

Wolsink-van Harlingen, A.O., Groen-van de Ven, L., Hasselaer, J., Thalen, J., Jukema, J., Vissers, K., Uitdehaag, M. Developing a toolkit for patients with COPD or chronic heart failure and their informal caregivers to improve person-centredness in conversations with healthcare professionals: A Design Thinking approach. *Patient Education and Counseling*: 2022, 105(1), p. 3324-3330

Postprint version : 2.0

Journal website : <https://www.sciencedirect.com/science/article/abs/pii/S0738399122003007>

Pubmed link : <https://pubmed.ncbi.nlm.nih.gov/35843846/>

DOI : 10.1016/j.pec.2022.07.002

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Developing a toolkit for patients with COPD or chronic heart failure and their informal caregivers to improve person-centredness in conversations with healthcare professionals: A Design Thinking approach

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Abstract

Background: The perspective of patients and informal caregivers is often not expressed in conversations with healthcare professionals which can have a negative impact on quality of care and quality of life.

Objective: Describe the development of a toolkit for patients with COPD or chronic heart failure and their informal caregivers enabling them to explore and express their perspective in conversations with healthcare professionals.

Patient involvement: Patients, informal caregivers and healthcare professionals were involved in the design process from problem definition to solution development.

Method: Design Thinking Approach using eight co-creation sessions and qualitative data-collection methods. Nineteen patients, ten informal caregivers and thirteen healthcare professionals participated in one or more cocreation sessions. Homogenous

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subgroups of participants were used in session 1, 2 and 4 and mixed groups were used in session 3, 5 and 6. Session 7 and 8 were used to test prototype toolkits.

Results: Three challenges to expressing the personal perspective to healthcare professionals, four statements defining the desired situation for conversations, eleven design criteria for the toolkit and ten selection criteria for tools were identified. This information was used to develop a prototype toolkit.

Discussion: Most patients and informal caregivers had moderate to high levels of education and all participating healthcare professionals were female with a majority of nurses and only three physicians. It is possible that this has influenced the design of the toolkit.

Practical value: The toolkit can support patients and informal caregivers in exploring and expressing their perspective in conversations with healthcare professionals. Feasibility of the toolkit and implications for healthcare professionals will be examined in a pilot implementation study.

1. Introduction

In order to provide person-centred palliative care it is essential that patients with chronic life-limiting diseases and their informal caregivers express their personal perspective to healthcare professionals (HCPs) [1–5]. In this study the personal perspective refers to what patients and informal caregivers value, need and prefer in their life, health and care based upon the essentials of person-centred and palliative care [2–5]. However, not every patient or informal caregiver is ready to express their perspective in conversations with HCPs because they have not thought about it, are not used to doing so or find it challenging [6–8].

Patients with chronic diseases experience barriers to participation in conversations with HCPs including not wanting to be bothersome, experiencing not enough time and only remembering topics afterwards [7]. Active participation in decision making and discussing end-of-life issues is especially challenging for patients with COPD or chronic heart failure (CHF) because they are often not well informed about their disease [9].

Multiple tools exist to support patients and informal caregivers to become active participants, use effective communication, and explore and express their values, needs or preferences [10–12]. However, these tools have not been specifically developed for patients with COPD or CHF and their informal caregivers, and often only address one aspect of the personal perspective, are difficult to find and use for people with low levels of health literacy as is prevalent among patients with COPD or CHF [13–18].

A toolkit was to be developed using Design Thinking (DT), a humancentred design approach. Patients, informal caregivers and HCPs were to be involved in the process of problem definition and solution development in order to develop a toolkit to meet their needs.

The aim of the present study is to develop an attractive and easy to use toolkit with relevant, high quality and accessible tools to support patients with COPD or CHF and their informal caregivers in exploring and expressing their perspective in conversations with HCPs.

This study aims to answer four questions: 1) Which challenges do patients and informal caregivers experience when exploring and expressing their perspective in conversations with HCPs? 2) What is the desired situation regarding the exploration and expression of the perspective of patients and informal caregivers in conversations with HCPs? 3) What are the design criteria for the toolkit? 4) Which selection criteria are important for the tools to be included in the toolkit?

2. Method

2.1 Design

Design Thinking (DT) is a human-centred design approach where the problem and solution are explored and discovered in co-operation with relevant stakeholders. The general aim of DT is to find better solutions to complex problems. DT contains five phases; empathize, define, ideate, prototype and test [19–21]. In this study the first four phases were used.

2.2. Process of development

2.2.1. Co-creation sessions

Data was collected during eight co-creation (CC) sessions. The first four sessions (CC1-CC4) were used to explore and select the problem. The next four sessions (CC5-CC8) were used to develop the solution. All eight sessions were prepared in consultation with designers familiar with the DT approach in health care.

CC1-CC6 had a similar structure with a plenary introduction and closure combined with working in subgroups (see Table 1). The introduction was used to present the insights of the prior session and explain the objective and working methods of the upcoming session. The plenary closure was used to share the information collected in the current session.

Homogenous subgroups of patients, informal caregivers and HCPs were used in CC1, 2 and 4 in order to create a safe environment to share personal information, experiences and opinions. Mixed groups were used in CC3, 5, and 6 to create a context where the different perspectives of participants could be shared and discussed.

In CC7 three different prototype toolkits were presented and discussed in a mixed group of participants. CC8 was used to test the most feasible prototype toolkit in three different situations; waiting room, consultation room and individually with a HCP.

See Table 1 for detailed information about the specific objectives and methods per session.

2.2.2. Tool collection and selection

Parallel to the CC-sessions, authors MU, LG and AO collected national and international tools via scoping searches in general and professional databases, on internet, during national and international congress meetings and via their professional network, LinkedIn and Twitter. Tools developed for patients with chronic or life-threatening diseases and related to the challenges discovered during CC1-CC4 were included in an Excel sheet. Between CC7-CC8 tools were added to this sheet based upon the requested input of patients, informal caregivers and HCPs. Based upon the structure of the prototype toolkit developed after CC8 researchers LG and AO performed a final search on internet and results were included in the Excel sheet. The identified selection criteria were used to select tools from the Excel sheet to be included in the final prototype toolkit.

[Tabel 1]

2.3. Participants

2.3.1. Patients and informal caregivers

Patients and informal caregivers were recruited during scheduled consultations with their HCP in hospitals and general practices in the region of two palliative care networks in the Eastern Netherlands. Interested patients and informal caregivers received additional information both in person and on paper. After giving oral consent an informed consent form and a demographic

information sheet were completed. If patients or informal caregivers dropped out before the end of the study, new ones were recruited and added after performing the same informed consent procedure. All recruited patients and informal caregivers received an invitation for each co-creation session. The aim was to include at least five patients and five informal caregivers in CC1-CC6 to create sufficient variety in participants and keep groups small to make sure every participant would be seen and heard during the sessions. If insufficient patients and informal caregivers had signed up for sessions, additional participants were personally approached to ensure sufficient participants for each sub-group. Testing the prototype toolkits in CC7-CC8 required fewer patients and informal caregivers and these were personally invited to participate in these sessions. Purposive sampling was used in the recruitment and invitation of patients and informal caregivers to ensure diversity in disease, gender, age, level of education and years since diagnosis.

2.3.2. Healthcare professionals

Purposive sampling was also used in the recruitment of HCPs in order to form a pool of HCPs with variation in disciplines and work setting. We were looking for HCPs such as pulmonologists, cardiologists, specialist nurses COPD and specialist nurses CHF working in secondary care settings and General Practitioners (GP) and GP practice assistants working in a primary care setting. The aim was to include at least five HCPs in every session of CC1-CC6 for the same reasons as described above. In CC7-CC8, fewer CPs were needed to test the prototype toolkits and HCPs were randomly invited to participate in these sessions. The same informed consent procedure was used for HCPs.

2.4. Analysis

All conversations in the subgroups were audio-recorded and verbatim transcribed. The transcripts were thematically analysed using ATLAS.ti 8 after each co-creation session [22]. Both researchers LG and AO analysed and coded the transcripts independently. The codes and insights of the analyses were then compared and differences were discussed. Subsequently, different codes were sorted into categories and themes which were discussed by authors MU, LG and AO to improve the quality of the analyses. Finally, the themes and categories were reviewed and refined by checking their relation to the coded extracts and the entire data set by LG and AO. Trustworthiness was ensured by member-checking of synthesized analysed data in text during the plenary introductions of CC1-CC4 and in prototype toolkits during CC7 and CC8 [23,24].

2.5. Ethical considerations

The Clinical Ethical Committee Twente declared that the Clinical Research Involving Human Subjects Act was not applicable to this study. Informed consent of participants was not applicable to this study. Informed consent of participants was applied according to good clinical research practice guidelines.

3. Results

3.1. Participants

Nineteen patients, 10 informal caregivers and 13 HCPs, contributed in eight CC-sessions. Demographic characteristics of patients and informal caregivers and their attendance during the CC-sessions are presented in Table 2. The information of participating HCPs is included in Table 3.

3.2. Challenges (CC1-CC4)

Three challenges to expressing the personal perspectives of patients and informal caregivers during conversations with HCPs were identified and prioritised, 1) making yourself known as a unique

individual, 2) being heard in your experience and expertise in living with the disease, 3) thinking and talking about the future. Patients, informal caregivers and HCPs agreed that knowing the person behind the patient is important in providing person-centred care. Informal caregivers also want to be seen and heard as unique individuals. This means that you need to inform your HCP about how you would like to be approached during consultations, what you value in life and what your personal circumstances are.

The second challenge is mainly experienced by patients and informal caregivers in acute situations and in conversations with unfamiliar HCPs. There seems to be tension between experiential expertise of patients and informal caregivers and the disease-centred approach and use of guidelines and protocols by HCPs. Patients and informal caregivers would like HCPs to be more approachable while HCPs want patients to become more empowered.

The third challenge regarding the future, is experienced and expressed in different ways by patients, informal caregivers and HCPs. Most patients do not want to think and talk about end-of-life. They think this topic is more important to relatives. Some informal caregivers express more need for information about prognosis and end-of-life decisions than patients. HCPs know what the future can bring and want to discuss this topic as early as possible. They want to prepare patients and informal caregivers for the future and organise appropriate future care. HCPs find it difficult to find the right moment to bring these subjects into the conversation (see Table 4).

[Table 2]

[Table 3]

3.3. Desired situation (CC5)

Participants find it important that HCPs, patients and informal caregivers are well prepared for the conversation. HCPs should know who they are meeting, both as patient and person. They should know how this person wants to be approached, what their values are and relevant topics for discussion. Patients and informal caregivers need to know what their expectations are and how to explain the impact of the disease and treatment on daily life and the future. During the consultation patients and informal caregivers need to have a central role and should experience control over what is discussed and decided (see Table 4).

3.4. Design criteria toolkit (CC7-CC8) and selection criteria tools (CC6-CC8)

Eleven design criteria were identified based on the input of patients, informal caregivers and HCPs during the evaluation of three prototype toolkits in CC7 and one prototype toolkit in CC8. The design criteria for the toolkit covers three themes; content, use and form (see Table 4).

Ten selection criteria for tools were identified relating to content, use, form and accessibility. Based upon the searches of MU, LG and AO a total of 135 tools were included in the Excel sheet. Five tools were added to this sheet based on the input of patients, informal caregivers and HCPs between CC7 and CC8. After CC8 five tools were collected and added to the sheet. Based on the ten selection criteria (see Table 4), LG and AO selected 42 tools to be included in the toolkit (see Table 5).

3.5. Prototype toolkit

We developed a prototype toolkit based on the results, consisting of a hardcopy and an online toolkit containing 42 tools (see Table 5). The hardcopy toolkit was designed to introduce and select tools offline. The online toolkit was designed to introduce, select and access the freely available and purposively selected online tools.

4. Discussion and Conclusion

4.1. Summary

This explorative DT study enabled us to define three challenges, four statements for the desired situation, eleven design criteria for the toolkit and ten selection criteria for tools. Based on this information we developed a hardcopy and an online toolkit in co-creation with patients, informal caregivers, HCPs and designers. The toolkit has been designed for users with low levels of literacy and digital skills, and has been developed for independent use at home. One particular strength of this study has been the involvement of patients, informal caregivers and HCPs in the design process, so supporting the acceptance and integration of the toolkit in the care process. The diversity among participants can contribute to the recognition of the identified challenges and the effectivity of the toolkit.

4.2. Challenges

First, it is important to know the person behind the patient and informal caregiver. Preparation is important for patients and informal caregivers to define what is important to them and what they want to discuss with the HCP [25,26]. However, most patients and informal caregivers do not prepare themselves.

Secondly, patients and informal caregivers do not feel heard in their experience and expertise in living with a disease, especially in situations of acute professional care or with an unknown HCP. The integration of patients and informal caregivers' experiential expertise in conversations with HCPs can support the cultural change to person-centred care [27, 28].

Finally, patients and HCPs had conflicting preferences regarding thinking and talking about the future. Patients find it challenging and want to focus on staying alive. Informal caregivers want to know more but do not want to confront their relative. HCPs find it challenging to find the right moment to talk about the future without causing distress and reducing hope. This makes early communication about advanced care planning and end-of-life care a delicate task for HCPs [29,30].

4.3. Methodological lessons

Lessons learned relating to the Design Thinking Approach were 1) organise sessions at a neutral location 2) adjust data-collection methods to the characteristics of participants 3) explore differences in perspectives before moving to the next step in the design process. The first session was at a local hospital and one HCP refused to remove her white coat and stethoscope. Subsequent sessions were held at a neutral and more homely location. During CC2 it transpired that some participants had low levels of literacy. More visual techniques were subsequently used. Between CC4 and CC5 the project team decided to exclude the third challenge based upon the expressed preferences of the patients. However, this decision was not supported by HCPs. The project team reconsidered their decision and included challenge three again because of its importance to provide person-centred palliative care. It became clear that it is crucial to explore the differences in perspectives in mixed groups and create shared understanding and agreement before moving on to the next step.

4.4. Limitations

Although demographic characteristics were diverse, most patients and informal caregivers had moderate to high levels of education and all participating HCPs were female with a majority of nurses. Physicians were enthusiastic about the study. However, we were only able to include three physicians who attended the CC-sessions once or twice. It is possible that this has influenced the design of the toolkit.

[Table 4]

4.5. Conclusion

The Design Thinking Approach proved to be an effective method for developing a prototype toolkit in co-creation with patients, informal caregivers and HCPs. The toolkit aims to enable patients and informal caregivers to prepare themselves for conversations with HCPs and express their perspective to different HCPs from diagnosis until end of life.

4.6. Practice implications

The feasibility of the toolkit will be tested during a pilot implementation study. During the pilot implementation study we will also pay attention to what HCPs need to enable them to integrate the toolkit in their conversations with patients and informal caregivers.

CRediT authorship contribution statement

Annet Olde Wolsink – van Harlingen: Methodology, Investigation, Data curation, Formal analysis, Writing – original draft, Visualization. Leontine Groen – van de Ven: Methodology, Investigation, Data curation, Formal analysis, Writing – review & editing, Project administration. Jeroen Hasselaar: Supervision, Writing – review & editing. Jos Thalen: Methodology, Investigation, Writing – review & editing. Jan Jukema: Supervision, Writing – review & editing. Kris Vissers: Supervision, Writing – review & editing. Madeleen Uitdehaag: Conceptualization, Funding acquisition, Project administration, Methodology, Investigation, Data curation, Formal analysis, Writing – review & editing, Supervision.

Declaration of Competing Interest

None.

[Table 5]

Acknowledgement

The study is part of a three year research project named EMPATIE (EMpowerment of PATIENTs with COPD or chronic heart failure and their informal caregivers) with project number 844001501 subsidised by the Dutch Organisation for Health Research and Development (ZonMw).

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Tables

Table 1 Overview of objectives, methods and subgroups per co-creation session

Phase	Session	Date	Objective	Method	Subgroups
Empathize	1	October 2 nd 2018	Explore patient journey – important moments – important themes	Topic list Group interview	Homogeneous
	2	November 14 th 2018	Explore conversations with HCP – important themes – experienced challenges	Individual work sheets including identified themes CC1 Individual assignment Group discussion	Homogeneous
Define	3	December 18 th 2018	Explore challenges in conversations with HCP – concretise challenges – prioritise challenges	Conversation cards based upon identified challenges CC2 Individual assignment Group discussion	Heterogeneous
	4	February 6 th 2019	Select challenges in conversations with HCP that require a solution	Scenarios based upon prioritised challenges CC3 Group discussion scenario Individual voting	Homogenous
Ideate	5	March 19 th 2019	Discover desired situation conversation	Group assignment Write newspaper headings about desired situation conversation	Heterogeneous
	6	May 15 th 2019	Discover selection criteria tools	Presentation of sixteen existing tools Evaluate pros and cons of these tools in small subgroups	Heterogeneous
Prototype	7	January 30 th 2020	Discover design criteria toolkit and selection criteria tools	Three prototype toolkits Presentation of each prototype Group discussion about pros and cons of each prototype	Heterogeneous
	8	March 3 rd 2020	Discover design criteria toolkit and selection criteria tools	One prototype tested in three different situations: 1. Waiting room simulation session with a patient and an informal caregiver 2. Consultation room simulation session with a patient and a HCP 3. Evaluation and discussion of the toolkit with a HCP	Not Applicable

Table 2 Demographic information of patients and informal caregivers and attendance during CC sessions.

Characteristics	Patients (n = 19)	Informal caregivers (n = 10)
Disease patient		
COPD	10	6
CHF	9	4
Gender		
Male	11	3
Female	8	7
Age		
≤ 60	3	3
> 60	12	4
Missing	4	3
Level of education^a		
Low	2	–
Medium	5	5
High	7	2
Missing	5	3
Years since diagnosis patient		
< 6 years	4	2
6–10 years	5	2
> 10 years	6	3
Missing	4	3
Attendance CC1-CC8		
1–2 sessions	12	5
3–4 sessions	4	4
5–7 sessions	3	1

^a Level of education High = college or university, Medium = high school, Low = vocational training;

Table 3 Demographic information of healthcare professionals and attendance during CCsessions.

Characteristics	HCP (n = 13)
Profession	
Physician	3
Nurse	10
Setting	
Primary	8
Secondary	5
Age	
≤ 50	5
> 50	7
Missing	1
Years of experience	
2–5	4
6–10	2
> 10	6
Missing	1
Average number of patients per month	
≤ 50	9
> 50	3
Missing	1
Attendance CC1-CC8	
1–2 sessions	4
3–4 sessions	7
5–6 sessions	2

Table 4 Challenges, desired situation, design criteria and selection criteria.

1. Challenges	
Themes	Categories
Making yourself known as a unique individual	Your preferred participation and communication style Your values Your personal situation
Being heard in your experience and expertise in living with the disease	What the impact is of the disease and treatment What does or does not work for you How to stand up for yourself
Thinking and talking about the future	Thinking about your future Expressing your wishes/needs to talk about your future with HCPs Talking about your future
2. Desired situation	
Themes	Categories
Preparation	HCP is prepared for the individual (person and patient) Patient and informal caregiver are prepared for the conversation
Consultation	Patient and informal caregiver have a central role in the conversation Patient and informal caregiver experience control over what is discussed and decided in the conversation
3. Design Criteria Toolkit	
Aspects	Requirements
Content	Clear user-instructions Preparation and communication tips Support with formulation and prioritisation of questions
Use	Independent use at home Self-selection of tools Use toolkit in self-paced manner
Form	Easy access to tools included Non-clinical or homely appearance Structured overview of tools included Stay structured and organised during use Attractive colours and descriptions
4. Selection Criteria Tools	
Aspects	Requirements
Content	Relevant ^a Reliable ^b Specific for target population and setting Dutch language, understandable and readable
Use	Easy to use Takes little time or effort
Form	Different modes of delivery ^c Attractive in lay-out and colours
Accessibility	Online available Free available ^d

^a related to challenges, conversation, question asking.

^b provided by trustworthy organisations.

^c e.g. websites, video's, folders, booklets, questionnaires.

^d no personal information or payment required.

Table 5 Content of the toolkit based upon challenges, included tools and objectives.

Challenge 1	Title tool	Modes of presentation	Objective
1	What matters to me in my life	Online questionnaire	Explore what is important to you
2	Listening line	Phone-number	
3	Communication after receiving bad news	Three questions	
4	To tell how I am doing	Scoring instrument	
5	Positive Health	Scoring instrument	
6	Conversation sheet "What would you like to talk about?"	Sheet with pictures of topics	
7	Intimacy and sexuality COPD/CHF	Folder	
8	Symptom diary	Questionnaire	
9	Distress thermometer and problem list	Questionnaire	
Challenge 2	Title tool	Modes of presentation	Objective
10	Cheat note conversation	Tips	Prepare conversation
11	Conversation tool palliative care	Questionnaire and question prompt list	
12	Cheat sheet surgery	Question prompt list	Prepare questions medical tests and interventions
13	Tips for conversations about treatment	Question prompt list	
14	Tips for conversations about medication	Question prompt list	
15	Tips for conversations about medical evaluation	Question prompt list	Prepare questions disease and care
16	Questionnaire Lung Fund	Question prompt list	
17	Questions for your doctor	Question prompt list	
18	Standing up for yourself smart	Website	
19	Dialogue Trainer	Online training tool	Effectively express your view on your illness and care
20	Start a good conversation	Website	
21	Three good questions	Three questions	Prepare for shared decision making (SDM)
22	Talking to your doctor	Photo story	
23	Shared decision making hospital	Worksheet	Information about living a healthy life
24	Shared decision making at home	Worksheet	
25	Healthier in three steps	Infographic	
26	Healthier together with support	Infographic	
27	COPD	Website	
28	COPD Me and my doctor	Website	
29	I have COPD, what can I do?	Folder	
30	Guide you to a lung attack	Folder	
31	Care path COPD	Video's (animation)	
32	Heart Failure	Website	
33	What is heart failure	Website	Information about your disease and care: CHF
34	Heartfailure: what is it?	Folder	
Challenge 3	Title tool	Modes of presentation	Objective
35	Explore your wishes for treatment and care	Online questionnaire	Explore and describe your wishes for the future
36	My end of life wishes	Workbook	
37	Conversation tool treatment restrictions	Folder and questionnaire	
38	Good care for people with severe heart failure	Folder	
39	Talk about the final phase of life	Website	
40	Talk about the end of life	Videos	
41	Talking about your end of life	Website and folder	
42	Building trust together	Video and folder with picture stories	

All included tools can be directly accessed via the website www.mijn-blik.nl