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Original Research

Development of my medication plan involving patients and patient representatives as co-designers

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Abstract

Background: Patient safety is at risk during the transition of care, and a lack of information about medications at hospital discharge could be a contributing factor. To be adherent, many patients request more information about their medication treatment. **Objective:** My Medication Plan aims to involve patients and patient representatives as co-designers in developing a tool to meet these information needs. **Methods:** A framework for the Designing Thinking model involving patients and patient representatives was applied. During the inspiration phase, patients' needs were explored by observing discharge conversations between patients and hospital physicians, followed by an information conversation between the patient and the first author (MS). Patient representatives were invited to participate in the ideation phase to generate ideas and designs for My Medication Plan. **Results:** Twelve patients and three patient representatives were included in the inspiration- and ideation phases. Among the patients, the most frequent themes during the discharge conversations were medication and medication changes. Least frequent theme was disease prevention. The patient representatives discussed the importance of My Medication Plan being a non-electronic tool with additional pages to document non-prescription medications and boxes for free text. Furthermore, a glossary over medical terms was added in My Medication Plan for explanation. To ensure patient safety the already existing Shared Medication Record given to patient was combined with My Medication Plan. **Conclusion:** My Medication Plan was developed as a non-electronic tool consisting of a print of the Shared Medication Record and specific documents sharing important medication-related information. Patients and patients' representatives becoming co-designers are innovative, as the inclusion of both patients and patients' representatives is innovative as both groups present different perspectives.

Keywords: Medication Plan; Patient safety; Adherent; A non-electronic tool, Medication Record

INTRODUCTION

Patient safety is at risk during the transition of care[1,2]. A contributing factor is the lack of information about medications at hospital discharge, possibly resulting in unintentional non-adherence to medication treatment or adverse drug events such as falls[2,6]. Many patients need more information about their medication treatment to be adherent[2,7,11]. Patient safety is at risk when patients can't recall the provided medication information or if the information is not conveyed to the patient in an understandable manner[9].

Ensuring medication safety includes effective communication and patient empowerment at hospital discharge[11,13]. However, patients report not being sufficiently empowered to manage medications or communicate relevant information to their general practitioner[14,15]. The need for more explicit information at hospital discharge could be accommodated by including medication information in the discharge summary[2,16,17]. Alternatively, patients preferred to have a combination of verbal- and written instructions about medication information, such as patient booklets and arrangements for follow-up after discharge, could be applied[9,10]. Tools to improve communication have been developed with a focus on medication treatment at discharge[2,10,18], and these increase patients' satisfaction[19,20], capacity for recall [19,21], and compliance with the medication[19,21].

In Denmark, physicians across sectors prescribe medication electronically in the patient's personal Shared Medication Record (SMR)[22]. The SMR contains information about the patient's medication purchases from the community pharmacy[22]. Unfortunately, no information about the patient's medication during hospitalization is available in the SMR. Despite good intentions to ensure that SMR reflects the patient's actual medication treatment, 75-81% discrepancies have been detected between the patient's actual use of medication and their SMR[23,25]. The most common discrepancies are prescriptions not used and incorrect dosing frequency[24,25]. More patient and carer involvement is needed to ensure that the provision of medication information results in the correct medication regimen.

Previous studies have highlighted the successful involvement of patients as co-designers of patient tools [2,26–28] . The Design Thinking Framework focuses on creating human-centered products, services, or solutions by involving the end-users [29]. This framework is an iterative process with the inspiration,

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ideation, and implementation phases (the three I's) forming the basis for data generation and design[28]. End-users actively contribute in the stage involving prototypes [2,26,28]. Therefore, this study aims to develop the patient tool My Medication Plan by involving patients and patient representatives as co-designers in the inspiration and ideation phase.

METHODS

The study design

The Design Thinking Framework was inspired by Hahn-Goldberg et al. to involve patients and patient representatives as co-designers in developing My Medication Plan[28]. The patients' needs were investigated in the inspiration phase, and the preferred approach, as described by the model, was to observe rather than utilize surveys or focus groups [28]. The first author, a clinical pharmacist and a PhD student, observed the patients during the discharge conversation with the physician, followed by an informal conversation with the first author. Patient representatives were invited to participate in the ideation phase with two group sessions to generate ideas and designs for My Medication Plan[28].

This study is reported using the standards for consolidated criteria for reporting qualitative research[30]. The checklist and authors preunderstanding is available in Appendix A.

Patients and Setting

Purposive sampling included patients from the Internal Medicine Ward specializing in Renal Diseases from Hospital Sønderjylland, Sønderborg, Denmark from 27 March 2023 until 17 May 2023[31]. The patients were eligible for inclusion if they had five or more medications listed in their SMR before hospital admission, were expected to be discharged on the respective day, and could converse about medication information needs.

Patients were not eligible if they were unable to communicate in Danish or were cognitively impaired, e.g. suffering from dementia or Alzheimer's.

All patient representatives (two males and two females) affiliated with Hospital Sønderjylland were invited by e-mail to participate in the ideation phase. The patient representatives are involved as board members in projects. Three representatives accepted and participated in the group sessions. These sessions were conducted in June and July 2023.

Each patient and patient representative provided written informed consent.

Inspiration Phase – Observations and Informal Conversations

The inspiration phase aimed to explore (1) which medication information was presented to the patients during the discharge and (2) the medication information the patient needed.

Observations

The first author performed qualitative observations of the communication between the physician and patient during discharge to substantiate the type and extent of information the patient was given[32]. Field notes were written by the first author immediately afterwards, and then a more comprehensive text was written dependent upon memory recall and these field notes. The discharge conversations were not audio-recorded, as the information given verbatim was not necessary to develop My Medication Plan.

Information of interest during the observation of discharge communication were:

- Information communicated about the medication
- Provision of any written information material
- Whether the patient recorded any information
- Presence of the patient's relative
- Time taken for the discharge conversation between the patient and the physician

Informal Conversations

The first author performed informal conversations with patients to explore which medical information was considered relevant for the patient during the discharge conversation. Informal conversations are described as a type of interview without any given structure[32,33]. No interview guide or audio recording was performed, and the conversations occurred if an opportunity arose[33]. The informal conversations were conducted immediately after the discharge communication with the physician.

The questions of interest during the discharge conversations included:

- When you receive a new medication list, how do you use it?
- Why did you choose to receive a new medicine list in print?
- Whom do you contact if you have questions about your medication?
- What is the information regarding your medication that is important to you?
- Is there a difference in what information you would like to have now compared to before your hospital admission?

The first author wrote field notes during the informal conversations, and a comprehensive text was written down by recall of memory and field notes immediately after the end of the informal conversation.

Analysis – Observations and Informal Conversations

The observations and informal conversations were to improve understanding of the information given or needed in order to create and design My Medication Plan. The thematic analysis was based on the comprehensive texts written after the observations and informal conversations.

The reflexive thematic analysis described by Braun and Clarke was used for the analysis[34]. In brief, the reflexive thematic analysis consists of six phases: 1. Familiarizing yourself with the data, 2. Generating initial codes, 3. Searching for themes,

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4. Reviewing themes, 5. Defining and naming themes, and 6. Producing the report[34]. Data were analyzed to form codes and themes related to the presented and needed medication information. The thematic analysis was initiated after the first patient to capture any information gaps and was an iterative process. The software program NVivo version 1.7.1 was applied to the analysis. MS conducted the analysis, which was discussed with TG.

Ideation Phase with Patient Representatives

Three patient representatives were involved during the ideation-generating sessions. MS and LJK were present at the sessions, which MS facilitated, and they presented the reasons for the study. Brainstorming was applied as the idea-generating technique[35]. Brainstorming was chosen because it is easy to apply and an effective way of generating ideas relatively quickly[35]. Alex Osborn's four rules were presented initially and adhered to during the two sessions[36]. In short, the rules applied were: 1. Criticism was ruled out, 2. Freewheeling was welcome, 3. Quantity was wanted, and 4. Combinations and improvements were sought[36]. These rules aimed to create a psychological safe space to welcome all ideas.

The patient representatives argued their standpoints in cases of disagreement. The patient representatives were allowed to discuss and disagree. However, the authors made the final decision considering the overall purpose, feasibility, and technical production of My Medication Plan.

First Session – Creating My Medication Plan

During the first session, patient representatives were asked, "How can we create a useful booklet for patients to take control of their medication?" The overall findings from observations and informal conversations were presented to initiate the brainstorming process. At the request of the first author, a patient representative drew a picture of the discussion during the brainstorming. Field notes were written during the session.

Second Session – Designing My Medication Plan

The basis for discussions during the second session were five prototypes of My Medication Plan designed by the first author and the existing SMR. Participants were asked, "How can we design a useful booklet for patients to take control of their medication?" The patient representatives discussed the prototypes' advantages, disadvantages, and possibilities for improvements. Field notes were written during the session.

Analysis – Developing the Final Version of My Medication Plan

The first author designed a draft of the final prototype of My Medication Plan. In collaboration with the authors, the Graphical Center at the University of Southern Denmark created the final design and layout of My Medication Plan.

Ethics

According to Danish regulations, qualitative studies do not need ethical approval from the ethics committee[37]. Management from the Department of Internal Medicine, Endocrinology and Nephrology Unit approved the study. The study was registered at The Region's Internal Directory, Journal number: 23/16077. All participants gave written content according to the Declaration of Helsinki[38]. The participants consented to publishing data anonymously. We confirm all patient identifiers have been removed or disguised so the patient described are not identifiable and cannot be identified through the details of the results.

RESULTS

Participants

There were 12 individuals included during the inspiration phase (5 female and 7 males) and three patient representatives were included for the both sessions of the ideation phase (2 males and 1 female).

Results of the Inspiration Phase

Twelve patients participated in the observations. Fourteen conversations during the discharge were observed between the patient and physician. Ten of these 14 conversations were actual discharge conversations with an average time of 15 minutes. Two patients were observed over several days because their discharges were delayed. The physician performed one as a desktop discharge (PT2), and one discharge conversation was not performed due to miscommunication (PT3) (Figure 1).

The 11 informal conversations lasted, on average, 15 minutes. Due to the timing of discharge, it was not possible to have an informal conversation with one of the patients.

The most frequent theme of the conversations between patient and physician was medication and medication changes (all patients) (Figure 2). Examples included whether the medication or dosage had been changed. The most infrequent theme was Disease prevention and self-care or the function of the medication list (4 patients).

Only one patient (PT8) had a relative present at the discharge conversation. Although none of the patients made records during the discharge conversation, the relative did take notes. The nurses handed all patients a hard copy of their SMR before discharge and enough medication for treatment over the subsequent 24 hours. Patients were expected to present at a community pharmacy after 24 hours to fill the necessary prescriptions.

Results of the Ideation Phase with Patient Representatives

Ideation Phase – First Session - Content and Creation of My Medication Plan

The most predominant and recurring discussion was about substitution. Based on experiences with substitution, patient representatives emphasized concerns about patient safety (purple boxes, Figure 3). When medications are substituted for a cheaper alternative, they contain the same active ingredients, but the product can change its appearance or name. This practice can confuse patients and raise concerns about whether the medications is correct. This confusion can compromise patient safety due to potential medication duplication or

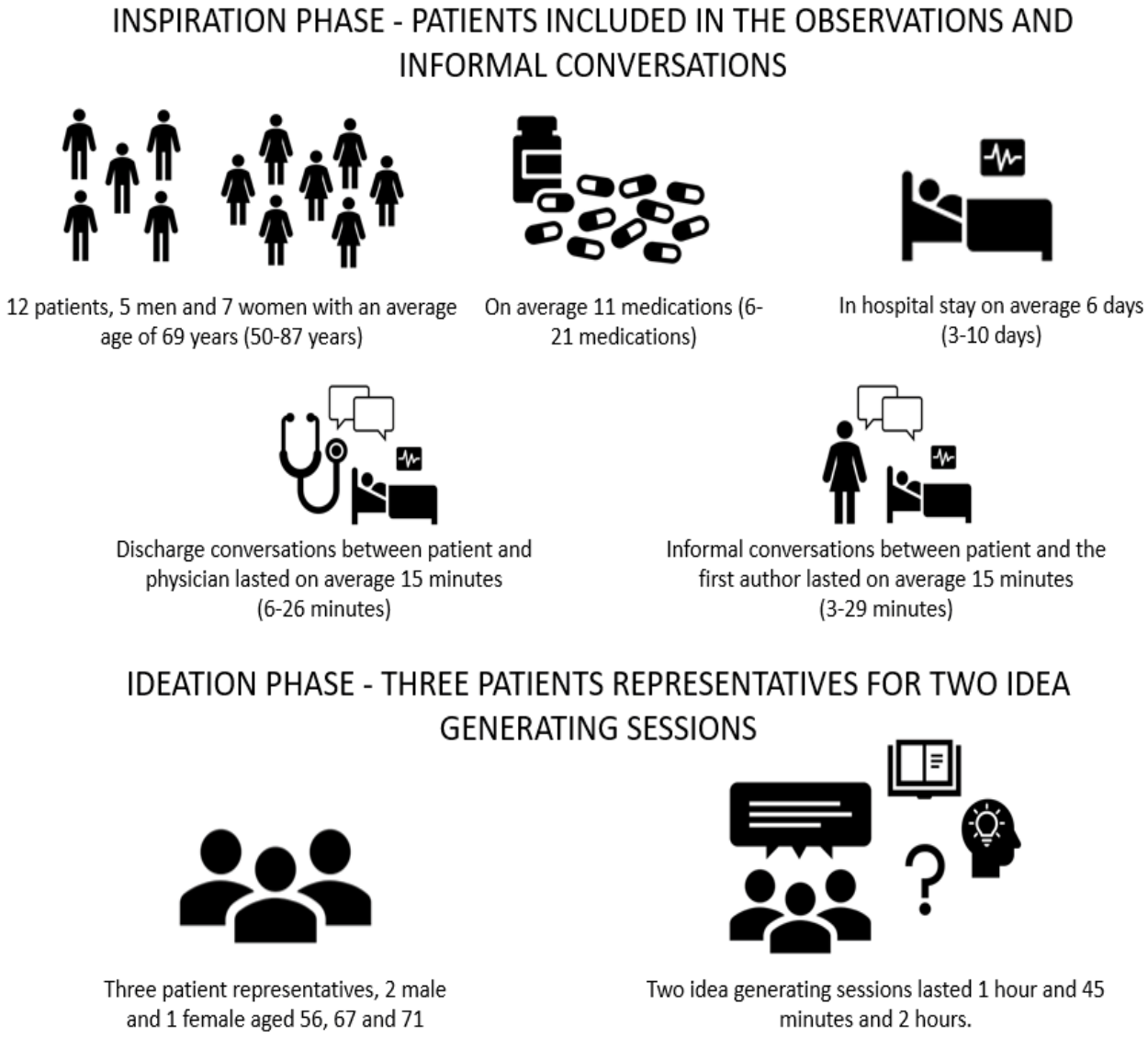

Figure 1. The demographics of the patients and patients representatives

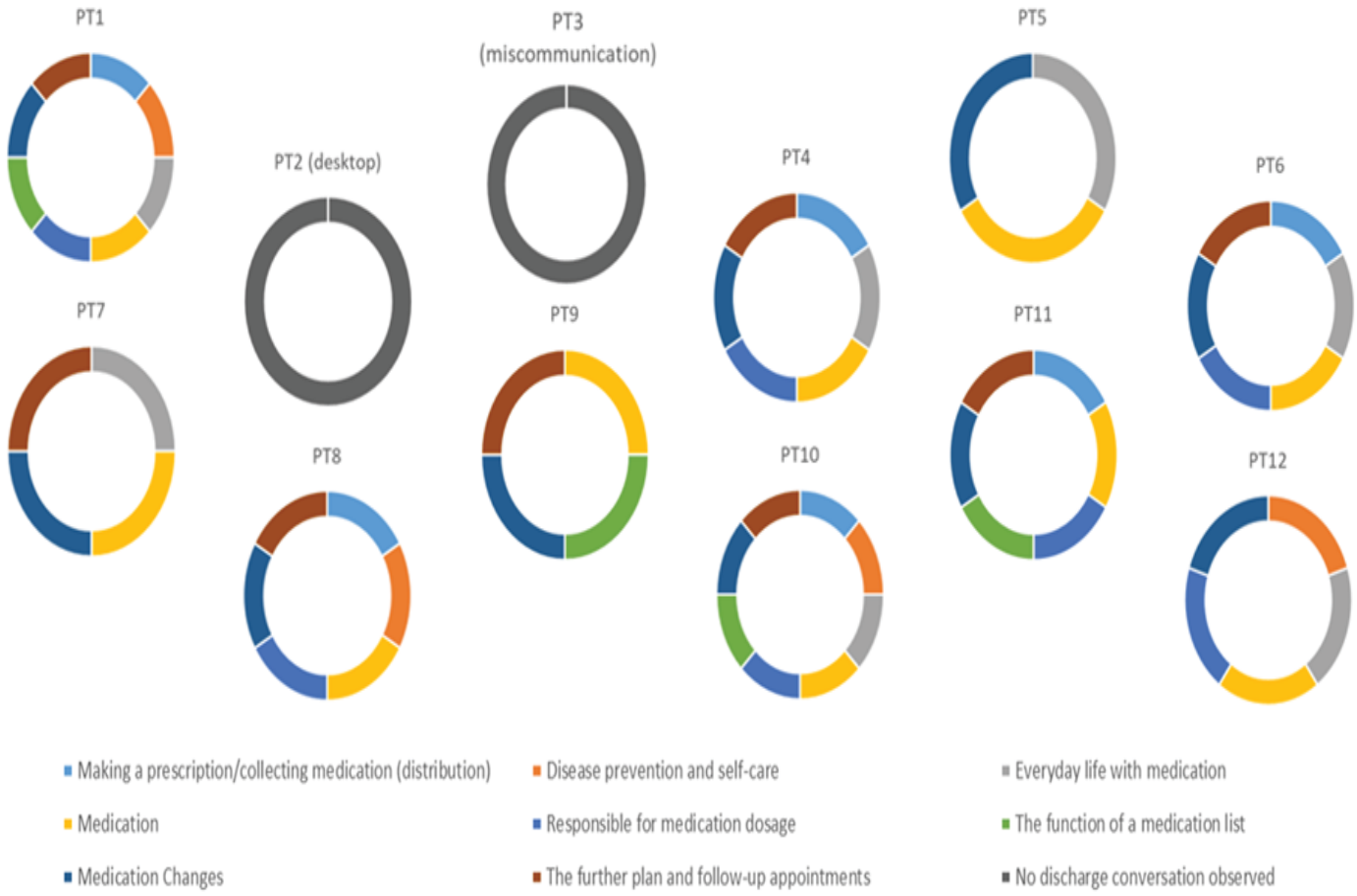

Figure 2. Themes occurring during the observations of the patient discharge conversations. Every ring represents a patient (PT1-PT12), and the colors represent the themes that occurred during the observations and discharge conversation. PT2 and PT3 did not have an observed discharge conversation.

Figure 3. Occurring during the first ideation session focused on: needs for specific instructions about medication application (blue boxes), questions about over-the-counter medicines, dietary supplements and herbal remedies (red boxes), queries about follow-up healthcare appointments (green boxes), concern about patient safety and substitution with generic medication (purple boxes) and patient empowerment (orange boxes).

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non-compliance. Patient representatives suggested a picture of the substituted tablet should be available in the SMR. Unfortunately, at this stage it is not technically possible.

My Medication Plan may empower patients by supporting them in gaining control and responsibility for their medication treatment. My Medication Plan could allow patients' relatives to retrieve information contributing to further patient and relative empowerment (orange boxes, Figure 3).

All patient representatives expressed concern about mentioning medication side effect information in My Medication Plan. They were worried patients would become discouraged, focus too much on side effects, and risk non-adherence if they were mentioned explicitly in My Medication Plan. The solution discussed was a free-text box for comments, with some disagreement about how many of these boxes were necessary. The solution agreed upon was to include a free-text box where patients can freely write anything they desire to present and share with their physician(s). The patient representatives strongly requested a non-electronic format for My Medication Plan, so it was possible to write notes.

Designing the Layout of My Medication Plan – Second Session

During the second session, the five suggested prototypes of My Medication Plan (1)-(5) and the existing SMR were presented and discussed with the patient representatives (Figure 4, Appendix B).

Building upon the existing Shared Medication Record

"Then the patient or pharmacist must write everything down themselves by hand?" was the predominant focus of the discussion regarding the advantages and disadvantages of the five prototypes and SMR. If one of the five prototypes of My Medication Plan was chosen, all the prescription and non-prescription medications would have to be written up manually, increasing the risk of transcription errors. The existing SMR was considered optimal in relation to patient safety despite lacking space to note comments. A new SMR print can be requested when changes are made to the medication regimen, and this information can be accessed from home or by request from their primary physician, hospital, or community pharmacy.

Glossary to explain medical terms

"What does gastro-resistant capsule mean? What am I going to use that information for?" The patient representatives stressed a need for a glossary to explain these terms in relation to relevance for the patient, e.g. suspension and that the medication has to be prepared before usage. As a result, a glossary of medication terms was included in the final layout of My Medication Plan.

Free-text boxes for non-prescribed medication

"I know what over-the-counter medications are, but I don't know the difference between dietary supplements and herbal remedies, I just think it would be confusing." If this confusion increases the risk of patients not using free-text boxes, important information may not be presented to healthcare professionals. Healthcare professionals need this information, as interactions between medication and over-the-counter (OTC) medicines, dietary supplements, and herbal remedies can result in adverse effects. Therefore, it was preferred that non-prescribed medication should have a free-text box, whilst dietary supplements and herbal remedies were combined in another free-text box. A phrase was included in the final layout of My Medication Plan regarding how the patient takes the non-prescribed medications and whether the physician was informed about any self-adjustments.

The Layout of My Medication Plan

"The design should not remove the focus of what is important - the medication". The patient representatives considered My Medication Plan prototype (1), (2), and (3) too basic. The size of My Medication Plan was of no concern, but there was an expectation that it could easily be transportable and was also functional for patients with visual impairments. Different folding techniques that created a pocket-sized and easily transportable too were discussed. However, these solutions would not enable printing or distribution elsewhere other than the hospital, so the designs were not considered practical.

"The medication list is five pages! What if the patient's lose page three? Then they are in trouble." The final solution aimed to minimize the risk of losing a page. My Medication Plan was finalized with the requested information in an interchangeable design with a print of the SMR on predefined A4-sized paper within a plastic sleeve.

DISCUSSION

Patients and patient representatives developed My Medication Plan as co-designers and created a practical and feasible patient tool. The most important themes for the patients were medication changes, indications of drug treatment, specific medication instructions, and a record of future appointments for follow-up. This information will contribute to patients adhering more to medication treatment. Previous studies have reported comparable findings about the need for medication information identified in previous studies[2,4,9,10,39] . There is a greater chance of creating an appealing and feasible tool for medication information if it is done in collaboration with end-users - the patients. Previously, patients, relatives, and healthcare professionals have been co-designers of patient medication lists[2,39]. Scott-Horton et al. describe the design of three medication lists[39]. The first was a simplified medication list with drug names, doses, and indications for medication treatment. The second list included a moderately detailed medication list with drug names, doses, instructions on how to use the medication, and details of the prescriber. The third was the most complex, including pictures to symbolize the indication, drug names, drug dosages, start dates, side effects, monitoring clinical parameters, and prescriber details. Patients were asked which design was preferred via electronic questionnaires, and 54% preferred the complex medication list to manage medication at home[39]. This result correlates with our study, where the need for detailed information about prescription medication was very important for the patients and

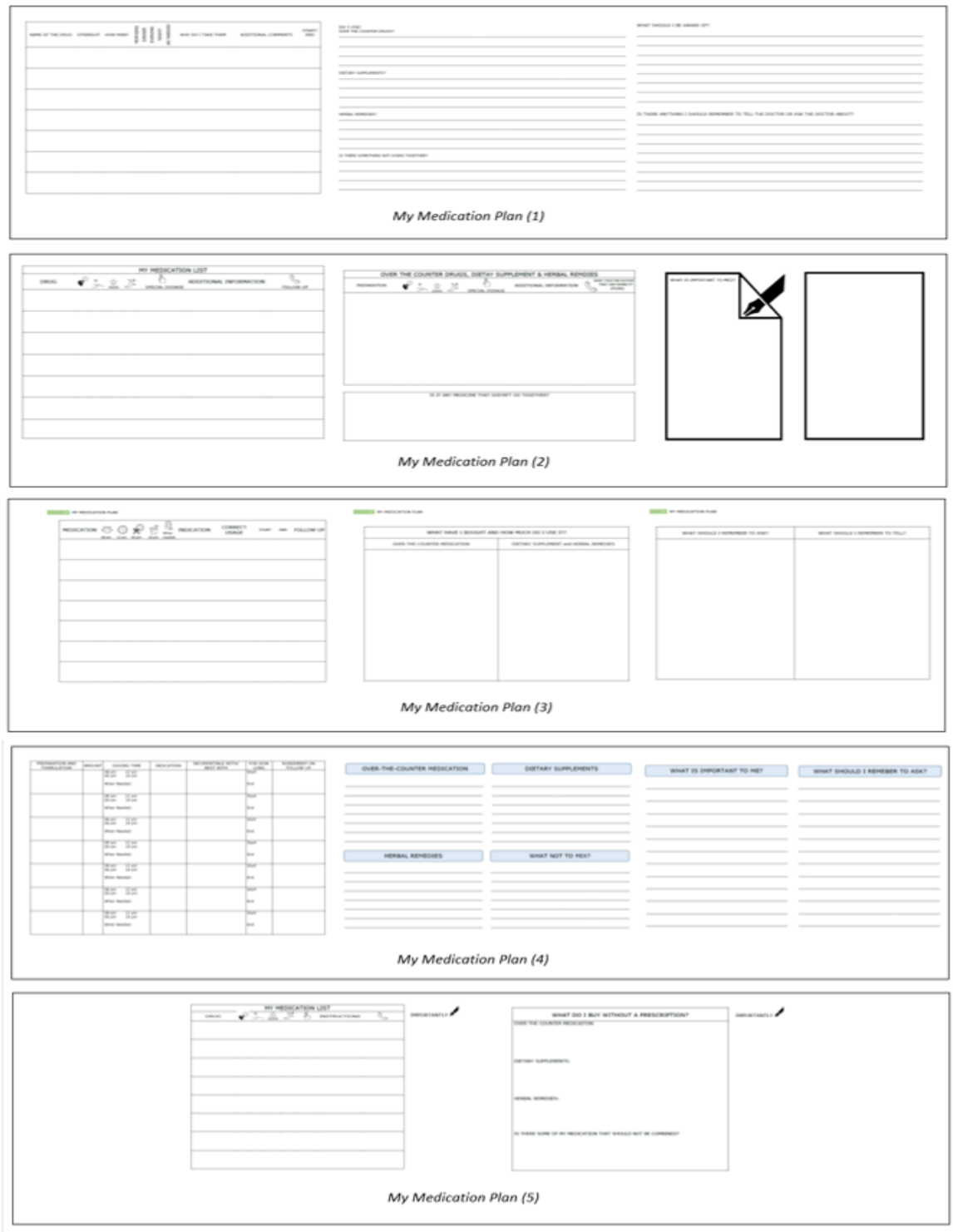

Figure 4. The five prototypes of My Medication Plan (1), (2), (3), (4), and (5) presented to the three patient representatives and discussed during the second session.

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patient representatives. The patient representatives expressed no need for information about side effects, comparable to Scott-Horton et al.[39]. Most patients found information about side effects beneficial, adding a sense of certainty about managing potential side effects[2,4,9,10].

The Danish SMR combines a moderately detailed medication list and the complex medication list as described by Scott-Horton et al.[39]. The SMR does not include pictures to symbolize indications, side effects, or monitor clinical parameters. The design and content of the current SMR was described as insufficient in accommodating patient's needs. As the SMR is limited to prescription medication, it was lacking the flexibility to include usage and consumption of OTC-medicines, dietary supplements, and herbal remedies. These non-prescription medications can have clinical effects or interact with the prescribed medication regimen[40].

The involvement of patients and relatives gave a more in-depth insight into the needs for medication lists[2,39]. In another study, Hahn-Goldberg et al. included the opinions of healthcare professionals involved in medication information transfer in the hospital and the community pharmacist[2] . Specifically, the community pharmacists elaborated upon patient safety in the transition of care[2]. This study described first-hand experiences of patients who had not been sufficiently instructed about medication treatment and, as a result, were at risk of adverse drug events[2]. A tool like My Medication Plan could also be a visual clue prompting conversations about medication[11].

Interestingly, despite digitalization, patients and patient representatives describe needing the old-fashioned, hardcopy patient journal represented by a non-electronic tool like My Medication Plan. This finding is similar to previous studies[2,11,39]. Care needs to be taken in relation to the size of My Medication Plan as the size may compromise utilization. Scott-Horton et al.'s complex medication list was 21 cm x 29.7 cm, and described as 'unhandy' by some patients[39]. Although creative folding techniques and sizes were discussed in this study, the proposed solutions were not practical. Hahn-Goldberg et al. developed a whiteboard used during hospitalization as a visual, written record of medication changes and a paper record for patients to take home[2]. This exercise aimed to visualize the medication changes[2]. Patients who receive a tool like My Medication Plan can bring it to appointments across healthcare sectors as a tool for empowerment[11,13,15]. The tools will give a visual clue, and they might assist in giving patients more control over their medication treatment.

In this study, the patients were verbally presented with information about their updated medication treatment during the discharge conversation, but no written information was available to support this conversation. However, the nurses gave a printout of the SMR at hospital discharge. Therefore, there is a risk that patients may forget this information[19,21]. My Medication Plan could support patient information recall[9,19]. Patients and relatives need the opportunity to write questions or information of relevance in free-text boxes[2]. My Medication Plan provides a tool for this that can be shared with healthcare professionals. Relatives can empower the patient, encouraging them to note important information in the free-text boxes. They can also, with the patient, discuss the information from My Medication Plan, which contributes to empowering the patient.

This study included the needs of frail patients at hospital discharge and utilized resourceful patient representatives during the ideation phase. A strength of this process was involving frail and robust individuals as co-designers, as different perspectives could be included. A limitation is that the patients was not included in the ideation phase to support the generation of ideas and designs for My Medication Plan as they are the end-users.

If other methods had been considered such as utilizing questionnaires more responses could have been gained[39], but questionnaires would not enable patients to elaborate on their answers. Furthermore, predefined categories are required in a questionnaire with a risk of bias due to patient or researcher preunderstanding[41].

A limitation during the development of My Medication Plan is that we did not include the views of healthcare professionals. However, this has been done previously by Hahn-Goldberg et al[2]. My Medication Plan was developed for the patients as end-users, and the perspectives of healthcare professionals may not necessarily have reflected the needs of patients.

There was a risk of the Hawthorne effect during the observations[42,43]. The observer was present which could influence how physicians, nurses, or patients behave during the observations of the discharge.

Interviewer bias was probable[41]. The author probed or may have influenced the answers about needs for medication information. In addition, two of the patients were admitted to a four-patient ward, which did not allow full discretion during the informal conversation, possibly influencing patient responses. However, these were not considered important for the overall objective, as the observations and informal conversations were triangulated with the ideation phase's two sessions with patient representatives[44].

Although the patient representatives were affiliated with Hospital Sønderjylland, they did not know the first author, however, this prior selection and affiliation may have resulted in some degree of selection bias[41]. Another limitation was the limited number of patient representatives. However, as the patient representatives knew each other in advance, a good group dynamic was established from the start of the sessions. The patient representatives were not hesitant to discuss differing opinions, strengthening the results.

This study is innovative as patients and patients' representatives are involved early in the process of designing My Medication Plan, and they hereby become co-designers. When developing a patient tool, involving patients and patient representatives early in the process is an advantage. It improves practical usability and feasibility of My Medication Plan, and it could create a more straightforward implementation process.

In addition, the inclusion of both patients and patients'

representatives is innovative as both groups present different perspectives. The patients are in the process of being discharged from the hospital; hence, they can elaborate upon their experience of the discharge conversation and express, which information they need during this process. The patients' representatives are able to reflect upon these needs and engage in discussions about how to incorporate the patients' needs for information regarding their medication into a practical tool such as My Medication Plan. Furthermore, they present and discuss real life challenges when their relatives handle their medication. They can also contribute with possible solutions to these challenges, and the solutions can become incorporated in My Medication Plan.

CONCLUSION

My Medication Plan was developed by involving patients and patient representatives as co-designers to design a non-electronic tool consisting of a print of the Shared Medication Record in combination with fixed pages. These fixed pages consists of text boxes to note appointments with healthcare professionals, over-the-counter medicines, herbal remedies and dietary supplements. All additional information patients and patient representatives named important were combined into this tool. From a clinical perspective, My Medication Plan can be used in any setting, any ward, and with any patient group.

AUTHORS' CONTRIBUTIONS

MS conducted the funding, MS, LJK, and TG conceptualized, MS performed the data curation, MS and TG made the formal analysis, MS, LJK, and TG conducted the methodology, MS performed the project administration, MS wrote the original draft and LJK and TG reviewed and edited.

CONFLICT OF INTEREST

None to declare

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