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How to co-design a health literacy-informed intervention based on a needs assessment study in chronic obstructive pulmonary disease

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ABSTRACT

Objective To develop a co-designed health literacy (HL)-informed intervention for people with chronic obstructive pulmonary disease (COPD) that enables them to find, understand, remember, use and communicate the health information needed to promote and maintain good health.

Design This study used a co-design approach informed by the programme logic of the Ophelia (Optimising Health Literacy and Access) process. The co-design included workshops where possible solutions for an HL-informed intervention were discussed based on an HL needs assessment study.

Settings Five workshops were performed in a local community setting in the specialist and municipality healthcare services in Oslo, Norway.

Participants People with COPD, multidisciplinary healthcare professionals (HCPs) from the municipality and specialist healthcare services, and researchers (n=19) participated in the workshops. The co-designed HL-informed intervention was based on seven focus groups with people with COPD (n=14) and HCPs (n=21), and a cross-sectional study of people with COPD using the Health Literacy Questionnaire (n=69).

Results The workshop co-design process identified 45 action points and 51 description points for possible intervention solutions to meet the HL needs of people with COPD. The final recommendation for an HL-informed intervention focused on tailored follow-up after hospitalisation, which uses motivational interviewing techniques, is based on the individual's HL, self-management and quality of life needs and is implemented in cooperation with HCPs in both the specialist and municipality healthcare services.

Conclusion During the codesign process, the workshop group generated several ideas for how to help patients find, understand, remember, use and communicate health information in order to promote and maintain good health. People with COPD need tailored follow-up based on their individual HL needs by HCPs that have knowledge of COPD and are able to motivate them for self-management tasks and help them to improve their quality of life (QOL) and decrease hospitalisation.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ A strength of this study is that it included people with chronic obstructive pulmonary disease (COPD), a diverse sample of multidisciplinary healthcare professionals (HCPs) from the specialist and municipality healthcare services and researchers.
⇒ Another strength is that the co-designed health literacy (HL)-informed intervention for people with COPD was based on a recently performed HL needs assessment study.
⇒ The co-design process allows stakeholders to feel more engaged, included and prepared to take the intervention forward with practical and financial solutions.
⇒ A study weakness is that our methods differed in several ways from the health standard Optimising Health Literacy and Access (Ophelia) process for developing literacy-informed interventions.
⇒ Another study weakness is that the idea-generating workshops included mixed groups of patients with COPD, HCPs and researchers; patients may have been more open to sharing their ideas in a separate group without HCPs and researchers.

INTRODUCTION

People with chronic obstructive pulmonary disease (COPD) have a high burden of symptoms such as breathlessness, depression and anxiety, low quality of life (QOL), high comorbidity, exacerbation of distressing symptoms and hospitalisations that result in high healthcare costs.[1] They often require complex follow-up with lifestyle interventions to assist with managing the disease.[2 3] Despite much research, we still have not found the key to providing effective follow-up of people with COPD. Interventions, such as medications, pulmonary rehabilitation, smoking cessation programmes and self-management programmes, have shown beneficial effects on several outcomes in COPD such as

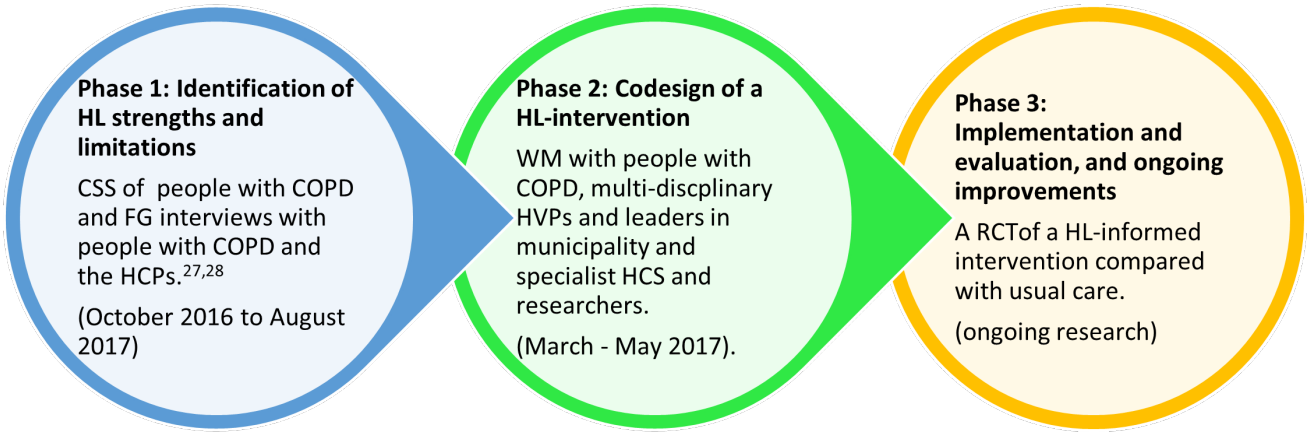

Figure 1 Overview of the study informed by the Optimising Health Literacy and Access (Ophelia) process. COPD, chronic obstructive pulmonary disease; CSS, cross-sectional study; FC, focus group; HCP, healthcare professional; HCS, healthcare service; HL, health literacy; RCT, randomised controlled trial; WM, workshop meeting.

reduced respiratory symptoms, hospitalisations and healthcare costs, as well as improved quality of life (QOL) and coping.[4–8] However, many people with COPD do not fully benefit from such interventions, and low health literacy (HL) has been suggested as a possible explanation. Despite HL being identified as an important issue to address in COPD,[3 4 9] there is currently a gap in the literature in this area, as few studies have focused on HL, either as an aim or as an outcome of COPD interventions.[5–7]

The concept of HL is defined as the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand, remember and use information in ways that promote and maintain good health.[10] For people with COPD, low HL is associated with poor inhalation technique,[11 12] living alone and having a minority background, lower education,[13] multiple comorbidities,[14] low lung-specific health-related QOL,[15] limited self-management skills or more hospitalisations.[13]

In general, intervention development is based on current practice, prior research and theory[16–18] and uses a top-down approach.[19] Intervention development is also frequently undertaken in small unrepresentative samples, often executed by a highly trained and motivated therapist and with highly selected and compliant patients. However, in the real world, contexts and patients' lived experience may be different from the research setting, resulting in weak and often ineffective interventions.[20] Bottom-up approaches that include rich information about the diverse needs of patients and input from stakeholders on the viability of an intervention (ie, its suitability, practicability, affordability and helpfulness) ensure that the developed interventions are directly informed by end users and are more likely to be needed, wanted and implementable.[19 20] However, few have used a 'bottom-up approach' in designing interventions for people with COPD, and the bottom-up approach may be a particularly effective solution to designing HL interventions.

A programme logic model can be useful in order to engage stakeholders in designing, planning and finding solutions on evaluation and outcomes of an HL intervention from their perspective. This is a framework or a descriptive/schematic representation of activities and outcomes showing a link between different steps of activities in a process.[21] The Optimising Health Literacy and Access (Ophelia) process is an example of a programme logic model specifically focused on developing and testing HL interventions, informed by an HL needs assessment study. Ophelia has been applied in wide range of settings where teams focus on developing interventions to improve outcomes for people who experience disadvantage and vulnerability,[22 23] including within the WHO's National Health Literacy Demonstration Projects.[24]

Given the likelihood that unmet HL needs are contributing to poor health outcomes among people with COPD, the aim of this study was to co-design a HL-informed intervention that helps people with COPD to find, understand, remember, use, and communicate the health information needed to promote and maintain good health outcomes. This aim addresses the current gap in the literature on HL-informed interventions to improve outcomes for people with COPD, such as reducing symptom burden and hospitalisation rates and improving self-management and QOL.

METHODS

The results presented in this paper are part of a larger study called 'Health Literacy: a Key to Health in COPD'. The study was informed by the Ophelia process, which includes three phases:

- In phase I, the HL needs of a representative cross-sectional sample of the target population are systematically assessed using the Health Literacy Questionnaire (HLQ)[25] and qualitative interviews.[26] Cluster analysis is then performed to identify groups of individuals with similar HL profiles on the HLQ, and vignettes are written based on the clusters and qualitative interviews.[26]
- In phase II, the vignettes are presented to stakeholders in workshops for discussion and interpretation to

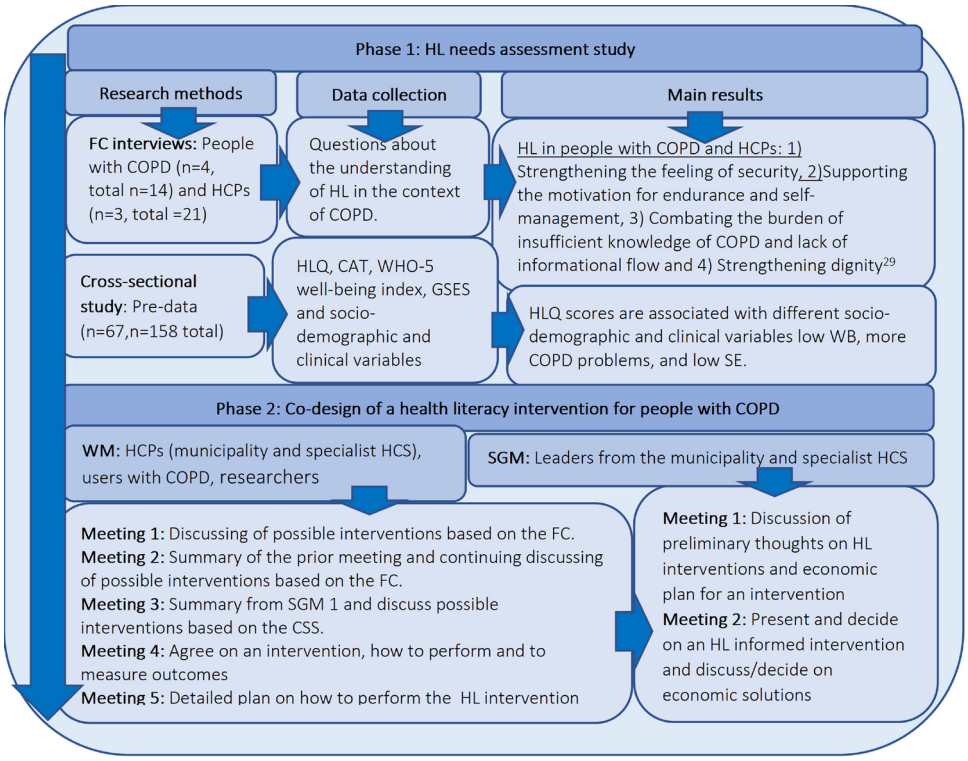

Figure 2 Flowchart of phases I and II. CAT, COPD Assessment Test; COPD, chronic obstructive pulmonary disease; CSS, cross-sectional study; FC, focus group; GSES, Generalised Self-efficacy Scale; HCP, healthcare professional; HCS, healthcare service; HL, health literacy; HLQ, Health Literacy Questionnaire; SE, self-efficacy; SGM, steering group meeting; WHO-5, WB, well-being; WHO-5, Five-Item WHO Well-being Index; WM, workshop meeting.

generate innovative and implementable HL intervention ideas. Further to take the ideas that were generated and decided oninto the final intervention to implement.[26]

- In phase III, the HL intervention is implemented and evaluated.[22 23 26]

The present paper focuses on phase II. This is the phase where the co-design of an HL-informed intervention for patients with COPD is formed from the results of an HL needs assessment study. However, our co-design process was based on an evaluation of preresults, which consisted of simple associations from a cross-sectional survey of the HLQ (n=69) and qualitative analysis of seven focus group interviews of people with COPD (n=14) and multidisciplinary healthcare professionals (HCPs) (n=21), and not the cluster analysis and vignettes described in the Ophelia manual. See figure 1 for an overview of the study.

A detailed description of the methods and results for the phase I cross-sectional study (total n=158) and qualitative focus group interviews (n=7) has been previously published.[27 28]

DESIGN

Based on the results from phase I, a phase II co-design process of five workshop discussions was formulated and performed at one medium-sized hospital in cooperation with four healthcare services located in municipalities in Oslo, Norway.

A steering committee was established as part of the larger study. In the co-design phase, they reviewed the emerging results, decided on the study's direction, and provided input on the practical and financial feasibility of implementing the recommended intervention. The committee was composed of leaders from the municipality healthcare service, the hospital and the University of Oslo. Two steering committee meetings were held, each lasting 1 hour and led by the main researcher (CRB).

Figure 2 shows a detailed flow diagram of the phase I data collection and the phase II co-design process with the content of what was presented and discussed at each workshop meeting.

We used Standards for Quality Improvement Reporting Excellence V.2.0 as the reporting guideline for this paper.[29]

Study population and inclusion criteria in the workshops

In each workshop, people with COPD and multidisciplinary HCPs of healthcare services (ie, hospital/specialist and municipality healthcare services) and researchers were included. A study nurse or the main researcher contacted leaders in the specialist and municipality healthcare services through email to assist in recruiting members for the workshop. They were asked to recruit a diverse group of multidisciplinary HCPs from both the municipality and the specialist healthcare service.

Inclusion criteria included

- HCPs with experience working with COPD in the specialist or municipality healthcare service.

Table 1 Data from the HL need assessment study that were presented in the workshop meetings

Data from the qualitative interview focus groups	
Characteristics of the participants in the focus groups In total, 35 participated in the interviews; 21 were HCPs (age range 26–64, n=13 women); and 14 were patients with COPD (age range 64–96, n=10 women).	
Main theme	**Summary of the themes**
1. Strengthening the feeling of security.[27]	People with COPD may experience insecurity, and this seems to be a consequence of several factors when it comes to HL. HCPs believe that they create security through giving information and health tasks, while people with COPD believe that they need a personal follow-up by few and dedicated HCPs that have knowledge in COPD.[27]
2. Supporting motivation for endurance and self-management.[27]	It requires great self-effort, perseverance and motivation to take care of health for the person who have COPD and the HCPs who follow them up, but this not something everyone have.[27]
3. Combating the burden of insufficient knowledge of COPD and lack of informational flow.[27]	People with COPD and HCPs experience that information and follow-up of the disease are provided, but time, resources and knowledge of COPD are a bottleneck. They express a need for more information and follow-up at the same time as they do not know what they need.[27]
4. Strengthening dignity.27	Several people with COPD may experience impaired dignity that can affect a lack of imitative to seek healthcare and ask health questions. It may seem that the dignity of people with COPD in not taken seriously by HCPs.[27]
Data from the quantitative cross-sectional study	
Characteristics of the participants in the cross-sectional study: Frequencies: male, n=31 (46.3%); lives alone, n=45 (67.2%); education ≤high school, n=52 (77.6%); smoker, n=29 (43.3%); no use of a computer and internet, n=37 (55.2%); wrong use of medication, n=36 (53.7%); wanted home visit to participate in the study, n=16 (23.9%); mean (SD): age 67.8 (12.6), years with COPD 9.7 (6.1), predicted lung function 58.1 (18.5), BMI 26.7 (7.0), number of diseases 5.1 (2.1), hospitalisation last year 1.1 (2.6), CAT score 19.2 (9.3), well-being score 51.6 (23.3), self-efficacy score 30.4 (5.8)	
HLQ scales (n=69)	**Mean (SD)** **Low HL associated with (P value, R^2)**
1: feeling understood and supported by healthcare providers: Low score: 'People who are low on this domain are unable to engage with doctors and other healthcare providers. They don't have a regular healthcare provider and/or have difficulty trusting healthcare providers as a source of information and/or advice'.[25]	2.7 (0.8) Living alone (p=0.07, R^2=0.05), low BMI (p=0.02, R^2=0.08), low well-being score (p=0.01, R^2=0.09), high CAT score (more COPD problems) (p=0.05, R^2=0.06)
2: having sufficient information to manage my health: Low score: 'Feels that there are many gaps in their knowledge and that they don't have the information they need to live with and manage their health concerns'.[25]	2.6 (0.7) Smoker (p=0.06, R^2=0.05), low BMI (p=0.005, R^2=0.04), low well-being score (p=0.03, R^2=0.12)
3: actively managing my health: Low score: 'People with low levels don't see their health as their responsibility, they are not engaged in their healthcare and regard healthcare as something that is done to them'.[25]	2.8 (0.6) Men (p=0.003, R^2=0.13), low age (p=0.03, R^2=0.07), low well-being score (p=0.02, R^2=0.09), low self-efficacy score (p=0.001, R^2=0.16)
4: social support for health: Low score: 'Completely alone and unsupported'[25]	2.5 (0.8) Living alone (p=0.002, R^2=0.14), low well-being score (p=0.01, R^2=0.10), high CAT score (more COPD problems) (p=0.04, R^2=0.06), no use of internet/computer (p=0.05, R^2=0.06)
5: appraisal of health information: Low score: 'No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information'.[25]	(2.2 (0.7)) Living alone (p=0.09, R^2=0.04), low pulmonary lung function (FEV_1) (p=0.09, R^2=0.04), more years with COPD (p=0.04, R^2=0.34), more diseases (p=0.04, R^2=0.06), low BMI (p=0.02, R^2=0.08)
6: ability to actively engage with healthcare providers: Low score: 'Is passive in their approach to healthcare, inactive, that is, they do not proactively seek or clarify information and advice and/or service options. They accept information without question. Unable to ask questions to get information or to clarify what they don't understand. They accept what is offered without seeking to ensure that it meets their needs. Feel unable to share concerns'.[25]	3.5 (0.9) Low education (p=0.06, R^2=0.06), smoker (p=0.06, R^2=0.06), low well-being score (p=0.03, R^2=0.07), low self-efficacy score (p=0.02, R^2=0.08), wrong use of medication (p=0.04, R^2=0.10)
7: navigation to healthcare system Low score: 'Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to'[25]	3.0 (0.9) Low pulmonary lung function (FEV_1) (p=0.08, R^2=0.04), more years with COPD, (p=0.08, R^2=0.15), high CAT score (more COPD problems) (p=0.04, R^2=0.08), low well-being score (p=0.05, R^2=0.08), low SE (p=0.003, R^2=0.12), more hospitalisations (p=0.05, R^2=0.06), low BMI (p=0.04, R^2=0.07), wrong use of medication (p=0.09, R^2=0.05)

Continued

Table 1 Continued

Data from the quantitative cross-sectional study	
8: ability to find good health information: Low score: 'Cannot access health information when required. Is dependent on others to offer information'[25]	3.1 (1.0) Low education (p=0.001, R^2=0.15), more years with COPD (p=0.003, R^2=0.37), high CAT score (more COPD problems) (p=0.02, R^2=0.10), low self-efficacy (p=0.001, R^2=0.13), more hospitalisations (p=0.04, R^2=0.06), need of home visits (p=0.002, R^2=0.14), wrong use of medication (p=0.10, R^2=0.05), don't use internet/data (p=0.05)
9: understand health information well enough to know what to do: Low score: 'Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms'[25]	3,5 (0.9) Low education (p=0.03, R^2=0.07), high CAT score (more COPD problems) (p=0.08, R^2=0.05), low self-efficacy (p=0.004, R^2=0.12), more hospitalisations (p=0.01, R^2=0.11), need of home visit (p=0.01, R^2=0.10), wrong use of medication (p=0.04, R^2=0.07)

CAT possible score from 0 to 40, where high score indicates more problems with COPD or high disease-specific quality of life.
In the HLQ, items are scored from 1 to 4 in the scales 1–5 (strongly disagree, disagree, agree and strongly agree) and from 1 to 5 in scales 6–9 (cannot do, very difficult, quite difficult, easy, very easy. In the Self-efficacy Scale, possible scores are from 0 to 40, where high scores indicate greater self-efficacy. In the WHO Well-being Index, possible scores are from 0 to 100, where high scores indicate greater well-being.
FEV_1: Forced Expiratory Volume in 1 s., where low value indicate low lung function
.BMI, body mass index; CAT, COPD Assessment Test; COPD, chronic obstructive pulmonary disease; FEV_1, forced expiratory volume in 1 s; HCP, healthcare care professional; HL, health literacy; HLQ, Health Literacy Questionnaire.

- People with experience living with COPD at any stage of the disease.
- Researchers with experience in COPD research.

Workshop processes, data collection and analyses

In phase II, five workshops, each lasting 2 hours, were conducted during a 3-month period. Attendance records were kept for each meeting. All meetings were held and administered at the main hospital in the specialist healthcare service. In the workshops, simple associations between HLQ scores and patient characteristics (ie, sociodemographic, clinical, COPD problems, well-being and self-efficacy) and the main themes and summary of the focus group interviews were presented, explained and discussed. The discussion of the results was guided toward identifying potential areas of HL needs, problems, goals, measures/actions, and realistic solutions and strategies for how to achieve the goals.[26] Recent COPD-related research on HL, self-management support, pulmonary rehabilitation, medication and action plans was presented in the discussion.

The main researcher has clinical and research knowledge in COPD and facilitated the workshops together with a research nurse who also had clinical knowledge of COPD. At the start of the meeting, the workshop members were informed of the backgrounds of the researcher and study nurse. The content of the workshop discussions was analysed as described in the Ophelia manual.[26] This consisted of taking workshop notes on paper and written on a whiteboard at the meetings. After the meeting, these notes were summarised and checked against an audio-recording. At the next meeting, the summarised notes were presented, and a final decision on the content was made before moving on to the next topic. Ideas for actions that could be an intervention or part of an intervention and a description on how to perform these actions were counted based on the discussions on different HL needs. All the data from all workshops were summarised to finalise the intervention at the end of the workshops (see figure 2, phase II, for more information).

Results of the HL needs assessment study presented in the workshop meetings

Results from the phase I HL needs assessment study that were presented to the participants are summarised in table 1. The information included results from the qualitative focus group interviews that had been analysed using content analysis to identify patterns and themes.[30] The previously published[27] main themes are presented with summaries of the interviews.

The results from the cross-sectional study focused on the following variables: HL as measured using the HLQ,[25] COPD problems/disease-related QOL using the COPD Assessment Test (CAT),[31] well-being using the WHO-5 Well-Being Index,[32 33] and self-efficacy using of the Generalised Self-Efficacy Scale.[34] The results also included sociodemographic variables such as, age, gender, living status, education level, smoking status, internet/computer use and whether the participant wanted a home visit, as well as clinical variables, such as the number of comorbidities, years with COPD, use of medications, hospitalisations and other clinical information (eg, lung function and body mass index). We also gave a description of the content in each HLQ domain to the workshop members.[25]

In the workshop meetings, we presented the summarised analyses as frequencies, means and SD, and the p value of associations. However, in this paper, we have presented the R^2 as a measure of explaining variance.[35 36]

Patient and public involvement

To design this study, people with COPD, the main hospital in Oslo and four municipality healthcare systems in Oslo, Norway, and national and international researchers participated in deciding on the aim, performance and outcomes of this whole study that were inspired by the Ophelia process. We had two patients with COPD involved in the need assessment study (ie, cross-sectional, focus groups) and two new patients with COPD in the co-design phase (ie, this paper). The need for starting the whole inspired Ophelia process was based on finding solutions

on how to follow up people with COPD who have several hospitalisations and to help them improve their health.

RESULTS

In total, 19 multidisciplinary HCPs participated in the workshops (ie, 7 nurses, 3 physiotherapists, 2 clinical nutritionists, 1 occupational therapist, 1 pulmonary physician, 2 people who have COPD, 1 social worker and 1 pedagogue). Of the 19 participants, 16 were women and 3 were men. The overall attendance rate was 84% across all five meetings.

In total, nine members participated in the steering group meetings (ie, four leaders from each of the four municipality healthcare sites in the home care unit, four leaders from the specialist healthcare service (a clinic manager of a medical department, a senior charge nurse of a medical ward, a senior charge nurse of a medical outpatient unit and a director of field in the administration, and one leader/researcher from the university). Five were female and four were male.

Workshop recommendations based on the focus group interviews

Table 2 presents the workshop discussion results on the four themes and the HL needs, problems, goals, actions and possible solutions (ie, how) relevant to each theme. The four themes discussed were (1) strengthening the feeling of security, (2) supporting motivation for endurance and self-management, (3) combating the burden of insufficient knowledge of COPD and lack of informational flow, and (4) strengthening dignity.[27]

The discussions were about the general HL needs of both patients and HCPs who work with patients with COPD in relation to the themes. The discussions revealed 19 action points with 30 description points for relevant and feasible solutions on how to carry out the actions. The workshop generated new ideas for interventions that either had been and not previously been tried out in the local setting. Improvement work was also proposed for existing interventions. The workshop members were eager in the discussion and actively engaged in the opportunity to develop an HL-informed intervention in COPD.

For the theme 'strengthening the feeling of security', several problems, goals, actions and solutions were identified. Patients who have problems with anxiety often connected this symptom to breathlessness. In such cases, the goal should be to reduce anxiety, and suggested actions from the workshop meetings included assisting patients with a plan for coping and providing individually tailored plans. Patients also need tailored follow-up based on their individual needs and provided by small teams of HCPs. Suggested actions included a nurse who could act as a 'bridge' between the specialist and municipality healthcare services and with multidisciplinary HCPs in situations where an individual plan on goals and actions is created and followed up after hospital discharge. In order to help patients with loneliness, it was suggested to provide patients with a designated nurse who coordinates healthcare service options and whom the patients can call if needed.

For the theme 'supporting motivation for endurance and self-management', actions that may help patients to find their inner motivation were suggested. To do this, HCPs need to have competence in how to motivate, for instance, using motivational interviewing (MI) techniques.

For the theme 'combating the burden of insufficient knowledge of COPD and lack of information flow', patients with COPD could be referred to COPD courses/rehabilitation and welfare technology programmes to improve their competence in relation to their disease. HCPs could teach the patients how and where to find reliable information on the internet, and provide individual follow-up and information on COPD-related problems and medication use, for instance, through the use of the 'teach-back method'.[37] Moreover, in order to increase the quality of the follow-up of patients with COPD, a nurse with knowledge in COPD could conduct visits with patients in their home.

For the theme 'strengthening dignity', the actions of offering the same health resources as for other diseases and using good communications strategies such as shared decision making were suggested (see table 2 for more information).

Workshop recommendations based on the cross-sectional study

Table 3 summarises the workshop participants' recommendations based on the nine HLQ domains and their associated factors. These results show that people with COPD have a wide range of potential HL challenges across sociodemographic, clinical, COPD problems, well-being and self-efficacy variables. The discussion resulted in 26 action points and 21 description points for relevant and feasible practical action solutions based on the presence of the different associations.

For instance, the discussions from HLQ domain 'feeling understood and supported by healthcare providers' was about a need for an HCP that the patient can trust and who can give information/advice and follow-up with special focus on loneliness, nutrition problems, COPD as a disease and its symptoms and psychological symptoms. The goal should be to help such patients to get in contact with HCPs who can provide follow-up assistance with nutrition, psychological and COPD-related symptoms. This process may be supported by mapping individual HL problems, COPD-related problems and coping needs and by providing individual follow-up. For example, the Conversational Health Literacy Assessment Tool (CHAT)[38] could be used to help clinicians understand patients' HL, and the CAT[3 31] could be used to map COPD-related problems.

Further, for HLQ domain 'having sufficient information to manage my health', the workshop discussed that patients need more knowledge/information with special focus on those who smoke, have nutrition problems and have psychological symptoms. The goal should be to help

Table 2 Workshop recommendations based on HL needs from the qualitative focus group interviews

Main themes from the focus group interviews	Potential patient needs and service improvement strategies			
	Potential areas of HL need	Goals	Actions	How?
1. Strengthening the feeling of security.	Anxiety (often due to breathlessness)	To decrease anxiety	1. Someone to call. 2. Anxiety coping. 3. Self-management to master distress.	1. Psychologist follow-up/psychiatric nurse. 2. Plan for coping. 3. Tailored individual plan. 4. Customised anxiety courses. 5. Self-help group.
	Different needs for follow-up	To meet the patients' individual HL needs	4. Tailored and individual follow-up. 5. Small team of HCPs.	6. Nurses that cooperate between specialist and community healthcare services. 7. Create an individual plan on goals and actions. 8. Follow-up during and after COPD courses. 9. Follow-up after hospitalisations.
	Loneliness	To increase contact network	6. Visitor service. 7. Someone to call when needed.	10. A designated nurse that helps with logistics, who coordinates healthcare services and that the patient can call if needed.
2. Supporting motivation for endurance and self-management.	Difficult for HCPs in helping patients to increase motivation	To help patients find their inner motivation	8. Knowledge of MI techniques for HCPs.	11. Arrange courses in MI and have a routine practice on using MI with patients.
3. Combating the burden of insufficient knowledge of COPD and lack of informational flow.	Patients have limited information and knowledge about COPD.	To increase competence on the disease through good communication To increase competence on medication To increase follow-up rates	9. Self-management COPD courses and/or pulmonary rehabilitation. 10. E-learning courses on the internet. 11. A nurse with knowledge of COPD. 12. Physical training courses. 13. Management of everyday life.	12. Refer to patient courses. 13. Refer to welfare technology. 14. Nurse teaches patients on technology 15. Individual follow-up and information on COPD-related problems using shared decision making. 16. Use the teach-back method to inform.
	Limited knowledge about COPD among HCPs	To increase knowledge of COPD for HCPs	14. Education of HCPs in the community service about COPD.	17. COPD coordinator in every community. 18. A nurse who can serve as a connection between the specialist healthcare service and the community healthcare service. 19. Courses for HCPs on medicine, equipment and how to follow-up patients with COPD. 20. HCPs visit each other's workplace. 21. A nurse who educates the HCPs in the community service when needed.
	A need to follow-up on patients with COPD	To increase the amount and quality of follow-up consultations	15. Rapid appointments at outpatient units.	22. Appointment with a respiratory nurse and a respiratory physician. 23. A COPD nurse who visits the patients at home.
	Information flow	To increase information flow between specialist healthcare service and the community healthcare services	16. Improved connections between those who care for the patients.	24. A nurse position. 25. All in the multidisciplinary team have a responsibility to give information. 26. Electronic messages to all HCPs.
4. Strengthening dignity.	Stigma (different available health services in other diseases such as cancer and patients are not included in decisions)	To increase dignity	17. Same health offers as other diseases. 18. Shared decision making.	27. A nurse contact person on COPD. 28. Teach HCPs about shared decision making.
	HCP's attitude	To change how HCPs work and communicate with patients	19. Communication.	29. Communication courses. 30. Listen to the patient's needs and thoughts.

.COPD, chronic obstructive pulmonary disease; HCP, healthcare professional; HL, health literacy; MI, motivational interview.

such patients to increase their motivation to stop smoking by using different smoking cessation strategies (eg, medication and MI) and discuss how to reduce psychological symptoms and nutrition problems.

For the HLQ domain 'navigation in the healthcare system', the need was to help people with COPD to get information on where to find help and coordinate help in the healthcare system with focus on those who have low lung function, have lived with COPD for many years, have more COPD problems, have more psychological problems, need help to cope with the disease, have more hospitalisations, need nutrition follow-up and use their medication wrong. The goal should be to increase patients' knowledge about where to find the right healthcare help. This could be provided, for instance, by giving information on who and where to contact by having easy-to-access and updated lists for different healthcare tasks in the municipality and specialist healthcare services. The use of medications should be mapped, and inhalation medications and technical equipment, such as oxygen

Table 3 Workshop recommendations for service improvements based on HL needs and associated clinical and sociodemographic variables from the cross-sectional study

Potential patient needs and service improvement strategies				
HLQ scales (n=69)	Potential areas of health literacy need	Goals	Actions	How?
HLQ scale 1: feeling understood and supported by healthcare providers	An HCP the patient can trust and who can give information/advice and follow-up with special focus on loneliness, nutrition problems, COPD as a disease and its symptoms and psychological symptoms	To help patients to get in contact with healthcare providers, with nutrition, psychological symptoms and COPD-related problems	1. Provide contact with a nurse who has knowledge of COPD treatment and problems. 2. The nurse will be the person that patients can call. 3. Map individual health literacy, COPD and coping needs. 4. Map smoking status. 5. Offer home visits. 6. Provide coordinator to help with different health resources. 7. Provide individual follow-up. 8. Nutrition follow-up. 9. Teach HCPs how to help patients in regard to smoking cessation, COPD problems, medication use, technical equipment (oxygen, nebuliser and weaning) and how to follow-up psychological issues. 10. Repeat information that is provided (teach-back method) 11. Use existing e-learning programmes on the internet (such as medication use). 12. Teach and practice use of medications and technical equipment (oxygen equipment, nebulizer and weaning equipment). 13. Motivate the patient to cope with their disease. 14. Psychiatric follow-up. 15. Treatment plans.	1. A nurse who can coordinate, have good knowledge of COPD and its treatments, be the person that the patient can call and follow-up individual needs based on individual problems. 2. The nurse can coordinate contact with persons between community healthcare service and specialist healthcare service. 3. The nurse may follow-up with the patients at home. 4. The nurse uses different strategies (ie, medication knowledge and motivational interview) to help patients stop smoking. 5. Use developed mapping instruments to assess patients' individual health literacy and coping needs. 6. Check inhalation and medication use and technique. 7. Check use of oxygen equipment, nebuliser and weaning equipment. 8. Teach individuals about medications and technical equipment. 9. Smoking cessation courses/individual follow-up. 10. COPD courses/self-management courses and/or pulmonary rehabilitation programmes in the specialist healthcare service or the community services.
HLQ scale 2: having sufficient information to manage my health	Patients need more knowledge/ information with special focus on those who smoke, have nutrition problems and have psychological symptoms.	To increase knowledge about how to stop smoking, to reduce psychological symptoms and to reduce nutrition problems		
HLQ scale3: actively managing my health	Help patients on how to cope with their disease with special focus on men, those with low age, and with psychological symptoms	To increase the patients' engagement in how to actively manage their disease through practice and contact with healthcare providers		
HLQ scale 4: social support for health	To help with social support with special focus on those who live alone, with psychological symptoms, with more COPD-related problems and who do not use the internet and/ or computers	To increase social support to the patients who live alone and follow up on their psychological symptoms and COPD-related problems and help to understand how to use internet/computer and to find places to get social support		
HLQ scale 5: appraisal of health information	Help with the understanding of health information with special focus on those: with low education, who have had COPD for several years, with comorbidities, with low pulmonary function and with nutrition problems	To help patients to critically understand the health information they receive on COPD, other diseases and nutrition		

Continued

Table 3 Continued

Potential patient needs and service improvement strategies				
HLQ scales (n=69)	Potential areas of health literacy need	Goals	Actions	How?
HLQ scale 6: ability to actively engage with healthcare providers	Help to actively engage with their own disease with special focus on those who live alone, need help to cope, smoke, have psychological symptoms, use their medication wrong and need of home visits	To increase the patients' engagement in asking and contacting HCPs when needed and they don't understand, motivation to use medications in the right way, at the right time and understand the difference between different types of medications and self-efficacy to help patients stop smoking	16. Routine appointments. 17. Shared decision making. 18. Help patients to increase their network through visitor service and day care offers. 19. Give information in different ways: written, demonstrate technical devices and let the patient try. 20. Be aware of changes in treatment, severity stages and exacerbations. 21. Give information on who and where to contact when they have a problem. 22. Help patients to talk about their difficulties. 23. Help the patient to find the information and healthcare services. 24. Give telephone numbers and contact information. 25. Teach the patient to use internet and computers/tablets to find information. 26. Teach the patient to use welfare technology.	11. Use movies from the pharmacy companies. 12. Provide regular motivational interviewing courses for the HCPs that follow up the patients. 13. Design medication action plans, teach, follow up/update and repeat/update the patient on how to use this. 14. Schedule routine follow ups based on individual issues. 15. Coordinate psychiatric follow-up when needed. 16. Learn how to include patients in decision making. 17. Refer to voluntary visitors and day care centres. 18. Motivate patients to use community centres where people can meet, eat, be physically active and attend to COPD courses/pulmonary rehabilitation programmes. 19. Have a system to update a list over different health tasks in the community and who to contact. 20. Use standardised questions in communicating with patients on how to talk about their ability to actively engage with healthcare providers (eg, the CHAT). 21. Get in contact with welfare technology services on the patients' behalf
HLQ scale 7: navigation to healthcare system	Help to get information on where to find help and coordinate help in the healthcare system with focus on those who have low lung function, have lived with COPD for many years, have more COPD problems, have more psychological problems, need help to cope with the disease, have more hospitalisations, need nutrition follow-up and use their medication wrong	To increase knowledge on where to find the right help in the healthcare system on help when they have exacerbations and need of hospitalisation, to cope with their disease and medications and nutritional problems		
HLQ scale 8: ability to find good health information	Help to find the right health information with special focus on those with low education, who have lived long with COPD, with more COPD problems, who have had hospitalisations, who use their medication wrong and who do not use internet/computer to find information	To increase the patients' understanding of where to find the right sources of information on the internet and other places on topics such as COPD, how to cope with their disease and use of medications		
HLQ scale 9: understand health information well enough to know what to do	Help to use the information in the right way so the patients know how to: deal with COPD problems, deal with exacerbations and use their medications correctly.	The patients understand and cope with their COPD-related problems and know which medications to use when they have exacerbations.		

Items are scored from 1 to 4 in scales 1–5 (strongly disagree, disagree, agree and strongly agree), and from 1 to 5 in scales 6–9 (cannot do, very difficult, quite difficult, easy and very easy).
CHAT, Conversational Health Literacy Assessment Tool; COPD, chronic obstructive pulmonary disease; HCP, healthcare professional; HL, health literacy; HLQ, Health Literacy Questionnaire.

therapy, nebulisers and respiratory support treatment, should be individually adjusted to each patient. HCPs should be more aware of giving information on who and where in the healthcare system patients may seek consultation to get help for their health problems. Lastly, after hospitalisation, COPD patient follow-up should be provided at home in order to reduce hospitalisations. Some of the ideas were given several times to the different HLQ domains and thus were not presented as separate ideas to each HLQ domain (see table 3 for more information).

Final co-designed HL-informed intervention for people with COPD

Based on the specific action points described in tables 2 and 3, the workshop members recommended a final version of the HL-informed intervention, which was proposed to steering group members.

The subsequent discussion in the steering group was about finding both practical and financial solutions to the intervention that was proposed. The steering group was positive about the intervention and expressed ownership of the project. As a result, all partners (the hospital and its four districts in the municipal health service) decided to share the operating costs of a nurse to follow up patients with COPD in the HL-informed intervention.

The follow-up should be home-based after discharge from the hospital to reach those with severe disease and those who normally have difficulties reaching the outpatient units and attending doctor appointments. Given the complexity of COPD, the patients' needs vary greatly, and the intervention should therefore be tailored individually based on patients' HL and health needs and self-management. This could be operationalised through nurses being trained in clinical, community and social issues of COPD. Further, to give nurses a tool for motivating patients, MI techniques should be learnt. Importantly, the nurses need increased confidence and competence through specialised education in COPD pathophysiology, medications, technical equipment, self-management tasks, and how to build and sustainably implement tailored action plans. The nurse should function as a coordinator between multidisciplinary HCPs in the municipality and the specialist healthcare services. A list of actions (see table 4) was made based on the possibilities in the local community for nurses in the follow-up of patients with COPD. The outcomes recommended to be used to evaluate the effectiveness of the intervention were hospitalisation, HL, self-management, experience of symptoms and QOL.

DISCUSSION

Bringing together patients with COPD, HCPs and researchers working with COPD and discussing results from an HL needs assessment study made it possible to develop a HL-informed intervention that may improve services and meet the complex HL needs of people with COPD and improve their outcomes.

An HL-informed intervention focused on the follow-up of people with COPD after hospitalisation using MI techniques, tailored follow-up based on their individual HL, self-management and disease-specific QOL needs, and in cooperation with multidisciplinary HCPs in the specialist and municipality healthcare services was suggested. The co-designed intervention gave ownership to all partners and resulted in a joint responsibility for implementation and financial costs. Co-designing research has been suggested as a priority in clinical trials, but research priorities seem to be inconsistent.[39] For instance, in a recent systematic review, patients suggested research priorities that focus on psychosocial consequences and disease education, while HCPs suggested research priorities that focus on their attitude, roles, education, communication and effectiveness. [40] By using data obtained from both qualitative focus groups with people with COPD and HCPs and a cross-sectional study of people with COPD, it was possible to identify the HL needs of both patients with COPD and the HCPs who work with them in a local setting. The workshop discussions made it possible to identify problems and goals and to provide suggestions for actions to reach these goals.

Although it requires more research, the Ophelia process has been found to successfully implement interventions.[22 23] The Ophelia process informed us and gave us the opportunity to let all partners access ownership of the study. Solutions that were feasible and within an economical financial framework were suggested, which should make the intervention more implementable.

Tailored follow-up has previously been tested in COPD and shown to have beneficial effects on medication adherence.[41] Pulmonary rehabilitation programmes and self-management programmes also aim to provide tailored follow-up for people with COPD[42 43] and show effectiveness on respiratory symptoms, hospital readmission and healthcare costs, as well as coping and QOL.[5–7] Moreover, tailoring interventions with home follow-up by nurses has been found to reduce disease-related symptoms in COPD.[44] However, these interventions have not been tested to meet individual HL needs or evaluated on HL effectiveness. Thus, testing tailored follow-up care in relation to patients' HL needs may have an additional benefit for people with COPD.

HCPs' knowledge of MI is likely to be highly relevant to providing effective follow-up for patients with COPD. MI is a counselling method that involves enhancing a patient's motivation to change. MI counsellors rely heavily on core communication skills, such as open-ended questions, reflective listening, affirmations, summarising and eliciting change talk.[45] Thus, using MI may not only help patients with COPD to feel more secure and more motivated for endurance and self-management, but may also strengthen their feeling of dignity by being met and communicated with in a positive and supportive way. MI has been shown to be effective for a broad range of

Table 4 Summary of actions selected for use in the intervention

Standard tasks/actions provided to all patients in the intervention group	
Breathing exercises	Nurses will provide patients with training and practice with pursed lip breathing, diaphragmatic breathing, slow breathing, deep breathing or device-guided breathing.
Medication and medication action plan	Nurses will work with patients to ensure the correct use of medications and understanding of their medication action plan.
Use of technical medical equipment such as oxygen therapy, home respirator and nebuliser	Nurses will follow-up with patients on the correct use of medical equipment.
Individualised tasks/actions that patients can choose from	
Psychological stress follow-up	Recommendations regarding local community resources on coping with depression will be provided to the participants. If needed, the patients will be referred to a psychologist by the pulmonary physician or the patient's main doctor.
Welfare technology	A tablet computer will be given to participants so that they can measure their oxygen levels and pulmonary lung function, schedule and monitor their medication taking and engage in distance follow-up of their symptoms. The welfare technology and distance follow-up are provided by the community healthcare service.
Smoking cessation	Individual follow-up and advice on how to stop smoking will be provided following the Norwegian health directorate method using motivational interviewing techniques together with nicotine products such as tablets, patches and gums.
COPD self-management course in groups at the hospital	Information and discussion of COPD as a disease, medication/inhalation, medication action plan, smoking cessation, physical activities, social rights, nutrition and dental health are provided by an interdisciplinary team over 3 days (5 hours each day). Individual follow-up with nurses at the outpatient unit (3–4 appointments) and if needed with a physiotherapist, social workers, nutritionist, and pulmonary doctor at the outpatient unit.
Pulmonary rehabilitation	Pulmonary rehabilitation, a hospitalisation of 4–6 weeks with physical activity and self-management tasks (described in the aforementioned self-management course) delivered by an interdisciplinary team.
Nutritional advice	Nurses will give nutrition advice based on advice from a nutritionist. If needed, oral healthcare will be provided.
Physical training groups	Weekly training groups tailored to patients with COPD will be provided for 20 weeks by a physiotherapist at the hospital.
Healthy life centre	Nutrition courses, quitting smoking courses, physical training groups or mindfulness courses
Visitation service	Voluntary organisations such as the Red Cross and local churches have volunteered to visit patients who need this.
The office of applications in the home care service	► Service from nurses who provide help with personal healthcare such as showering, clothing and wound care. ► Service from physiotherapist who helps increase activity at home ► Service from occupational therapist who helps with assistive devices such as shower chair and labor-saving methods. ► Service from psychiatric nurses with help to solve special psychiatric problems. ► Nutrition help and practical guidance on how to make nutritious breakfast, lunch, dinner and evening meals. ► Everyday rehabilitation with help from a multidisciplinary team in the home care service (note that only those in special need of this service will receive everyday rehabilitation and eligibility is determined by the visitation service). ► Home cleaning for those in need, such as cleaning floors, bath and kitchen. ► Shopping by the use of telephone and internet, different systems used in different sites. ► Day centre serving food and having activities for patients on site. ► Other actions that the community healthcare service may offer. Note that home care service can only be provided to those given priority for it by the healthcare service.
Information on how to navigate the healthcare service	Nurses will guide patients on how to find information on health issues, find contact information for the healthcare services, use electronic devices and apply for taxi service funding.
Information booklets	Information booklets on COPD, pulmonary organisations such as the Norwegian Heart and Lung Patient Organisation and the Norwegian Asthma and Allergy Organisation, and from the Norwegian government will be given to patients when needed.

COPD, chronic obstructive pulmonary disease.

diseases and problems.[46–48] In COPD, the method has been shown to positively impact patients' perceptions of their disease-related problems and to reduce hospital readmission.[49]

Our study methods differed in several ways from the HL-informed intervention development system described as the Ophelia process.[22 24 26] First, we did not perform a cluster analysis on the HLQ in order to identify strengths, limitations and preferences of our target population.[22 24 26] The cluster analysis would have provided more information about unique groups than our analysis of the means and associations of the nine domains of the HLQ. However, at the time we started the codesign phase, we considered the sample of 69 too small to perform the cluster analysis. Second, we did not generate vignettes based on the HLQ cluster analysis and qualitative interviews. In the Ophelia process, the vignettes help workshop members to recognise and relate to the narrative

to generate solutions.[26] This method has previously been used as a unique method to assess HL in a population[50] and has helped stimulate ideas for solutions in several workshops.[22 23 50] However, in the co-design phase of our study, we presented the themes and summaries from the qualitative focus group interviews that we had performed in the needs assessment study of phase I. These summaries may have functioned in the same way as the vignettes.

Our method of using summaries from the focus group interviews and presenting the means and associations of the nine HLQ domains from the cross-sectional study in the workshops may be the reason why the co-design ended in a tailored intervention and was not focused on a specific group of patients such as immigrants or people affected by social inequities. Such groups have in previous literature been shown to have HL challenges.[51]

In our workshops, we presented associations between the nine HLQ domains and a broad selection of other patient variables. The explained variance in these analyses ranged from 4% to 34%, with most being less than 10%. Our aim in the co-design phase was not to perform hypothesis testing but rather to inform the workshop members of potential HL needs, engage them and find solutions to developing and implementing an HL-informed intervention for people with COPD in a local setting that in the end may help the patients with their disease and improve their coping and QOL. The effect of an HL intervention like this must be tested in future studies.

CONCLUSION

The workshop groups generated several ideas on how to help people with COPD with their individual HL needs in order to promote and maintain good health outcomes such as reduced symptoms and hospitalisations and improved self-management and QOL. People with COPD need tailored follow-up based on their individual HL needs by HCPs that have knowledge of COPD and are able to motivate them on self-management tasks and help them to improve their QOL, and decrease hospitalisation. Further research is needed to evaluate the recommended HL intervention of a tailored follow-up and MI techniques based on individual HL, self-management and disease-specific QOL needs after hospitalisation and in cooperation between multidisciplinary HCPs in the specialist and municipality healthcare services.

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