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Identifying Personal Goals of Patients With Long Term Condition: A Service Design Thinking Approach

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Abstract. Care for patients with long term conditions is often characterized as fragmented and ineffective, and fails to engage the resources of patients and their families in the care process. Information and communication technology can potentially help bridge the gap between patients' lives and resources and services provided by professionals. However, there is little attention on how to identify and incorporate the patients' individual needs, values, preferences and care goals into the digitally driven care settings. We conducted a case study with healthcare professionals and patients participated applying a service design thinking approach. The participants could elaborate some personal goals of patients with long term condition which can potentially be incorporated in digitally driven care plans using examples from their own experiences.

Keywords. Patients with long term conditions, personal goals, digital care plans

1. Introduction

The prevalence of patients with chronic diseases (people with long term conditions (LTC)) and the healthcare cost for them are much higher than patients with no long-term conditions [1,2]. According to the World Health Organization (WHO), forty million people die every year due to chronic illness and this is equivalent to 70% of all deaths globally [3]. However, LTC care is often characterized fragmented, ineffective, and disconnected. The disjoint between what is important to patients' lives and the health services they receive is not only wasteful but potentially harmful. While healthcare is often guided by treatment goals, the personal goals, values and preferences of patients have been ignored [4,5]. The tension between personal goals and the functional goals can disappear when the patient's personal goals can determine the healthcare professional's functional goals [6]. Goals for persons with LTC have shown to increase motivation. Involving patients in their own cares and pay attention to their own priorities and resulted better health outcomes [7,8].

Home telehealth care for patients with LTC seems to empower patients and potentially improve their medical conditions and reduce the cost [9,10]. However, it has

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been little attention on how to identify and incorporate the patients' individual needs, values, preferences and care goals in the ICT supporting settings. This paper considers following research question: How to identify and incorporate personal goals of patients with LTC into the digitally driven care settings?

2. Methods

We conducted a case study in June 2017 to identify personal goals of patients with LTC which can be potentially incorporated in digitally driven care settings. For our case study, we chose a pilot site in Norway where a patient-centered health service has been implemented for the patients with multimorbidity.

The pilot site has a patient-centered health services team that a regional hospital created together with two municipalities in Norway in 2013. The team consists of healthcare professionals from both municipalities and hospitals (e.g., homecare nurses employed by the municipalities, pharmacists employed by the hospital, etc.), and have supported patients with LTC through early assessments at the need of emergency help or the risk of acute (re-)admission. Most of the patients are frail patients, elderly with complex and chronic illness.

For the design of our study, we considered *service design thinking* approach. Service design thinking is an interdisciplinary approach to make services more useful, usable, desirable, efficient, and effective [11]. User-centered, co-creative, sequencing, evidencing, and holistic are the five core elements of service design thinking. We applied these elements when identifying criteria for case study design (See Table1.).

Table 1. Five core elements of service design thinking and the decided action points

Principles	Meanings [11]	Criteria for our case study design
User-centeredness	Designing service from customers' perspective	Involving patients
Value co-creation	Including all stakeholder groups in the service design process	Involving care professionals with different background in the team
Sequencing	Seeing service as a sequence of interconnected activities	Considering service journeys concept in relation to personal goals
Evidencing	Visualizing intangible service with physical elements	Using visual artefacts to articulate the service journeys
Holistic	Considering the whole environment where the service is delivered	Reflecting specific examples from actual experiences

Based on the criteria, a focus group discussion was designed. To support and user-centeredness and value co-creation, patients and healthcare professionals with different specialties were invited to the focus group. Visual artefacts presenting two components of a service journey (actor and touchpoint [12]) and six life areas (**Figure 1**-on the left) were created. For the involved actors, a researcher first investigated who the *service workers* [13] of at the pilot site are and who the *secondary service customers* [13] of patients with LTC might be. Fifteen actor icons representing a service customer (patient), five secondary service customers (family and friends), and nice service workers (healthcare professionals two from the municipalities and seven from the hospital) were created (**Figure 1**-in the middle). Twelve touchpoint icons representing types of communication were created (**Figure 1.**-on the right). All icons were attached on different colors of sticky notes. Two group exercises using the icons were then designed to support the principles of sequencing, evidencing, and holistic. Each group was asked to choose a group leader who could lead the discussion, write down the answers in a large paper sheet, and report the results in a plenary session.

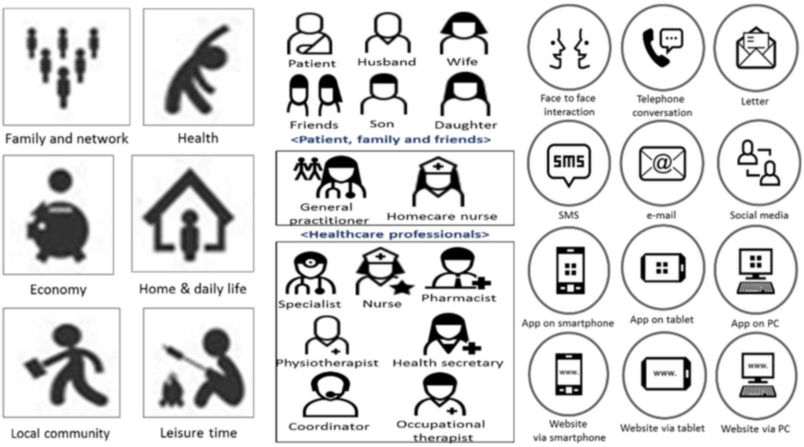


Figure 1. Icons created for the focus group discussions

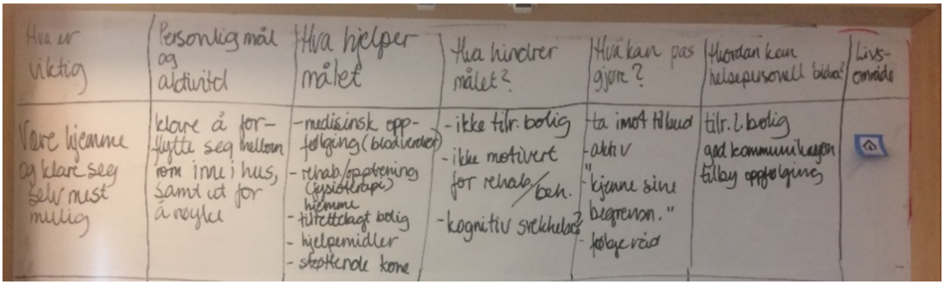
The first exercise was designed to identify potential personal goals for patients with LTC. Total seven questions were asked to discuss (Q1. Give an example of what can be important in the LTC patient's life by reflect your experience. Q2. What can be a personal goal or activity of the patient that is associated with the previous answer? Q3. What can be enablers to achieve the goal? Q4. What can be barriers to the goal? Q5. What can the patient do to achieve the goal? Q6. What the healthcare professionals can contribute to achieve the goal? Q7. Discuss the relevance of six life areas (**Figure 1**) that the personal goal is belonging to and place the applicable icon(s) on the sheet.).

The second exercise was designed to investigate possible clinical actions that can support the personal goals identified in the first exercise. Total six questions were requested to discuss (Q8. What type of clinical data is important to be collected and monitored to support the personal goal? Q9. Why do you think this data type should be collected and monitored? Q10. Who can collect this data? Place the applicable icon(s) or write on the sheet. Q11. Who can use this data? Place the applicable icon(s) or write on the sheet. Q12. What type of communication medium (**Figure 1**) would you like to use to monitor the clinical data? Place the applicable icon(s) or write on the sheet. Q13. How does the above answers link to the personal goals discussed in the previous exercise?).

Total twenty people participated in the discussion including six researchers, one patient, and thirteen healthcare professionals from the two municipalities representing various stakeholder groups. The participants were divided into three groups, and the participants representing same stakeholder group were distributed evenly. Each group had two researchers who mainly observed and took field notes. Two groups had four healthcare professionals, while one group had five. Only one group had one patient participant. The discussions were audio-recorded and the results sheets were collected.

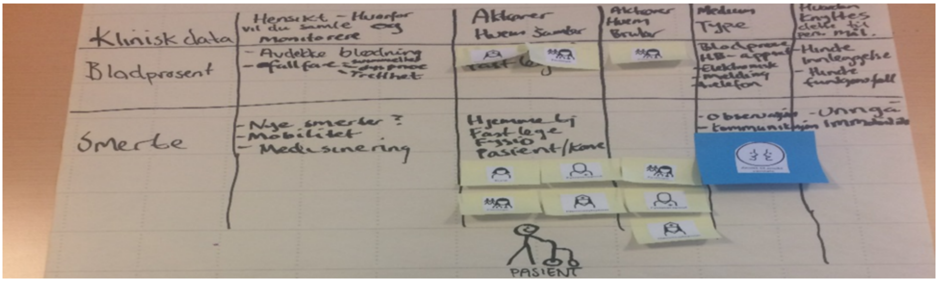
3. Results

In this section, we only present preliminarily results since analysis of the data (audio recorded files) is still ongoing. **Figure 2** shows a result from the first exercise. One group answered that for the frail patients to stay at home and manage themselves as much as possible could be important. The personal goal related to this might be able to move between rooms at home. Medical follow-up, rehabilitation or training, adapted housing, aid equipment, supportive wife could be enabler to achieve the patient's goal. Living in a non-adapted housing, not being motivated for rehabilitation or treatment, and cognitive weakness might possibly be barrier to the personal goal. By taking the offers, being active, knowing own limit, following the treatment, the patient could achieve the personal goal. Offering adapted housing, good communication, and follow-up by the healthcare professionals might contribute to achieve the patient's personal goal. A life area that the personal goal belongs to could be *home and daily life*. **Figure 3** shows a result from the second exercise. The group chose *blood test* and *pain assessment* as clinical data types which can be important to collect and monitor to support the patient's goal. The reason for monitoring might be to uncover bleeding and to prevent eliminate dizziness, dyspnea, fatigue. Homecare nurse and/or GP could collect the blood test data and the GP self might use the data. SMS, telephone, or electronic (internet or app) communication might be used to monitor the data. Monitoring blood test results could prevent hospital admission and disability which allows the patient to stay at home.



Hva er viktig	Personlig mål og aktivitet	Hva hjelper målet	Hva hindrer målet?	Hva kan pas gjøre?	Hvordan kan helsepersonell bidra?	Livs-område
Være hjemme og klare seg selv mest mulig	klare å forflytte seg mellom rom inni hus, samt ut for å røyke	- medisinsk oppfølging (blodverdier) - rehab./opptrening (fysioterapi) hjemme - tilrettelagt bolig - hjelpemidler - støttende kone	- ikke tilr. bolig - ikke motivert for rehab./beh. - kognitiv svekkelse?	- ta imot tilbud - aktiv - "kjenne sine begrensn." - følge råd	tilr. l. bolig god kommunikasjon tilby oppfølging	⌂

Figure 2. The result of the first exercise done by a group



Klinisk data	Hensikt – Hvorfor vil du samle og monitorere	Aktører Hvem Samler	Aktører Hvem Bruker	Medium Type	Hvordan knyttes dette til pers. mål.
Bladprøsent	- Avdekke blødning - fall fare – svimmelhet dyspnoe Tretthet	Fastlege		Blodprøve HB-apparat -Elektronisk melding -telefon	- Hindre innleggelse - Hindre funksjonsfall
Smerte	- Nye smerter? - Mobilitet - Medisinering	Hjemmetj. Fastlege Fysio Pasient/Kone		- Observasjon - kommunikasjon	- Unngå immobilitet

Figure 3. The result of the second exercise done by the same group

Another group also responded that *living at home as long as possible* might be an important matter for the frail patients. They said having good health, self-reliance, proper nutrition, and confident could be personal goals for this. The other group answered that social activities, helping at the right time, increased services might be important for the patients. They stated that reading time in the common place, visiting friends, getting up early can be personal goals for these. Various types of clinical data were raised up by the participants to be collected and monitored to support the personal goals.

4. Discussion and conclusion

There has been little attention on how to identify and incorporate the patients' individual needs, values, preferences and care goals in the ICT supporting settings. We could elaborate several concrete personal goals of patients with LTC which potentially be incorporated in a digital clinical pathway by facilitating discussion and supporting participants to articulate their own opinions and concepts using service design thinking approach. Generating criteria for our case study by applying the five principles of service design thinking allowed us to learn that *listening both patients' and healthcare professionals' voices*, *supporting them to articulate their own opinions by providing visual artefacts of important elements of the service*, and *stimulating them to reflect specific examples from their own experiences* could be important when incorporating of a new function to a health service.

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