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Engaging Stakeholders in the Design and Usability Evaluation of a Decision Aid to Improve Secondary Stroke Prevention

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Abstract. Stroke survivors have a nearly 40% risk of recurrent stroke during the first 10 years. Effective secondary stroke prevention strategies are sub-optimally used, and hence, developing interventions to enable healthcare professionals and stroke survivors to manage risk factors more effectively are required. In this paper we describe the usability evaluation of a decision aid designed in collaboration with stakeholders to reduce the risk of a recurrent stroke. The decision aid was found usable and acceptable by both general practitioners and stroke survivors. Concerns and suggestions for improving the decision aid are discussed.

Keywords. Stroke, decision aid, decision support system, usability testing, learning health system

1. Introduction

In 2015, there were 3.7 million people living with stroke as a chronic condition in Europe and this number is expected to reach 4.6 million in 2035 [1]. Stroke survivors have a nearly 40% cumulative risk of recurrence within 10 years [2]. Risk factors associated with recurrent stroke can be reduced by patients changing lifestyle behaviours (e.g., smoking, obesity) and adhering to preventative medications (e.g., blood pressure). However, these risk factors are currently not well managed or controlled post stroke. Physician adherence to treatment guidelines is sub-optimal and compliance among patients is low [3]. Interventions designed to improve risk factor management among stroke survivors have shown modest or no effect. Possible reasons for this limited success is that these interventions were not integrated into the clinical decision making process of practitioners.

In collaboration with a range of stakeholders [4], we designed and developed DOTT, a decision aid software tool intended for use in primary care during the clinical consultation between the healthcare professional (HCP) and stroke survivor. The decision aid is based on a learning health system (LHS) approach, and uses knowledge generated from routinely collected data, by integrating with the HCP's electronic health records (EHR) system, to improve clinical outcomes. The rules in DOTT are generated from linked primary care datasets including the South London Stroke Register (SLSR) [5] and Lambeth Datanet [6]. The tool enables the stroke survivor to indicate their

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perceived risk of having a recurrent stroke and calculates their predicted stroke risk. Based on the stroke survivor's characteristics, the system will suggest the most effective evidence-based treatments to reduce the risk of stroke recurrence (e.g., take anticoagulants, stop smoking), enabling the HCP and stroke survivor to jointly decide on treatments that best suit the stroke survivor's preferences.

The aim of this paper is to describe the formative usability evaluation of the decision aid with stroke survivors and general practitioners (GPs) in order to understand whether they find it usable and acceptable and what are their concerns and suggestions for improving the tool.

2. Methods

2.1. Participants

Ten participants, 5 stroke patients and 5 GPs, participated in usability testing. Patients were recruited from the SLSR dataset and GPs were recruited from South London practices. Testing with five users provides maximum benefit-cost ratio and identifies the majority of the usability problems [7].

2.2. The decision aid

For the usability evaluation, the decision aid had the following functionality and flow:

- Patients indicated their perceived risk of having a recurrent stroke.
- GPs entered the patient's characteristics (age, gender, clinical conditions).
- The system displayed a typical recurrent stroke risk (average according to age) and the most effective treatments based on the patient's characteristics.
- The benefit of each treatment in terms of reducing the stroke risk was displayed. Estimated benefits were calculated based on existing literature.
- Information and common concerns for each treatment were displayed.
- The GP and patient would decide on a management plan whilst identifying desired clinical and patient outcomes.
- Patients were told that their management plan would be printed to take home.

2.3. Usability sessions

The usability sessions were simulated consultations using the DOTT decision aid tool. GPs were given a short tutorial on how to use the decision aid before the simulated consultations and patients were given a short explanation about the decision aid. GPs and patients were interviewed after the simulated consultation and answered an acceptability questionnaire [8] and the System Usability Scale [9]. Ratings were provided on 5-point Likert scales from 1 (strongly disagree) to 5 (strongly agree), with higher ratings indicating higher satisfaction. A thematic analysis approach was used to identify themes [10] related to the usability and acceptability of the decision aid, concerns and

suggestions for improving the tool.

3. Results

3.1. Demographics

Five GPs participated in the usability testing (3 males). Average years of experience as a GP was 12.6. All GPs had experience consulting stroke patients. GPs had medium to high confidence in using new technology and low to medium experience using decision support tools. Five stroke patients participated in the usability testing (3 males), average age was 64.6 years. All were diagnosed with hypertension. One had heart problems, one was suffering from depression, two had minor mobility issues. Three of the participants had minor cognitive deficiencies (attention and memory).

3.2. Usability and acceptability

Both GPs and patients found the decision aid usable and acceptable. GPs found the decision aid easy to use (score 4.2), easy to understand (4) and felt very confident using it (4.2). They thought that this decision aid is better than how they usually help patients decide about treatments for controlling their risk factors (4.4), that this strategy is compatible with the way they think things should be done (4.2), that this type of decision aid is suitable for helping patients make informed choices (4) and that the decision aid complements their usual approach (4.4). Stroke patients would like to use the decision aid frequently (4), thought that it was easy to use (4.2) and felt confident using it (4). Utilising thematic analysis for the interview transcripts, we identified 5 main themes relating to the usability and acceptability of the decision aid.

3.2.1. Logical and structured process that facilitates discussion

GPs and stroke patients (n=10) found the decision aid to be clear, consisting a logical flow that structures the consultation. They felt that the decision aid facilitates discussion on the different proposed treatments and elicits patients' preferences.

"GP pointing out what to do but the patient makes the decision since it's hard to get your head around everything. More doable if you have specific areas to work on with specific targets that suits you" [P2]

3.2.2. Powerful risk display showing the benefit of each treatment

GPs and stroke patients (n=9) found the risk display easy to understand and powerful.

"The most powerful thing is the visual shifting of risk" [GP5]

3.2.3. The patient takes home printed information

GPs and patients (n=4) thought that it is very important that the patient has the management plan and all the information printed so they can review it at home.

"The important thing is that the patient goes out with a piece of paper that summarises in bullet points the outcome of the consultation. If its black and white on paper it makes a difference" [P3]

3.2.4. Importance of a learning system

GPs (n=2) raised the importance of a learning system providing up-to-date information.

"The learning aspect is very important, since this system is based on evidence and evidence can change" [GP3]

3.2.5. Can motivate patients to change behaviour

All GPs and patients (n=10) believed that the decision aid could motivate patients to change behavior. Patients were asked this question and gave an average score of 4.4.

"I believe discussing the different options with the patients, shared decision making, is likely to improve adherence" [GP1].

3.3. Concerns

GPs and stroke patients raised two main concerns from using the decision aid.

3.3.1. Deals with one aspect of the consultation

GPs and patients (n=5) felt that the decision aid is good but focuses on one aspect of the consultation (reducing risk) and patients may have other concerns.

"This is good, but for me the most important thing is the emotional aspect, and this tool doesn't relate to that" [P4]

3.3.2. Time

The main concern for GPs was time (n=3), claiming they have only 10 minutes for the consultation, and they will not manage to fit it in.

3.4. Suggestions for improvement

GPs and stroke patients provided suggestions for improving the decision aid:

1. Cumulative risk should be added, the system should show reduction of the stroke risk for more than one treatment.
2. The terminology is too clinical, for example "treatments" and "management", could be changed to "possible strategies or approaches".
3. In addition to the management plan, information (a leaflet) on each of the selected treatments should also be printed.
4. Add clinical data, for example when clicking on "cholesterol" show the patient's last three values, same for blood pressure.
5. Enable more than one display of risk, each one prefers a different display and understands risk differently.
6. Add the emotional/mental aspect (e.g., depression)

4. Discussion

Stroke survivors and GPs found the decision aid to be both useful and usable. GPs felt that the decision aid helped with structuring the consultation and eliciting patients' preferences for treatments. Stroke survivors felt it provides a good way to understand the different treatment options and select the ones that best suits their preferences. There were also concerns. GPs main concern was that the decision aid would increase consultation times, indeed time constraints were identified as the main barrier for the adoption of innovations by GPs [11,12]. A possible solution could be to use the decision aid as part of a clinical review after stroke, which is usually longer (e.g., 3 month, 6 month and annual review). Another important concern, particularly for patients, was that the decision aid covers only one aspect of stroke survivors' needs (secondary prevention), and that they may have other concerns they wish to discuss with the GP. In this study the emotional aspect (such as depression) was raised as a concern and was suggested to be added to the decision aid. Depression is indeed a risk factor of stroke [13], and we will consider adding it to the decision aid. Improvements suggested by users will be incorporated into the updated version of the decision aid.

5. Conclusion

The decision aid was found useful and usable and has the potential to improve secondary stroke prevention by patients understanding their risk and taking ownership for the treatment decisions, improving their adherence to the agreed management plan and reducing their risk of a recurrent stroke. We identified some concerns that could be barriers to adopting the decision aid and should be addressed in the updated version.

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