need a visually clear guide of the steps to be followed.

The contact details of the technician and doctor should be clear and easy to find.

The chosen commercial devices should be easy to use and user friendly, mainly to avoid errors, for example plugging devices to the electric outlet, or reading the automatic measurements. They should be all in the same room to enable the patient to remember their use and also in the order of use.

4.2.3. Connectivity: The remote TeamViewer program is recommended in order to have the opportunity to solve technical problems without visiting patients' homes. It is less time consuming, cheaper and allows patients and caregivers to continue their everyday life without inconveniences.

The mobile phone should be always plugged in to the socket at night or rest time to avoid low battery operations.

4.2.4. Safety: The scale is not safe for same patients with hemiplegia; they must have a handle on the wall to avoid falls.

4.2.5. Functionality: They preferred outdoors activities (walking) compared to mini-bike as aerobic physical activity.

However, they appreciated having a tool (mini-bike) as an alternative in bad weather, even if they did not feel very comfortable on it.

It is relevant for the patient and the corresponding caregivers to obtain a feedback from the eHealth app about the data that are being registered (blood pressure, weight and exercise). To understand the results and visualise their evolution makes them more aware of their lifestyle and the necessity, or not, of changing their daily habits and customs. In summary, it allows them to have greater knowledge and control of their health status and gives them more self-stem. Feedback should be different every time and very natural, replicating the experience of going to a doctor's consultation. The sense of the application's utility is important to increase its perceived quality.

5 Discussion

The study results provide insight into the quality criteria needed to design, build and implement an eHealth application targeting personalised needs of chronic stroke survivors. [5]

To date the number of papers about user centred experience design are increasing[6 7 8 9], but some years ago, the health solution was developed and launched to the end user without considering their needs. Given the number of stroke survivors, it is important that this group be considered implicitly in the universal design. [5] In the design thinking, patients and staff as co-designer of health services are crucial to avoid failures when aligning healthcare needs with software requirements. [6, 7]

The STARR system aims to support self-management of stroke risk factors of patients who are able to self-manage, sometimes with some additional support, and who live at their own home. If effective, the results of this project will enable stroke patients and their caregivers to better deal with the everyday life obstacles of stroke, improve the adherence of the treatment, improve the control of cardiovascular risk control and, in consequence, reduce the risk of recurrence of secondary strokes, reduce the number of complications, reduce the number of consultations and re-admissions so that reduce the health systems costs. It also can help to make the patient responsible and aware of their treatment, which has been reported to be determinant in self-management behaviours. [10 11] However, it is important to develop the application's design based on the user experiences to enhance its adherence and to focus on the unsatisfied needs of this group of patients, the stroke survivors.

Evaluation of prototypes can help to assess functionality, perceived utility, and usability and to refine and improve the final product according to end user needs. Capturing patients' experiences by prototype testing reveals gaps, tips, and ideas to implement the final product.

6 Conclusions

End users experienced design is important in the development of effective eHealth interventions. Stroke patients have specific health care, physical and socio-familiar needs. In such circumstances, technologic needs and previous experiences are also very different, it is important to create a system for stroke survivors, able to adapt to their unsatisfied needs and expectations.
Pre-pilot or prototype feasibility studies are equally important to highlight the needs in real situations and to refine the prototype.
Quality criteria concerns trust, accessibility, connectivity, safety and functionalities

7 Limitations

The main limitations of the study were the number of participants, even though they were very motivated which was helpful, and the short study follow-up of only 8 days. However, a bigger sample size would be recommended, which would take into account a wider variety of complex care needs, literacy, age range and ethnicities. These aspects have been integrated in the randomised clinical trial, and results will be published in future papers.

8 Disclosure

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