PERSONAL GOAL SETTING IN PATIENTS WITH COPD AND COMORBIDITIES

Masterproef voorgelegd tot het behalen van de graad van Master in de Verpleegkunde en Vroedkunde

Door Mieke Lanssens

Promotor: Prof. Dr. An De Sutter
Co-promotor: Pauline Boeckxstaens
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Abstract

BACKGROUND: Patients with multiple chronic diseases are usually treated according to disease-specific guidelines focusing on bio-medical targets (e.g., blood sugar levels or lung function measurements). However, multimorbidity seems to ask for a goal-oriented approach aimed at patient-centered outcomes. Despite the clear advantages to include patient defined goals into clinical decision making for multimorbidity, this approach has not been investigated. COPD (Chronic Obstructive Pulmonary Disease) is a chronic disease which clearly challenges its current management. The disease-specific approach consisting of inhalation therapy and longfunction measurements have shown no effect on mortality, deteriorating lung function, patients’ functionality or quality of life (QoL). Moreover, COPD patients often suffer from comorbid diseases.

OBJECTIVES: This study aims to identify personal goals in patients with multimorbidity and search for underlying factors and mechanisms determining why patients appear to have difficulties to define their personal goals

DESIGN: Qualitative analysis of 19 interviews performed in patients diagnosed with COPD and comorbidities.

RESULTS: Participants appear to have difficulties defining goals. We defined four underlying hypotheses which may explain this finding: patients can-not identify with the concept of goal setting, goal setting is minimized due to acceptation, stressors have priority over personal goal setting and patients consider personal goals as selfish.

CONCLUSION: Despite the hypotheses on why patients would not define personal goals, we still tend to believe that multimorbidity asks for a goal-oriented care approach. It seems most important to differentiate between whether patients don’t have the need to set goals or whether they are hampered by external factors.

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# Table of Contents

Abstract ................................................................................................................................. I

Table of Contents ................................................................................................................... II

Acknowledgements ................................................................................................................ IV

Introduction ............................................................................................................................ 1

1.1. Problem statement ........................................................................................................ 1

1.2. Situation of the thesis within a larger study .................................................................. 3

1.3. Research question ......................................................................................................... 4

1.4. Added value to nursing practice ................................................................................... 5

1.5. Added value at the level of health care policy ............................................................. 5

1.6. Personal motivation ...................................................................................................... 6

1.7. Structure of the thesis .................................................................................................. 6

2. Problem statement .......................................................................................................... 7

2.1. Search Strategy ............................................................................................................ 7

2.2. Representation in the scientific literature ..................................................................... 7

2.3. Prevalence of chronic disorders .................................................................................. 8

2.4. Prevalence of multimorbidity ....................................................................................... 8

2.5. Need for a different approach in multimorbidity ......................................................... 9

2.6. The goal-oriented approach ......................................................................................... 10

2.6.1. Content and use of the goal-oriented approach ....................................................... 10

2.6.2. The value of the goal-oriented approach within multimorbidity ........................... 10

2.6.3. The role of health care providers in goal-oriented care ......................................... 11

2.7. Chronic Obstructive Pulmonary Disease (COPD) ..................................................... 12

2.7.1. The impact of COPD on health(care) ...................................................................... 12

2.7.2. The value of goal-oriented care within patients with COPD and comorbidity ... 13

3. Methodology ................................................................................................................... 14

3.1. Qualitative research ................................................................................................. 14

3.2. Research population and recruitment ...................................................................... 14

3.2.1. Phase one of the recruitment ................................................................................. 15

3.2.2. Phase two of the recruitment ................................................................................. 16
3.3. Interviewing techniques ................................. 17
3.4. Patients’ characteristics ................................. 18
3.5. Data collection and data analysis .......................... 19
  3.5.1. Data collection .................................... 19
  3.5.2. Data selection, coding and analysis .................. 20
3.6. Validity .................................................. 21
  3.6.1. Validity of the data collection ......................... 21
  3.6.2. Validity of the data analysis ......................... 22
4. Results ...................................................... 23
  4.1. Identifying personal goals ................................ 23
  4.2. What makes it so difficult to identify personal goals ... 24
5. Discussion .................................................. 29
  5.1. Summary of main findings ................................ 29
  5.2. Comparison with existing literature ..................... 29
  5.3. Strengths and limitations of the study .................. 31
  5.4. Implications for practice and for further research ..... 32
6. Conclusion .................................................. 34

Bibliography .................................................. 35

Appendices ................................................................

Appendix A: The article: Personal Goal Setting in Patients with COPD and Comorbidities ...II
Appendix B: The Canadian Occupational Performance Measure ..................................... XVI
Appendix C: Informed consent document attn. the management of ‘Wit-Gele Kruis West-Vlaanderen’ ................................................................. XX
Appendix D: Informed consent document attn. the nurses of ‘Wit-Gele Kruis West-Vlaanderen’ ............................................................. XXIV
Appendix E: Informed consent document attn. the GP ............................................ XXVIII
Appendix F: Informed consent document attn. the participant .................................... XXXII
Appendix G: Patients’ Characteristics .......................................................... XXXVI
Appendix H: Summary in Dutch ............................................................. XXXVIII
Acknowledgements

Completing a thesis is the final step to graduate, at the same time it is a first step in qualitative research. This thesis was an opportunity to transfer my theoretical knowledge into a personal study. However, this thesis could only be realized thanks to the support and effort of many others. Therefore, I will attempt to say a special thank you to those who made it possible.

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Third, the organization ‘Het Wit-Gele Kruis West-Vlaanderen’ for their cooperation to the study. In particular, I would like to thank my supervisor Joost Moeyaert, for his help in the search for possible participants. This involved some difficulties, but he never lost hope our weakened his efforts.
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Introduction

1.1. Problem statement

Ageing of the population implies a rising prevalence of chronic diseases, including a rise in multimorbidity: more than half of patients aged over 65 have two or more chronic diseases and 20% even have more than five [1]. The population of multimorbid patients will keep growing in the next decades. Despite the rise in multimorbidity, our current health care is not ready to tackle it in an appropriate way. Many studies have repeatedly reported the increasing prevalence of multimorbidity as a threat because evidence-based medicine has mainly been developed for single diseases [2]. The usefulness of the current disease-specific guidelines and disease management programs is limited in case of multimorbidity, due to complex needs in patients with multimorbidity [3]. Goal-oriented care has been suggested as an approach to tackle many of the challenges encountered in patients with multiple chronic diseases [3] [4]. The underlying idea is that explicitly focusing on patients personal goals instead of on biomedical outcome measures such as blood sugar levels or lung function measurements (i.e., disease-centered or problem oriented care) could be helpful in providing care which is tailored to the individual context of the patient (Table 1 compares problem-oriented care and goal-oriented care). Despite the clear theoretical and conceptual advantages of including patient-defined goals into clinical decision making for multimorbidity, this approach has not yet been investigated.
Table 1: Problem-oriented versus Goal-oriented care

<table>
<thead>
<tr>
<th></th>
<th>Problem-oriented care</th>
<th>Goal-oriented care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition of Health</strong></td>
<td>Absence of disease as defined by the health care system</td>
<td>Maximum desirable and achievable quality and/or quantity of life as defined by each individual</td>
</tr>
<tr>
<td><strong>Purposes of Health Care</strong></td>
<td>Eradication of disease, prevention of death</td>
<td>Assistance in achieving a maximum individual health potential</td>
</tr>
<tr>
<td><strong>Measures of success</strong></td>
<td>Accuracy of diagnosis, appropriateness of treatment, eradication of disease, prevention of death</td>
<td>Achievement of individual goals</td>
</tr>
<tr>
<td><strong>Evaluator of success</strong></td>
<td>Physician</td>
<td>Patient</td>
</tr>
</tbody>
</table>

Chronic Obstructive Pulmonary Disease (COPD) is an illness that often occurs with one or more comorbid disease(s) [5]. Moreover, the disease-specific approach with inhalation therapy has shown little or no effect on mortality or deteriorating lung function. Furthermore, the correlation between lung function measurements and patients' functionality and quality of life (QoL) is limited [6-8]. Therefore, COPD challenges the current established problem-oriented approach. Goal-oriented care with a greater focus on patient-centeredness could be a more suitable approach for patients suffering of COPD. Despite the clear theoretical and conceptual advantages of including patient-defined goals into clinical decision making for multimorbidity, this approach has not yet been investigated. Therefore, this study tries to deliver more insight into the process of individual goal setting, in order to provide goal-oriented care. It accentuates the importance of a paradigm shift from problem-oriented care towards goal-oriented care in patients with COPD and other comorbidities.
A first prerequisite to introduce goal-oriented care would be to gain more insight into patients’ personal goals. This study aims to identify personal goals in patients with multimorbidity using the case of COPD and comorbidity. Additionally, this study tries to deliver more insight into the process of individual goal setting, in order to provide goal-oriented care.

1.2. Situation of the thesis within a larger study

This thesis is a part of a larger study on personal goal setting in patients with COPD and comorbidity which was performed within the department Family Medicine and Primary Health Care at the University of Ghent. The main study concerns a qualitative research and was performed in three phases which are illustrated in Table 2. Based on new insights the researchers were repeatedly compelled to adjust the interviewing strategies.

In phase 1, open interviews were executed by three general practitioners (GP’s) (PB, PVDS, MDR). The results of phase 1 have been published in Chronic Respiratory Disease. The main conclusion of this study was that patients did not mention their personal goals spontaneously in a setting of open interviews [9]. The article emphasizes the need for further research focusing on how to elicit personal goals in patients with COPD and comorbidities in order to be able to tailor care to their complicated needs. In phase 2, the interview strategy was changed to semi-structured interviews focusing on patients’ expectations towards GP’s and discussing patients’ functional status. The researchers assumed that questioning the expectations towards the GP would provide a better understanding of the health-related goals. However, these expectations were not fulfilled. Goals were still difficult to elicit [10]. In phase 3, the Canadian Occupational Performance Measure (COPM) was introduced as a semi-structured interview guide (Appendix B). This instrument has been developed and validated for goal-setting in occupational therapy [11]. In this phase, deviant cases were sought to obtain a more heterogeneous group. Because, during the analysis of phase 2, the hypothesis arose that participants might not easily talk on personal goals with GPs, the semi-structured interviews in phase 3 were taken by a GP or by a nurse.

I got involved in the main study after phase 2. I was actively involved in the recruitment of participants and the data collection of phase 3. Furthermore I have actively
contributed to the data analysis, interpretation of the results and the writing of the article which were based on phase 1-3 of the study.

Obviously, the main document is the article (cf. Appendix A). In addition, this thesis describes in detail every aspect of the study to which I have contributed.

Table 2: Stepwise approach to patient inclusion and interview technique

<table>
<thead>
<tr>
<th>Phase</th>
<th>Interview Technique</th>
<th>Patients inclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase 1</strong> [10]</td>
<td>Open interviews</td>
<td>Five GP’s included ‘common’ patients with COPD and comorbidities.</td>
</tr>
<tr>
<td><strong>Phase 2</strong> [11]</td>
<td>Semi-structured interviews focusing on patients expectations towards general practitioners and patient’s functional status</td>
<td>Two GP’s included ‘common’ patients with COPD and comorbidities</td>
</tr>
<tr>
<td><strong>Phase 3</strong></td>
<td>Semi-structured interviews based on the Canadian Occupational Performance Measure (COPM)</td>
<td>One GP included ‘common’ patients with COPD and comorbidities including deviant cases (e.g. patients who were still working). One nurse included patients with COPD and comorbidities in a community nursing setting.</td>
</tr>
</tbody>
</table>

1.3. Research question

As the observations in both phase 1 and phase 2 led to the assumption that patients uneasily define individual goals, the major question formulated by the researcher still remains: ‘How to identify personal goals of patients with COPD and comorbidity?’
Besides the identification of personal goals of patients with COPD and comorbidities, this study will explore the underlying factors and mechanisms determining why patients appear to have difficulties to define and express their personal goals.

1.4. Added value to nursing practice

This qualitative study on personal goal setting in patients with COPD and comorbidities could allow nurses to obtain a new perspective on patients’ personal priorities. By being receptive to the stories and experiences of patients, nurses can be encouraged to provide good quality care for patients with multimorbidities, which is more personalized taking into account individual patient goals. In addition, by illuminating possible hypotheses on why the goal setting process seems to be difficult, this study could also assist nurses, who take care of patients with multimorbidities, to be attentive and supportive to goal-oriented care. Nurses who understand the goal-setting process of the patient are better placed to become facilitators of patients’ management. This thesis could intensify the awareness of the content of their role as a nurse in interdisciplinary (primary) care teams.

1.5. Added value at the level of health care policy

Currently, health care systems are shaped based on a problem-oriented and disease-specific approach with the continuous development of disease management programs which are not always useful for patients with multiple chronic diseases. At the policy level, the results of this thesis could contribute to a paradigm shift towards health care services which are more suited to tailor care to patients’ individual needs and goals. Changes at the policy level will not only include dialogue with people in need of health care but also require a dialogue with the providers (at practice- and policy-level). Throughout the possible reformation of care towards a more goal-oriented approach, the responsibilities of (head-) nurses will probably increase. From the health care managers, this requires a reflection of their health care organization. This thesis assesses and analyzes the individual needs of patients with the intention to allow the existing health care to respond to the results of this report, therefore the study can be an incentive to use a more ‘goal-oriented approach’ in primary practices. However, this study can only be a
first step. The reformation of care implies structural adaptations upon micro-, meso- and macro level. The ultimate goal is to provide high-quality care that meets the needs of people with COPD and comorbidity.

1.6. Personal motivation

During my work as a community nurse, my interest for the subject was caught by seeing the burden and disabilities of patients suffering of multiple chronic diseases. Taking the first interviews stimulated me even more to further explore this disease from the patients’ point of view. As a student ‘Master of Science in Nursing and Midwifery’ I hope to contribute to the enhancement of the current health care practices in order to strive for most qualitative care for patients.

1.7. Structure of the thesis

The corpus of this thesis is constructed according to the structure of the article, consisting of the sections introduction, background, methodology, results and discussion.
2. Problem statement

2.1. Search Strategy

The literature search for this study focused on the main topics of this work: multimorbidity, comorbidity or COPD (combined with other search terms in a search filter). The articles were assessed and evaluated by reading respectively the title, the abstract or the whole study to decide whether to include or exclude an article. Relevant articles were searched within the databases of PubMed, Web of Knowledge, and Google Scholar. Several limitations were applied which determined the selection of the articles. Only English, Dutch or French texts were selected. There were no geographical or demographical restrictions applied. Concerning the publication date only studies that were published between 1998 and 2013 were consulted in order to collect and compare up-to-date information. The exception was made for Knotterneus, Metsemaker, Höpperer and Limonard [12] and Mold, Blake and Becker [13] because they contained useful data.

The articles were assessed and evaluated by reading respectively the title, the abstract or the whole study to decide whether to include or exclude an article. Furthermore, four articles were retrieved out of the bibliography of other included articles. In addition, some articles about a certain issue were specifically searched to profound the subject (e.g., shared decision making [14]).

A total of 28 articles and 2 websites were used in the literature study

2.2. Representation in the scientific literature

The research interest on patients with multimorbidity is growing rapidly [15]. Although, research on COPD is over-represented in the literature, it had been mainly focusing on patients with only this disease. There has been limited exploration of COPD in combination with other comorbidities, even though other chronic conditions frequently occur within COPD patients. Patients with multimorbidity are usually excluded from the studies. However, the impact of comorbidities –next to COPD- on patients’ QoL is
considerable. Therefore, including patients with comorbidities in this study is an attempt to obtain results representing the primary care population suffering from COPD.

This study can of added value to the literature, because patients with COPD and other comorbidities become rather the rule than the exception in clinical care. Although multiple studies confirm that defining patients’ individual goals in primary care practice increases the quality of health care, to our knowledge, this study is the first to focus specifically on the process of goal setting at the level of the individual patient with COPD and comorbidities.

2.3. Prevalence of chronic disorders

Due to medical and social advances, the general health degree within the nation has improved spectacularly during the last few decades and consequently, mortality rate has drastically lowered. However, this increase of life-expectancy has also led to an increased prevalence of chronic disorders and disabilities [16]. Over the last century, chronic health problems have replaced acute diseases that used to be fatal as the dominant health care burden [17]. Worldwide, chronic diseases have become the leading cause of mortality, representing 60% of all deaths [18]. In Belgium, one out of four adults suffers from at least one chronic disease [19].

2.4. Prevalence of multimorbidity

A chronic disease rarely appears isolated, they often co-occur. The population of (primary care) patients with multiple coexisting medical conditions is rapidly growing [2]. The terms ‘multimorbidity’ and ‘comorbidity’ are frequently applied in this context. Multimorbidity is defined as the co-occurrence of two or more long-term conditions in an individual [19]. The term ‘comorbidity’ refers to the combination of additional diseases beyond an index disorder. This definition implies that an index condition is the main interest (in this study, the index condition is COPD) but, possible effects of additional diseases beyond the index disease are also of influence on the health experience of the patient [17] [18].
From the available data, the prevalence of multimorbidity within the Belgian population is counted between 10 and 20% within the group of 40-year olds and increases towards a range of 50 to 70% at an age of 72 or older [19]. Other epidemiological studies (covering different European countries such as Spain, France, the UK, etc.) estimate that 50 to 60% of patients with a chronic disease additionally have one or more comorbid conditions [12] [20] [21]. Moreover, the number of disabilities is greater and the general health status and QoL may decline more rapidly among those with multiple chronic conditions [20] [21]. For a patient, multimorbidity may include profound implications because the degree of physical and social disability rises with the number of medical conditions [20].

2.5. Need for a different approach in multimorbidity

Therefore, it is not surprising that increasing attention has been directed toward managing multimorbidity [21]. The disease-specific guidelines of the current established problem-oriented care may not be capable of meeting the complex needs of patients with multiple chronic diseases. Therefore, multimorbidity asks for an integrative approach which addresses the different dimensions of the multiple conditions (biological, psychological, and social dimension). Care should ensure respect for and responsiveness to individual patient needs and priorities, and should fit clinical decisions along patients’ personal values, i.e., it should incorporate patient-centeredness within primary health care [4] [14] [19]. Unfortunately, the importance of patient-centered care is widely acknowledged, but poorly applied in primary clinical practice. Especially in case of multimorbidity, providing patient-centered instead of disease-centered care could be of high added value to guide complex clinical decisions. As such multimorbidity could serve as an excellent use case to support and encourage this transition. If we want to adopt goal oriented care for our patients with multiple chronic conditions this calls for the identification of the patient’s personal goals and needs in order to set up priorities from his/her own perspective upon which health care can be adapted.
2.6. The goal-oriented approach

2.6.1. Content and use of the goal-oriented approach

The goal-oriented approach, originally composed by Mold, Blake & Becker [13] implies that health is defined from the perspective of the patient (instead of the provider or the health care system). Therefore, the patient defines personal priorities with respect to his/her health. Patients set goals (induced from those priorities) in order to achieve maximum desirable quality and/or quantity of life as defined by each individual. The goals, to improve patients’ health and QoL, are adjusted to the functional disabilities and personal perceptions and experiences. They assist patients in achieving a maximum individual health potential. Through the combined efforts of both the individual and the health care provider, health goals can be determined. It requires an assessment of personal strengths and resources, interests and needs, and personal values [13]. This approach can only be successful if the patient’s goals are achieved. Moreover, goal attainment could even be used to assess treatment effectiveness [4]. Therefore, the construction of goals should be acceptable and realistic [13]. Bodenheimer and Handley [22] agree by suggesting that proximal (short-term) and specific goals are more effective in primary care settings with respect to goal-oriented care.

2.6.2. The value of the goal-oriented approach within multimorbidity

The goal-oriented approach could serve as an alternative approach that tackles the current established problem-oriented approach within patients with multiple chronic conditions. Previous studies [23] [24] describe that the disease-specific lead to conflicts between the index disease and the existing comorbidities because the specific treatments of the index illness might interact negatively with the treatment or natural course of a co-existing disease. In order guide choices in case of the interacting effects of diseases and their management, patients’ personal goals can assist in providing a personalized care tailored to the individual medical, psychological and social context of the patient. Additionally goal-oriented care will support shared decision making because the patients will be more actively involved when his personal goals will be elicited and addressed. Compared to disease-specific and biomedical outcomes, patient-centered outcomes can cover the multiple conditions and allow different treatments for different
diseases to focus on one common goal [4]. Moreover, goal-oriented care represents a more positive approach to health care because it is characterized by a greater emphasis on individual strengths and resources. [4] [13].

Patients living with multiple chronic diseases interpret their illness(es) from a personal perspective impacted by their individual meaning [25]. Therefore, the goal-oriented approach (who specifically integrates patient-centeredness into clinical care) may be particularly suitable to support decision making in the case of multimorbidity. Because patients living with multimorbidities have more complex needs than patients with one chronic illness, insights of the providers into patients’ illness perspectives is a first step in identifying individual priorities in dialogue with the patient. These priorities are crucial for defining personal goals, and later for enabling the adjustment of care with respect to the desired patients’ health outcomes. Consequently, care can be provided at the measure of the patient. Moreover, patients report feeling disappointed when their needs are not taken seriously [19] [21] [26]. It is of importance to have attention for patients’ goals that matter to them in order to provide good care. After all, practicing nursing is about doing right for the patient.

Mold, Blake & Becker [13] describe that the practice of a goal-oriented approach leads to a greater satisfaction for the patient coping with his multiple diseases. This can be explained by the fact that patients direct their attention to activities upon which goals are based, and therefore affect their functional, emotional (i.e, self-efficacy) and even social performance. Self-efficacy in the goal-oriented approach stands for the self-confidence in being able to attain a certain proposed goal. The process of achieving goals increases patients self-efficacy (and consequently, also their self-esteem) which in turn stimulates the setting of even higher goals [22]. The ultimate aim of the goal-oriented approach is to achieve the highest possible level of health as the considered individual defines it, dependent of the attainment of their personal goals.

2.6.3. The role of health care providers in goal-oriented care

Providers should assist patients to set individual health goals and support them to accomplish these goals [4]. This allows patients to articulate the health outcomes they perceive as most important and achieve them in order of relative priority. Moreover, the
patient is in control of managing his/her multimorbidities by executing trade-offs [4] [27]. The concept of trade-offs involves patients commonly trading off advantages and disadvantages when defining a personal goal. Within this very personal process, therapeutic benefits are measured out towards the functional, physiological and social costs. Evidently, the health care provider should guide the patient throughout the process of goal setting by raising the patient's awareness and understanding of possible outcomes, determining what strategies are most likely to deliver a desirable outcome, and negotiating possible health plans together with the patient. The active engagement of patients in health care decisions (also referred to as effective shared decision making) is an important attribute in goal-oriented care. Goal setting should be performed in a collaborative manner [22] [28]. Consequently, health care providers should facilitate shared decision making by encouraging patients to inform clinicians about their individual priorities [14].

2.7. Chronic Obstructive Pulmonary Disease (COPD)

2.7.1. The impact of COPD on health(care)

COPD is highly prevalent, affecting approximately 210 million people worldwide and responsible for an estimated 5% of all deaths [18] [29]. By 2020, it will be the third leading cause of death globally [25]. Without interventions, the total deaths from COPD are projected to increase by more than 30% in the next 10 years [18]. The global prevalence rate of COPD is 4-10%. A further alleviation is predicted for the decades ahead [30]. In Belgium, COPD occurs in 3.7% of the population [31]. Mortality and disability-adjusted life years (DALY) figures show the remarkable burden of this progressive disease [32]. A DALY represents one lost year of "healthy" life. WHO [18] estimates of DALY’s attributable to COPD for some European countries are high: 270 years per 100 000 for France, 291 for Germany, 291 for Italy, and even 442 for the UK [33]. Furthermore, as COPD frequently implies comorbidities, the disabilities become even more complex. The physical, emotional and social impairments are not always the consequence of COPD itself but are more related to the other comorbidities of the patient [34]. A previous study reported that COPD causes only some specific impairments (e.g., physical functioning, vitality, and general health), while impairments
in all domains of patients lives (e.g., social and emotional functioning) can be attributed to comorbidity [34].

COPD is a chronic disease which clearly challenges problem-oriented care, particularly due to the fact that the presence of comorbidities with COPD patients is ubiquitous. Moreover, the problem-oriented approach with inhalation therapy has shown little or no effect on mortality or deteriorating lung function [35]. Disability, increased QoL and the complex needs of patients with COPD, especially in combination with other comorbidities, will remain challenging [36].

2.7.2. The value of goal-oriented care within patients with COPD and comorbidity

The symptoms of COPD and its inherent disabilities are experienced as radically influencing patients’ QoL [25]. However, by discussing illness perceptions and health related goals of COPD patients’, their QoL could improve and their levels of disability reduce [36]. Some studies have indicated the importance of goal-oriented care for single COPD in which meaningful goals of care can mitigate the illness related-effects. However, these health-related goals are very personal and are difficult to predict for health professionals [27]. Moreover, previous research states that health care professionals are insufficiently capable to really understand the challenges that patients encounter in the attempt to integrate COPD and their comorbidities in their lives [36]. Therefore, it is important that professional health care workers have knowledge beyond the illness COPD, thus also on how the disorder affects the everyday life of a patient. Therefore, improved communication during the patient-clinician encounter is of importance to elicit patients’ personal perspectives. This leads to improved patient outcomes [28]. Actively listening to patients should be considered as a standard method of developing care with a focus on strengthening patients’ influence on their own health by determining which needs are most pressing and identifying personal goals [38] [39].
3. Methodology

This study aims to identify personal goals and will explore the underlying factors and mechanisms determining why patients appear to have difficulties to define and express their personal goals. In short, the results are based on an in-depth qualitative analysis of 19 interviews performed with patients diagnosed with COPD and comorbidities. In the section ‘methodology’ the qualitative research approach, research population and recruitment, the interviewing techniques, patients’ characteristics, data collection and analysis and the validity of the data collection and analysis are described.

3.1. Qualitative research

In this thesis a qualitative approach was adopted using semi-structured patient interviews. More specifically, grounded theory is used as a qualitative method with an open and flexible data collection. According to Holloway & Wheeler [40], new data create new insights through which the essence of a phenomenon can be described. This research strategy allows being adjusted with new information throughout the process. The researcher does not start from a preconceived theory or assumption; therefore an inductive approach is used.

Qualitative research is best suitable because it tends to offer information in terms of the meanings that people bring to them. They try to expose the essence of an experience and try to understand the way participants interpret them. Individuals are best capable to describe their emotions and situations in their own words [40]. Through semi-structured interviews with individuals, researchers gather in-depth data. The data are collected with specific attention for the daily activities. The interviewer asks about sentiments, thoughts, argumentations, difficulties, and disabilities that interfere with activities and are linked to one or more diseases the patient suffers from. Quantifying is in this study not useful to answer the research question.

3.2. Research population and recruitment

In qualitative research, the sampling process cannot be a select [40], but should be executed in a well-considered way which is related to the research question.
Several restrictions were applied when building the research group. Firstly, only COPD patients (the condition is confirmed by spirometry) suffering from at least one other co-existing chronic condition (comorbidity) were selected for the study. Secondly, patients not being able to communicate appropriately (e.g., hearing impairment, speech impediments, cognitive problems, etc.) were not approached by the researchers. And thirdly, palliative patients and patients suffering from dementia were also excluded from the study, because the process of goal-setting develops differently.

Initially, with respect to this thesis, the focus was set on patients appealing to home-care services, namely community nursing. However, the recruitment of participants proceeded difficult, due to the lack of patients meeting the in- and exclusion criteria, and a drop-out due to death. Therefore, the focus of the study was extended to patients not appealing to community nursing. This resulted in two phases within the recruitment.

During the process of forming the research group the researcher searched specifically for deviant cases in order to obtain a maximum variance in the research group. A heterogeneous sampling was performed, in which the participants differ from each other in age, setting, extent of required professional support and disease stages.

3.2.1. Phase one of the recruitment

The methodological procedure for participant selection within a setting of community nursing (this part is described in more detail because this part of the project was completely performed by ML, the author of this thesis) A strict procedure was followed to comply with the argumentations the Ethics Committee of the Ghent University Hospital. This procedure consisted of the following steps (illustrated in Figure 1).

- Firstly, the approval for cooperation of a major institution for community nursing in Belgium (Wit-Gele Kruis West-Vlaanderen) was obtained in order to approach patients and their GP. The researcher received from Wit-Gele Kruis West-Vlaanderen a list of potential participants meeting the in-and exclusion criteria (n=13).
- Secondly, the researcher requested the permission of the concerned GP to contact a potential participant. By telephone, the GP could accept or reject the
participation to the study for him or his/her patient. If the GP agreed to participate, the researcher collected medical data (e.g., date of diagnosis of COPD and spirometry values, the other co-morbid diseases, medications...). In 3 cases (23%), the GP refused permission, due to different reasons (i.e., too emotionally burdening for the patient, “a difficult patient”, or COPD was not confirmed with the patiënt).

- Thirdly, the community nurse, who was responsible for the care of the potential participant, was contacted by the researcher to ask for his/her participation. According to the Ethics Committee of the Ghent University Hospital, somebody in whom the patient puts his/her confidence, needs to approach the patients before the researcher can. Another 3 patients (23%) dropped out because the nurse did not give her permission. In 2 cases, the nurse did simply not respond to the request; in the third case, she thought her patient was not adequate to be interviewed.

- Fourthly, when the patient was informed by his/her nurse and gave his/her approval, the researcher was allowed to approach the participant to arrange a date for the interview. Every patient who was asked by his/her nurse if he/she was willing to participate, accepted the request (100%).

Throughout this whole process another 3 potential participants (23%) dropped out. Two deceased and one got admitted in a hospital. Finally, only 4 patients became participants in the first phase of the study.

Every person involved (management Wit-Gele Kruis West-Vlaanderen, the GP’s, the nurses, and the participants) in one of the steps described above has read and signed the informed consent document. The informed consent documents are presented in Appendix C-F.

3.2.2. Phase two of the recruitment

Later, in the second phase of the recruitment, another 15 interviews were added by the second researcher (PB) in order to have a considerable number of interviews, 11 of which already obtained in phase 1 and 2 of the study (cf. Table 2). The remaining 4 interviews were executed by PB in the third phase.
Finally, this procedure yielded a research group consisting of 19 participants.

![Recruitment process diagram](image)

**Figure 1: Recruitment process**

**3.3. Interviewing techniques**

To explore personal goals of patients with COPD and comorbidity, we adopted a qualitative approach using semi-structured patient interviews. Semi-structured interviews offer the participant the opportunity to speak freely about the topic, but at the same time allows the researcher to keep a focus on the subject area so similar issues are covered within the group of participants. With qualitative interviews the researcher guides the conversation in a direction that allows achieving the purpose of the study and exploring the research topic [40].
The analysis of the first phase (cf. Table 2) [9] clearly indicated that patients do not mention their personal goals spontaneously within open interviews. Consequently, semi-structured interviews were used. In phase 2 these interviews specifically focused on patients’ expectations towards GP’s and discussed participants’ functional status. In-depth data analysis of these interviews revealed that exploring expectations towards the GP did not assist in the clarification of personal goals but the discussion of functional status did provide some useful information [10]. Based on those new insights the interviewing strategy was adjusted. In phase 3 (covered by this thesis) the Canadian Occupational Performance Measure (COPM), was adopted as an interview guide. It provides a semi-structured interview setting in which patients first discuss their daily functioning and personal life. Through a long discussion the researchers aimed to narrow the focus on participants’ priorities. Consequently the interviewer encourages and supports respondents to elicit and define personal goals by asking them to sum up 5 current priorities in their lives and define their personal goals for the 5 forthcoming years: “Where do you want to be in 5 years, what would you still like to achieve?”. There is no need for a separate interview guide, when the COPM is followed. Obviously the researchers anticipate the new information by adding more questions to profound the issue.

3.4. Patients’ characteristics

The sample consisted of 19 participants, 11 men and 8 women. The mean age was 71 years for women (range 50-88 years) and 72 years for men (range 51-84 years). Twelve participants were married or in a relationship and seven participants were living alone (five were widowered/widowed, one was divorced and one was a nun). The average number of comorbidities next to COPD was 5 (range 2-11). The most recurring comorbid diseases were hypertension (n=7), refluxoesofagitis (n=6), osteoarthritis (n=5) and a history of cancer (n=5). None of the participants with cancer was actively treated by chemotherapy or radiotherapy.

The majority of the participants were retired, two participants were still active in the labor force and two were on a sick leave (one permanently and one temporarily). Most participants lived their daily life independent of professional support. However, 5
received daily help from a community nurse, 7 participants relied on assistance for housekeeping and one got physical therapy. Four participants were in need of both a nurse daily and home assistance at the same time. One participant was institutionalized. Most participants also relied on the support of informal caregivers by means of their children (n=5), partner (n=2) or close relatives (n=1). In all cases, primary care was delivered by a GP. Additionally, eleven participants were actively treated or followed by second-line health caregivers (the number of specialists ranged from 1 to 5). Mainly pneumologists (n=8) and cardiologists (n=5).

The patients’ characteristics are listed in Appendix G.

3.5. Data collection and data analysis

3.5.1. Data collection

Interviews were performed by GP’s (PB, PVDS, MDR and CD) or a nurse (ML) who were all still actively working in primary care. All interviewers received a basic training to perform the interviews which included basic skills of qualitative interviewing. Interviewers engaged in phase 3 (PB and ML) were additionally trained on COPM by an occupational therapist. Introducing a nurse in phase 3 can be motivated by the fact that researchers with different backgrounds may affect the outcome of the interview. Because in phase 2, interviews might have been too GP centered, we assumed that the approach of the nurse may be less focused on disease-specific conditions and outcomes. Perhaps, because they feel less threatened, the participants may provide richer data and deeper thoughts [40].

Participants were preferably interviewed at their homes. The choice of setting was based on the argument of Holloway & Wheeler [39] that the researcher might gain richer data because the participant is more relaxed. However, in some cases the participant got distracted by e.g., someone who entered the room, the soup that was boiling, the need for a cigarette, etc. Four participants however preferred to be interviewed in the practice. The time and date was set in by the participant together with the researcher.

The process of data collection took place in the period from November 2008 till April 2013. The average time of an interview was 65 minutes. The longest interview was 99
minutes and the shortest 30 minutes. One participant was re-interviewed, after a time-period of one week, to explore whether time for reflection would add new substantial information to a patient’s interview. However, this approach did not lead to useful nor additional information and was experienced negatively by the patient. Consequently this approach was abandoned again.

The demographic data and information about the multimorbidities and medication were collected at the GP. The researchers had access to those data before the interviews took place.

3.5.2. Data selection, coding and analysis

Interviews were audiotaped and transcribed verbatim using F4-software. Initially, 3 randomly selected interviews (from the total set of 19) were carefully read and independently assessed by both researchers (ML and PB), and text-fragments related to personal goal setting where selected. Then, a meeting was organized where PB and ML discussed the quotes until consensus was reached. The selection of quotes of the other 16 interviews was obtained according to the same process applied to the first 3 interviews, consisting of a random selection of 3 interviews, independent selection of the text fragments, discussing them, and reaching consensus. The meetings also allowed making a first attempt to assign codes (open coding). These processes resulted in a list of quotes retrieved for further analysis. Consequently, ML collected the selected quotes in a new document which also included further coding (quotes were assigned a specific code). This was followed by another meeting during which the codes were discussed and consensus was reached on the coding of the fragments. Next, PB and ML grouped the codes into larger categories according to the perceived meaning of the codes (axial coding). Finally, they presented a report of the first findings to a panel of methodological experts (ADS and SW). This was followed by an extensive discussion which resulted in the interpretation of the goals that were identified and which included the identification of hypotheses related to underlying factors and mechanisms which determine why patients seem to be hampered to define and express their personal goals.

Originally, it was planned to use Nvivo10 for the data analysis, but the researchers agreed that an analysis by hand would be more clear and user-friendly. Each interview
was printed for ML and PB and the text-fragments were marked into the transcriptions. Thus, the comparison of the codes could be executed in a structured way. The processes of open and axial coding were also conducted by hand on paper.

3.6. Validity

3.6.1. Validity of the data collection

A threat to validity in qualitative research is incomplete or incorrect data. Therefore, in order to increase the validity of the data, the researcher has attempted to gain the trust of the participant in several ways. Firstly, the researcher took the interviews at the homes of the participants at a time picked by the participant and confirmed by the researcher. This way, the participant is interviewed in a place where he/she feels save enough to speak freely about the topics. In only 4 cases the participant preferred to perform the interview at the practice. Secondly, most of the participants had received the informed consent document in advance, sometimes it was not possible to deliver it in advance, but either way before the researcher started the interview, they went through it together. The participant was aware of the purpose of the study and the expectations of the researcher. The researcher emphasized the anonymity of the participant also orally. Thirdly, although the interview was recorded on tape with the approval of the participant, the participant was assured that the audiotape would only be used to transcribe the conversation and not for other purposes. Fourthly, the participant was informed that he/she could request a pause or even stop the interview at any time, and without any consequence.

Holloway and Wheeler [40] state that researchers generally have to trust that their participants are telling the truth. In one case the researchers had a suspicion that the participant adapted his/her answers to what he/she thought was to be expected. However, the interview was not excluded because this does not necessarily mean that there is no truth in the interview, as the participants describe their world as they see it from their own perspective in the context of their culture [40].
Another attempt to establish validity was by peer debriefing. The researcher (ML) received a basic training from Mrs. L. Deconinck, an occupational therapist who is familiar with taking interviews based on the COPM. She provided the researcher suggestions on how to use the COPM. The method was explained thoroughly, whereby we can assume that the researcher was trained and skilled to use the COPM correctly throughout the interviews.

3.6.2. Validity of the data analysis

Throughout the process of data analysis researchers triangulation was performed. The text-fragments and codes, retrieved independently by the researchers of all the interviews, were compared and discussed to develop a broader and deeper understanding of how the two researchers view the topic. The findings of the different researchers converged to a same conclusion, which increased the validity of the data analysis. Moreover, an extensive discussion with a panel of methodological experts (ADS and SW) was performed.
4. Results

This section will try to describe an answer to the research question by defining personal goals of patients suffering from COPD and comorbidities. However, this appears to be a difficult and complex process. Therefore, we will therefore describe possible hypotheses of why this is the case.

4.1. Identifying personal goals

Despite the different strategies to support participants in defining their personal goals, the main finding of this study was that -even with the use of COPM, an instrument specifically developed and validated for this purpose - goals were difficult to define and express. When a goal was defined, it was expressed in a very general way.

Q: ‘Being healthy is my first priority.’ (P6)

Q: ‘Being healthy.’ (P11)

Q: ‘What’s most important is that my partner’s health would be as good as it gets. And that the people I love are well, that they are happy.’ (P14)

In fact, respondents stated they wanted their current health status or situation to remain ‘the way it is now’, as a main goal. They focused on no further deterioration, but again they expressed this in a very general way.

Q: ‘To feel the way I feel now.’ (P1)

Q: ‘It can stay like this for a long time, as long as it does not get worse.’ (P17)

Q: ‘I wish it would stay as it is now.’ (P19)

Only a limited number of participants defined specific goals they wanted to maintain. These were especially defined at the level of participation: to continuing going out for dinner, travelling, practicing sports, etc.

Q: ‘To go out to the seaside and have a walk and look at the shops.’ (P6)
Q: ‘To travel once in a while, to be able to sail and to grow my own vegetables in the garden.’ (P16)

Q: ‘I would still like to do some sports.’ (P18)

Participants with more severe diseases tended to formulate goals at a more basic level. In more severe stages goals were set at the level of Activities of Daily Living (ADL).

Q: ‘To leave the house and enjoy myself.’ (P1)

Q: ‘To go to the toilet independently.’ (P7)

Only one participant formulated a goal which extended beyond his current level of activity. This patient was still recovering after a long episode on intensive care due to a complicated appendicitis.

Q: ‘Maybe this summer, since I feel so much better I can try to mow the lawn myself.’ (P6)

### 4.2. What makes it so difficult to identify personal goals

During the analysis we have identified a number of underlying hypotheses concerning why personal goals are difficult to identify.

**Hypothesis 1: Patients cannot identify with the concept of goal setting.**

Even in the most structured interviews where, at the end of a long discussion on patients’ functional status and personal life, participants were asked, to sum up 5 current priorities in their lives and define their personal goals for the 5 forthcoming years (COPM method) they often had no clearly conceptualized response. We sensed that participants did not understand the question. Patients did not seem to know what we meant with goal setting. They do not relate to the concept.

Q: ‘What do you mean?’ (P1)

Q: ‘That is a difficult question. How should I answer that?’ (P4)

Q: ‘Umm’ (P14)
The fact that patients could not identify with the concept of goal might be caused by a flawed technique of eliciting goals despite the use of the COPM. Another explanation might be that patients do not understand what the interviewer expects of them, because they are not used to this approach.

**Hypothesis 2: Patients have accepted their situation and do not feel the need to set goals.**

We found a considerable degree of acceptation throughout all interviews. Most participants feel like they must accept their disabilities in order to go on with their lives. They seem to have accepted their current situation and consequently may not feel the need to set ambitious goals.

Q: ‘I feel happy now.’ (P2)

Q: ‘If you accept it, you feel happy. If you don’t accept it, you feel unhappy.’ (P3)

Q: ‘I’m satisfied with how I am at this moment’. (P4)

Age seemed to support the process of acceptance and minimized goal setting because with increasing age, respondents did not feel like they had the right to expect anything more.

Q: ‘I have lived my life.’ (P3)

Q: ‘I am not 25 anymore.’(P13)

Q: ‘My time is passed.’ (P19)

The nature of chronic diseases may also influence acceptance. Because they have no cure, patients may feel like they have no choice but to accept it. Moreover, because most chronic diseases have a slow but progressive course patients can accept over time.

Q: ‘I can’t improve, I have to accept that. I do accept that as much as I can.’ (P12)
Q: ‘After some time, you get used to it.’ (P17)

Remarkably, many participants described a reduced need for social participation. They seemed to have gradually cut down on social activities and don’t feel the need to engage in the community anymore.

Q: ‘I used to enjoy asking people over for a visit. I thought this was fun and joyful, but now it is a burden.’ (P1)

Q: ‘I feel fine alone.’ (P3)

Q: ‘Now I enjoy peace and quiet. Before I didn’t, I would have been a nervous wreck if I had to stay home for one day.’ (P5)

Despite the observation that patients seem to reconcile with a shrinking life world, this might not always be true. Participants may express acceptance of their illnesses, but in fact, they have quit setting goals because they feel they have no perspective. In other words: they have just given up.

Q: ‘I accept my fate.’ Same participant: ‘I don’t like it that I watch TV all day.’ (P1)

Q: ‘I say we have to learn to live with it. I am used to the fact that I can’t do anything myself anymore.’ Same participant: ‘Sure it is difficult for me to accept that. I am often angry with myself.’ (P2)

Q: ‘There is nothing you can do about it, you just have to deal with it.’ Same participant: ‘That has always been a battle’. (P19)

**Hypothesis 3: Stressors have priority over personal goal setting.**

During the interview participants described stressors such as pain, fear or exhaustion. These might be so prominently present that the goal setting process disappears into the background. Patients were in sort of ‘survival mode’.

Q: ‘So I live with pain, constant pain.’ (P10)
Fear was a much-discussed subject throughout most interviews and was not merely related to COPD. Participants are mostly afraid of suffering or dying. Not being able to stay at home is also associated with anxiety. Fear can also be induced by life events like hospital admissions, a previous fall or the illness of a relative.

Q: ‘I am afraid of suffering.’ (P1)

Q: ‘It feels like you are suffocating, I would rip the clothes off my body, it feels so terrifying.’ (P3)

Q: ‘I fear death.’ (P10)

Q: ‘My biggest fear is that I will be admitted in the hospital. That I won’t return home.’ (P12)

Q: ‘Sometimes I have panic attacks. Afraid of dying of cancer or something else that goes wrong.’ (P15)

Despite the fact that in general, most participants were rather optimistic regarding their functional status, some reported that at some points they lack the physical and/or physiological capacity to perform certain activities. They want to, but they cannot. They felt a need to pace their life rhythm. Besides physical exhaustion some participants also reported to have less courage or to have a tendency to be down during certain periods.

Q: ‘I have been in the hospital for 18 months, my lungs are healed, but my mental health is shot.’ (P14)

Q: ‘Before I was a cleaning lady, and now I am not able to clean or 4 hours at a time. It makes me depressed that I have to do everything in bits and pieces.’ (P15)

Q: ‘Some days I feel strong, but then other days I have to lay down on the couch. That wears you down.’ (P19)
**Hypothesis 4: Patients consider personal goals as selfish.**

We observed that being dependent on others for executing daily activities or transfers, can be experienced as one of the biggest problems of having COPD and comorbidities. Patients felt like they were bothering others and they tried to avoid this as much as possible. Therefore, Participants tried to diminish the health care workers and even support them by doing what they can. Participants might feel uncomfortable defining personal goals, because they place others’ concerns before theirs. This holds true for both the professional health care workers (GP, nurses, etc.) and informal caregivers. Participants even see them as ‘victims’ of their disabilities.

Q: ‘The annoying part is that you always have to bother someone else.’ (P4)

Q: ‘I make sure everything is set when the nurse comes.’ (P4)

Q: ‘My daughter is the major victim, she has to do everything’ (P15)

In addition, we noticed that participants (used to) take care of others. Usually for their parent(s) or their deceived partner. Two patients reported taking responsibility as informal caregiver to a friend or a partner in need of help. Babysitting the children was mentioned by one participant.
5. Discussion

5.1. Summary of main findings

The main finding of this study was that, despite the use of various interview strategies, goals are difficult to elicit. Goal setting appears to be complicated and difficult. We have defined four underlying hypotheses which may explain this finding: patients cannot identify with the concept of goal setting, goal setting is minimized due to acceptation, stressors have priority over personal goal setting or patients consider personal goals as selfish. The first hypothesis could be due to a flawed technique of eliciting goals or a wrong approach in conveying the concept of goal-oriented care to the patients (hypothesis 1. researchers/providers side). Hypothesis 2-4 could be caused by the fact that patients are unable to or don’t feel the need to define and set personal goals (patient side).

5.2. Comparison with existing literature

Many authors have indicated the need to focus care for patients with multiple chronic diseases on patients’ individual goals, [4] [39] [41] [42] [43] [44] [45] but only a small amount of studies have investigated the process of goal setting. Junius-Walker et al. [42] have aimed to introduce patients’ priorities into clinical decision making in GP consultations. They have defined the process of setting shared priorities as challenging, mainly due to the fact that goals from patients and doctors did not match. Doctors’ priorities were more determined by medical aspects of care (e.g., state of the disease, the prognosis or necessary lifestyle changes). Patients however considered both medical problems as well as issues of daily functioning and social participation important. In our study we have specifically elicited personal goals separately from a health encounter to avoid interference with providers’ goals. This might, however, have increased the difficulties we encountered in conveying the concept of goal-oriented care to patients and could have reinforced the very general way in which goals were defined.

In this study, when a goal was defined, it was expressed in a very general way. So, not all goals were attainable. However, Bodenheimer, Handley [22] describe in their study that proximal and specific goals would be more successfully achieved than general
goals. They refer to it as action plans which include what, when, where, and how. This finding is confirmed by Reuben en Tinetti [4], they even describe the responsibility of the clinician to explain what is possible and negotiate potentially small and touchable goals with the patient in order achieve those goals. Providers and patients should be engaged in discussions with respect to personal goals, which leads to a collaborative goal setting. This approach should result in making a shared decision, which increases the possibility for a goal to be attained [4] [13] [22].

Irrespective of their disease(s) stage, participants seemed to define ‘no further deterioration’ as a main goal. At the same time, all participants seemed to have accepted more or less their current situation. This may indicate that patients are unable to predict or estimate the impact that chronic illnesses and disability will have on their future lives. This phenomenon has been previously described by Ubel et al. [46] as the disability paradox. The disability paradox implies that patients are not able to make accurate predictions about the impact of potential circumstances on their lives. People imagine that (further) physical or cognitive decline will hamper their well-being. We may also be susceptible to a disability paradox by misestimating the current impact of chronic diseases on patients. We expected patients to set goals beyond their current level of disability, but, in reality patients may accept, reconcile, and feel no need to set goals. So, despite the underlying patient-centered perspective within the concept of goal-oriented care this may still mainly be a researcher-defined concept with which patients themselves do not necessarily identify.

Our findings revealed that patients often take care for others. This phenomenon could be explained by the fact that patients feel selfish when setting personal goals and therefore consider others concerns as more important than their own. However, a further interpretation, suggests that taking care of others may be a goal –set by the patient- on its own. Taking care of others also seems to lead to an increased self –esteem for patients and gives meaning to their lives.

According to the literature the goal-oriented approach is already successfully integrated in the context of rehabilitation for many years [47] [48]. The reason why the implementation went easier can be explained by the fact that patients have a perspective. They focus and put efforts towards short-term, specific and achievable
ambitions or goals. However, this can be interpreted as part of a problem-oriented approach: attaining those goals is part of a disease-specific treatment. In our interviews, one case supports this finding. The only patient who was able to simply define health related goals, was also in rehabilitation. We have noticed that in the literature, the spectrum of the importance of goal-oriented care gradually broadens: besides application in rehabilitation processes, it is now also applied to specific diseases (e.g., diabetes, dementia, stroke, COPD, etc.) [49] [50] [51] [52] and recently also in patients with multimorbidity. Although many authors emphasize the significance of the integration of the goal-oriented approach within the population of patients with multimorbidity, it appears to remain challenging.

The fact that the concept of goal-oriented care is not easily translated to patients might also be related to the health care systems that shape patients’ perspectives towards care. Patients may not be used to providers focusing on patient-centered outcomes, and may conform to a biomedical and problem-oriented approach. In fact, patients may be too committed to a problem-oriented approach to health care. They may not be able to imagine that they could introduce their personal goals into providers’ clinical decisions. Reuben and Tinetti [4] have recently stated the fact that medicine is deeply rooted in a “disease-outcome-based paradigm” as the most important barrier to goal-oriented care.

5.3. Strengths and limitations of the study

Despite the clear theoretical and conceptual advantages of goal-oriented care in patients with multiple chronic diseases, to our knowledge, this is the first study which specifically focuses on the process of goal setting at the level of the individual patient. A main strength of this study is the diverse and broad patient sample in which we have recruited participants at different age, in differing disease stages and life situations. We specifically included participants still active in the labor force, independent persons, patients with a need for home care and institutionalized patients. A second strength of this study is that participants were recruited by their primary care providers (GPs or nurses) at a moment which was not related to a health encounter (elective interview) because the reason of the encounter might have influenced the process of goal setting as a predominating stressor. A third strength of this study is the diverse expertise of the
research group including GPs, a nurse, and a social scientist, to analyze the data and interpret the results.

Care for multiple chronic diseases is delivered mainly in primary care. This study specifically aimed to be embedded in the primary care setting. Therefore participants were recruited by their GP or nurse and interviews were performed by clinicians, who were actively working in primary care, and have received basic training to perform the interviews. Other providers like occupational therapists or psychologists might have been more skilled at eliciting goals. However these providers are currently not available in the Belgian primary care system. Future research might explore whether their expertise would be of added value in goal-oriented care for patients with multiple chronic diseases. From a methodological perspective, the fact that the interviewer was also engaged in patient care, might be considered a limitation due to the interaction with a clinician-interviewer which might interfere with the results. Respondents may be more prone to conforming to the perceived opinions and expectations when they know the interviewer is a clinician than when the interviewer would have been a lay person. These patient-researcher interactions were minimized by avoiding that the interviewer was also the main health care provider of the participant. Another limitation is that the participants themselves were not engaged in the interpretation of the data (member check [39]). Their engagement could have increased our insight into the phenomenon of personal goal setting and might have countered any possible overinterpretation of the results by the research group (both at the level of goal identification as on the definition of the hypotheses). Due to the long process of adapting interview strategies and the different phases of both data collection and analysis, this approach was not feasible. It would have been both difficult and probably useless to confront patients who had been interviewed in 2008 with our current interpretation for what they had reported back then.

5.4. Implications for practice and for further research

It is not always clear whether patients reconcile and accept or whether they throw in the towel and just give up setting goals. Moreover, other barriers such as, the health care system being insufficiently shaped towards goal-oriented care, dominating stressors
(such as pain, fear or exhaustion) or placing others concerns over their own can hinder the process of goal setting process in patients. Therefore, adequate communication with patients is of great importance to determine whether they feel a need to go through the goal setting process, or not. Further research should focus on the patient-provider interaction. It will be important to focus both on communication strategies which are e supportive to transfer the concept of goal-oriented care towards patients -to explore further critically whether patients are actually in need of goal-oriented care- as on the further development of adequate communication strategies to allow providers to explore and elicit personal goals.

At practice level, providers should become increasingly attentive to goal-oriented care and provide an atmosphere of open communication attentive and supportive to patients introducing their own goals in clinical decision making. The provider should be aware of his/her responsibility to reach out specific, attainable goals which need to be negotiated together with the patients with respect to their perspectives and expectations of personal health outcomes. Consequently providers will be able to act ‘change agents’ of the paradigm-shift from problem-oriented care to goal-oriented care [43]. At the policy level, the health care system should become more attentive to goal-oriented care, instead of problem-oriented care and support providers to engage in the time consuming process of goal-oriented care. This probably requires a fundamental reflection on payment systems. The current focus on fee for (technical) services does not seem well suited to a goal-oriented approach in health care.

Although we have indicated that goal-oriented care should become a common practice in care for patients with mulitmorbidity, it should not be limited to this group of patients. Especially in case of multimorbidity, providing patient-centered and goal-oriented instead of disease-centered and problem-oriented care could be of high added value to guide complex clinical decisions. As such multimorbidity could serve as an excellent use case to support and encourage a general transition from problem-oriented towards goal-oriented care for all (chronic) diseases.
6. Conclusion

Despite the different interviewing techniques we have used, participants appear to have difficulties defining goals. Additionally, four hypotheses were defined to explain why the goal setting process is experienced as difficult. Firstly, participant could not identify with the concept of goal setting. To the patients, it is not clear what the researcher expect from them, when they were asked to define goals. On the one hand, this can be explained by the fact that patients are too committed to a problem-oriented approach and consequently do not relate to the concept of a goal-oriented approach. On the other hand, the researcher may not able to adequately convey the concept of goal setting to the patients or he/she may not have the necessary communication skills to elicit goals. Second, the goal setting process within patients is hampered by the fact that patients have accepted their situation. Therefore, they do not feel the need to set ambitious goals anymore. Third, external (reversible) factors suppress the goal setting process. Fear, pain and exhaustion can be so prominently present in the daily lives of patients that setting goals does not have priority. Finally, patients consider setting personal goals as selfish. Patients feel uncomfortable defining personal goals, because they place others’ concerns before theirs.

Despite the different possible hypotheses on why patients would not define personal goals, we still tend to believe that multimorbidity asks for a goal-oriented care approach. In general it seems most important to differentiate between whether patients really don’t have the need to set goals or whether they are hampered by external (reversible) factors, therefore, optimal communication between patients and providers is crucial. Providers should become increasingly attentive to patients’ personal goals, especially in a health care system that is increasingly dominated by disease-management programs and biomedical outcomes.
Bibliography


Appendices

Appendix A: the article: Personal Goal Setting in Patients with COPD and Comorbidities

Appendix B: the Canadian Occupational Performance Measure

Appendix C: Informed consent document attn. the management of ‘Wit-Gele Kruis West-Vlaanderen’

Appendix D: Informed consent document attn. the nurses of ‘Wit-Gele Kruis West-Vlaanderen’

Appendix E: Informed consent document attn. the GP

Appendix F: Informed consent document attn. the participant

Appendix G: Patients’ Characteristics

Appendix H: Summary in Dutch
Appendix A: The article: Personal Goal Setting in Patients with COPD and Comorbidities

PERSONAL GOAL SETTING IN PATIENTS WITH COPD AND COMORBIDITIES

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ABSTRACT

BACKGROUND: Ageing of the population implies a rising prevalence of chronic diseases, including a rise in multimorbidity. Patients with multiple chronic diseases are usually treated according to disease-specific guidelines with outcome measurements focusing mostly on bio-medical indicators (such as blood sugar levels or lung function measurements). However, multimorbidity seems to ask for a goal-oriented approach aimed at patient-centered outcomes. Despite the clear theoretical and conceptual advantages to include patient defined goals into clinical decision making for multimorbidity, this approach has not yet been investigated.

OBJECTIVES: This study aims to identify personal goals in patients with multimorbidity.

DESIGN: Qualitative analysis of 19 interviews performed in patients diagnosed with COPD and comorbidities.

RESULTS: Despite the use of different interviewing techniques, goals are difficult to elicit. We have defined four underlying hypotheses which may explain this finding: patients can not identify with the concept of goal setting, goal setting is minimized due to acceptance, stressors have priority over personal goal setting and patients may consider personal goals as selfish.

CONCLUSION: Despite the different possible hypotheses on why patients would not define personal goals, we still tend to believe that multimorbidity asks for a goal-oriented care approach. In general it seems most important to differentiate between whether patients really don’t have the need to set goals or whether they are hampered by external (reversible) factors.

INTRODUCTION

Ageing of the population implies a rising prevalence of chronic diseases, including a rise in multimorbidity: more than half of patients aged over 65 have two or more chronic diseases and 20% even have more than five [1]. Patients with multiple chronic diseases are usually treated according to disease-specific guidelines with outcome measurements focusing mostly on bio-medical indicators. These guidelines are based on evidence from randomized controlled clinical trials who generally exclude patients with comorbid diseases. Consequently, disease management programs (DMP’s) do not always meet the
more complex needs of people with multimorbidity [2].

Already in 1991 Mold and Blake challenged this disease-specific and problem-oriented approach in healthcare and proposed a paradigm shift towards goal-oriented care (table 1) focusing on the patient’s individual and goals instead of biomedical outcome measures such as blood sugar levels or lung function measurements [3]. Consequently, goal-oriented care will be more tailored to the context of the individual patient and may be particularly suitable to support decision making in the case of multimorbidity. However, despite the clear theoretical and conceptual advantages to include patient defined goals into clinical decision making for multimorbidity, this approach has not yet been investigated.

COPD (Chronic Obstructive Pulmonary Disease) is a chronic disease which clearly challenges problem-oriented care. The disease specific approach with inhalation therapy has shown little or no effect on mortality or deteriorating lung function. Moreover, the correlation between lung function measurements and patients functionality and quality of life is limited [4-6] and COPD patients often suffer from comorbid diseases [7-8]. Care tailored to the individual goals of the patients instead of aimed at lung function measurements or other disease-specific outcomes seem to be suitable for this group of patients.

Previous work exploring patients’ perspectives in COPD and comorbidities concluded that patients do not mention their personal goals spontaneously in a setting of open interviews [9]. To provide goal-oriented care, more insight is needed into the process of individual goal setting. This study aimed to identify personal goals. Furthermore we wanted to know about possible underlying factors and mechanisms determining why patients appear to have difficulties to define and express their personal goals.

METHODS

1.1. Study design

We adopted a qualitative approach using patient interviews. To elicit patients’ personal goals interview techniques had to be adapted over time [10]. As a first step patients were interviewed by means of open interviews. The analysis of these interviews clearly indicated that patients do not mention their personal goals spontaneously in a setting of open interviews [10]. Therefore the interview strategy was adapted: to interview the patients included in a second wave semi-structured interviews were used which specifically focused on patients’ expectations towards GP’s and which explicitly discussed participants’ functional status [11]. In depth data analysis of these interviews revealed that exploring expectations towards the general practitioner did not achieve in clarification of personal goals but the discussion of functional
status did provide some useful information. Based on those new insights the interviewing strategy was adjusted a second time. For participants included in a third wave, the Canadian Occupational Performance Measure (COPM), was used as an interview guide. This instrument has been developed and validated for goal-setting in occupational therapy. It provides a semi-structured interview setting in which patients first discuss their daily functioning and personal life. Consequently, the interviewer encourages and supports respondents to elicit and define personal goals by asking them to sum up 5 current priorities in their lives and define their personal goals for the 5 forthcoming years.

1.2. Setting and sampling

Participants (n:19) with Chronic Obstructive Pulmonary Disease (COPD) who suffered from at least one other co-existing chronic condition (comorbidity) were invited to participate to the study by their general practitioner (GP) or nurse. Palliative patients and patients suffering from dementia were excluded from the study, because the process of goal-setting develops differently. The inclusion of participants was stepwise and aimed at diversity. Deviant cases were specifically selected.

1.3. Data collection

Interviews were performed by GP’s (PB, PVDS, MDR and CD) and a nurse (ML) who were also actively working in primary care. All interviewers received a basic training on qualitative interviewing skills. Interviewers (PB and ML) were additionally trained on COPM by an occupational therapist. Interviews were performed between November 2008 and April 2013. Participants were contacted by telephone to set a time and date for the interview. They were preferably interviewed at home because richer data may be collected when the participant is more relaxed [9]. Four participants however preferred to be interviewed in the practice. The average time of an interview was 65 minutes (range 30-99 minutes). All interviews were audiotaped and transcribed verbatim using F4-software.

1.4. Patient characteristics

The sample consisted of 19 participants, 11 men and 8 women with a mean age of 67 years (range 50-88 years). Twelve participants were married or in a relationship and seven participants were living alone: five were widowed, one was divorced and one was a nun. Participants suffered from 3 to 12 chronic diseases. The most recurring comorbid diseases were hypertension (n=7), refluxoesophagitis (n=6), osteoarthritis (n=5) and a history of cancer (n=5). None of the participants with cancer was actively treated by chemotherapy or radiotherapy. The majority of participants were retired, two participants were still active in the labor force and two were on a sick leave (one permanently and one temporarily). Most participants did not receive any professional
support at home, five participants received daily assistance from a community nurse, seven participants relied on assistance for housekeeping and one participant got physical therapy. Four participants were in need of both a community nurse and home assistance. One participant was institutionalized. Some participants also relied on the support of informal caregivers by means of their children (n=5), partner (n=2) or close relatives (n=1). In all cases a GP was involved in the care network. Eleven participants were actively treated or followed by a specialist (range of one to five specialists per participant). Mainly pneumologists (n=8) and cardiologists (n=5) were involved in the care of patients with COPD and comorbidities.

1.5 Data selection, coding and analysis

First all transcripts were carefully read multiple times both by PB and ML. This reading confirmed the fact that the process of goal setting had been difficult throughout all stages of the study. Many of the data, collected during the interviews, were not related to goal setting. Therefore, as a first step in the analysis quotes were selected which were considered as relevant to the phenomenon of goal setting. Three interviews were randomly selected from the total set of 19. These interviews were independently assessed by both researchers (ML and PB) to select text-fragments which they could related to the process of personal goal setting. Then, a meeting was organized in which PB and ML discussed the quotes they had independently identified until they reached consensus on a list of quotes to retrieve for further in depth analysis. The selection of quotes out of the other 16 interviews was obtained according to the same process which was applied to the first 3 interviews. Before each team meeting, 3 interviews were randomly selected, text fragments were independently highlighted and thoroughly discussed. These meetings also allowed to make a first attempt to assign codes (open coding). This process resulted in a list of quotes retrieved for further analysis. Consequently, ML collected the selected quotes in a new document which also included the first codes assigned. Based on this new document PB and ML independently grouped the codes into larger categories, according to the perceived meaning of the codes. They presented a report of the first findings to a panel of methodological experts (ADS and SW). This presentation was followed by an extensive discussion which resulted in the further interpretation of the goals that were identified and which included the identification of hypotheses related to underlying factors and mechanisms which determine why patients seem to be hampered to define and express their personal goals.
RESULTS

1. **Identifying personal goals**

Despite the different strategies to support participants to define their personal goals the main finding of this study was that -even with the use of COPM, an instrument specifically developed and validated for this purpose- goals were difficult to define and express. When a goal was defined, it was expressed in a very general way.

Q: ‘Being healthy is my first priority.’ (P6)

Q: ‘Being healthy.’ (P11)

Q: ‘What’s most important is that my partner’s health would be as good as it gets. And that the people I love are well, that they are happy.’ (P14)

Respondents stated they wanted their current health status or situation to remain ‘the way it is now’, as a main goal. They focused on no further deterioration, but again they expressed this in a very general way.

Q: ‘To feel the way I feel now.’ (P1)

Q: ‘It can stay like this for a long time, as long as it does not get worse.’ (P17)

Q: ‘I wish it would stay as it is now.’ (P19)

Only a limited number of participants defined specific goals they wanted to maintain. These were especially defined at the level of participation

Q: ‘To go out to the seaside and have a walk and look at the shops.’ (P6)

Q: ‘To travel once in a while, to be able to sail.’ (P16)

Q: ‘I would still like to do some sports.’ (P18)

Participants with more severe disease tended to formulate goals at a more basic level. In some cases goals were set at the level of Activities of Daily Living (ADL).

Q: ‘To leave the house and enjoy myself.’ (P1)

Q: ‘To go to the toilet independently.’ (P7)

Only one participant formulated a goal which extended beyond his current level of activity. This patient was still recovering after a long episode on intensive care due to a complicated appendicitis.

Q: ‘Maybe this summer, since I feel so much better I can try to mow the lawn myself.’ (P6)

2. **What makes it so difficult to identify personal goals.**

We identified a number of underlying hypotheses concerning why goals are so difficult to identify.

**Hypothesis 1: Patients cannot identify with the concept of goal setting.**

Even in the most structured interviews where COMP method was used, participants did not seem to know what we meant with goal setting. They did not relate to the concept.

Q: ‘What do you mean?’ (P1)

Q: ‘That is a difficult question. How should I answer that?’ (P4)

Q: ‘Umm’ (P14)
Hypothesis 2: Patients have accepted their situation and don’t feel the need to set goals.

We found a considerable degree of acceptation throughout all interviews. Participants seem to have accepted their current situation and consequently may not feel the need to set ambitious goals.

Q: ‘I feel happy now.’ (P2)

Q: ‘If you accept it, you feel happy. If you don’t accept it, you feel unhappy.’ (P3)

Q: ‘I’m satisfied with how I am at this moment’. (P4)

Age seemed to support the process of acceptance and minimized goal setting because with increasing age, respondents didn’t feel like they had the right to expect anything more.

Q: ‘I have lived my life.’ (P3)

Q: ‘I am not 25 anymore.’(P13)

Q: ‘My time is passed.’ (P19)

The nature of chronic diseases may also influence acceptance. Because they have no cure, patients may feel like they have no choice but to accept it. Moreover, because most chronic diseases have a slowly but progressing course patients can accept over time.

Q: ‘I can’t improve, I have to accept that. I do accept that as much as I can.’ (P12)

Q: ‘After some time, you get used to it.’ (P17)

Remarkably, many participants described a reduced need for social participation. They seemed to have gradually cut down on social activities and don’t feel the need to engage in the community anymore.

Q: ‘I used to enjoy asking people over for a visit. I thought this was fun and joyful, but now it is a burden.’ (P1)

Q: ‘Now I enjoy peace and quiet. Before I didn’t, I would have been a nervous wreck if I had to stay home for one day.’ (P5)

Despite the observation that patients seemed to reconcile with a shrinking life world, this might not always be true. Participants may express acceptance of their illnesses, but in fact, they have quit setting goals because they feel they have no perspective. In other words: they have just given up.

Q: ‘I accept my fate.’ Same participant: ‘I don’t like it that I watch TV all day.’ (P1)

Q: ‘I say we have to learn to live with it.’ Same participant: ‘Sure it is difficult for me to accept that. I am often angry with myself.’ (P2)

Q: ‘There is nothing you can do about it, you just have to deal with it.’ Same participant: ‘That has always been a battle’. (P19)

Hypothesis 3: Stressors have priority over personal goal setting.

During the interview participants described stressors such as pain, fear or exhaustion. These might be so prominently present that the goal setting process disappears into the background. Patients were in a sort of ‘survival mode’.
Q: ‘So I live with pain, constant pain.’ (P10)

Fear was a much-discussed subject throughout most interviews and was not merely related to COPD.

Q: ‘I am afraid of suffering.’ (P1)

Q: ‘My biggest fear is that I will be admitted to the hospital. That I won’t return home.’ (P12)

Q: ‘Sometimes I have panic attacks. Afraid of dying of cancer or something else that goes wrong.’ (P15)

Despite the fact that most participants were rather optimistic regarding their functional status, some reported that they lack the physical and/or psychological capacity to perform certain activities. They want to, but they can-not. They felt a need to pace their life rhythm.

Q: ‘I have been in the hospital for 18 months, my lungs are healed, but my mental health is shot.’ (P14)

Q: ‘Some days I feel strong, but then other days I have to lay down on the couch. That wears you down.’ (P19)

**Hypothesis 4: Patients consider personal goals as selfish.**

We observed that being dependent on others can be experienced as one of the biggest problems of having COPD and comorbidities.

Q: ‘The annoying part is that you always have to bother someone else.’ (P4)

Patients felt like they were bothering others and tried to avoid this as much as possible. Participants tried to diminish the health care workers and even support them. Consequently, participants might feel uncomfortable defining personal goals, because they place others’ concerns before theirs.

Q: ‘I make sure everything is set when the nurse comes.’ (P4)

Q: ‘I want my wife to continue to do what she likes most’ (P9)

Q: ‘my daughter is the major victim, she has to do everything’ (P15)

**DISCUSSION**

**Summary of main findings**

The main finding of this study was that, despite the use of various interview strategies, goals are difficult to elicit. Goal setting appeared to be complicated and difficult. We have defined four underlying hypotheses which may explain this finding: patients cannot identify with the concept of goal setting, goal setting is minimized due to acceptation, stressors have priority over personal goal setting or patients consider personal goals as selfish. The first hypothesis could be due to a flawed technique of eliciting goals or a wrong approach in conveying the concept of goal-
oriented care to the patients (hypothesis 1. researchers/providers side). Hypothesis 2-4 could be caused by the fact that patients are unable to or don’t feel the need to define and set personal goals (patient side).

**Comparison with existing literature**

Many authors have indicated the need to focus care for patients with multiple chronic diseases on patients’ individual goals [12-18], but only a small amount of studies investigated the process of goal setting. Junius-Walker et al. aimed to introduce patients’ priorities into clinical decision making in GP consultations. They have defined the process of setting shared priorities as challenging mainly due to the fact that goals from patients and doctors did not match. Doctors’ priorities were more determined by medical aspects of care (e.g., state of the disease, the prognosis or necessary lifestyle changes). Patients however, considered both medical problems as well as issues of daily functioning and social participation important. In our study we specifically elicited personal goals separately from a health encounter to avoid interference with providers’ goals. This might, however, have increased the difficulties we encountered in conveying the concept of goal oriented care to patients and could have reinforced the very general way in which goals were defined.

In this study, when a goal was defined, it was expressed in a very general way. So, not all goals were attainable. However Bodenheimer and Handley [20] describe in their study that proximal and specific goals would be more successfully achieved than general goals. They refer to it as action plans which include what, when, where, and how. This finding is confirmed by Reuben and Tinetti [14], they even describe the responsibility of the clinician to explain what is possible and negotiate potentially small and touchable goals with the patient in order achieve those goals [14]. Providers and patients should be engaged in discussions with respect to personal goals, which leads to a collaborative goal setting. This approach should result in making a shared decision, which increases the possibility for a goal to be attained [3] [14] [20].

Irrespective of their disease(s) stage, participants seemed to define ‘no further deterioration’ as a main goal. At the same time, all participants seemed to have accepted more or less their current situation. This may indicate that patients are unable to predict or estimate the impact that chronic illnesses and disability will have on their future lives. This phenomenon has been previously described as the disability paradox [19]. The disability paradox implies that patients are not able to make accurate predictions about the impact of potential circumstances on their lives. People imagine that (further) physical or cognitive decline will hamper their well-being. We may also be susceptible to a disability
paradox by misestimating the current impact of chronic diseases on our patients. We expected patients to set goals beyond their current level of disability, but, in reality patients may accept, reconcile and feel no need to set goals. So, despite the underlying patient-centered perspective within the concept of goal-oriented care this may still mainly be a researcher-defined concept with which patients themselves do not necessarily identify.

The fact that the concept of goal-oriented care is not easily translated to patients could also be related to the health care systems shaping patients’ perspectives towards care. Patients might not be used to providers focusing on patient-centered outcomes, and may conform to a biomedical and problem-oriented approach. In fact, patients may be too committed to a problem-oriented approach to healthcare. They may not be able to imagine that they can introduce their personal goals into providers’ clinical decisions. Rueben and Tinetti [14] recently stated the fact that medicine is deeply rooted in a “disease-outcome–based paradigm” as the most important barrier to goal-oriented care.

**Strengths and limitations of the study**

Despite the clear theoretical and conceptual advantages of goal-oriented care in patients with multiple chronic diseases, to our knowledge this is the first study that specifically focuses on the process of goal setting at the level of the individual patient. A main strength of this study is the diverse and broad patient sample in which we have recruited participants at different ages, in differing disease stages and life situations. A second strength of this study is that the interviews were performed at a moment which was not related to a health encounter (elective interview) because the reason of the encounter might have been a predominating stressor influencing the process of goal setting. A third strength of this study is the diverse expertise of the research group including GPs, a nurse, a pneumologist and a social scientist, to analyze the data and interpret the results.

Care for multiple chronic diseases is delivered mainly in primary care. This study specifically aimed to be embedded in the primary care setting. Therefore participants were recruited by their GP or nurse and interviews were performed by clinicians, actively working in primary care, who received basic training to perform the interviews. Other providers like occupational therapists or psychologists might have been more skilled at eliciting goals. However these providers are currently not available in the Belgian primary care system. Future research might explore whether their expertise would be of added value in goal-oriented care for patients with multiple chronic diseases. From a methodological perspective, the fact that the interviewer was also engaged in patient care, might be
considered a limitation due to the interaction effects. Respondents may be more prone to conform to the perceived opinions and expectations when they know the interviewer is a clinician than when the interviewer would have been a lay person. These patient-researcher interactions were minimized by avoiding that the interviewer was also the main healthcare provider of the participant. Another limitation is that the participants themselves were not engaged in the interpretation of the data (member check [9]). Their engagement could have increased our insight into the phenomenon of personal goal setting and might have countered any possible overinterpretation of the results (both at the level of goal identification as on the definition of the hypotheses) by the research group. Due to the long process of adapting interview strategies and the different waves of both data collection of analysis, this approach was not feasible. It would have been both difficult and probably useless to confront patients who had been interviewed in 2008 with our current interpretation of what they had reported back then.

Implications for practice and for further research

It is not always clear whether patients actively reconcile and accept or whether they throw in the towel and just give up setting goals. Moreover, other barriers such as, the healthcare system being insufficiently shaped towards goal-oriented care, dominating stressors (such as pain, fear or exhaustion) or placing others concerns over their own can hinder the process of goal setting process in patients. Therefore, adequate communication with patients is of great importance to determine whether they feel a need to go through the goal setting process, or not. Further research should focus on the patient-provider interaction. It will be important to focus both on communication strategies which are supportive to transfer the concept of goal-oriented care towards patients - to explore further critically whether patients are actually in need of goal oriented care - as on the further development of adequate communication strategies to allow providers to explore and elicit personal goals.

At practice level, providers should become increasingly attentive to goal-oriented care and provide an atmosphere of open communication attentive and supportive to patients introducing their own goals in clinical decision making. The provider should be aware of his/her responsibility to reach out specific, attainable goals which need to be negotiated together with the patients with respect to their perspectives and expectations of personal health outcomes. Consequently providers will be able to act ‘change agents’ of the paradigm-shift from problem-oriented care to goal-oriented care [17]. At the policy level, the healthcare system should become more attentive to goal-oriented care, instead of problem oriented care and support.
providers to engage in the time consuming process of goal oriented care. This probably requires a fundamental reflection on payment systems. The current focus on fee for (technical) services does not seem well suited to a goal-oriented approach in healthcare.

Although we have indicated that goal-oriented care should become a common practice in care for patients with multimorbidity, it should not be limited to this group of patients. Especially in case of multimorbidity, providing patient-centered and goal-oriented instead of disease-centered and problem-oriented care could be of high added value to guide complex clinical decisions. As such multimorbidity could serve as an excellent use case to support and encourage a general transition from problem-oriented towards goal-oriented care for all (chronic) diseases.

**Conclusions**

Despite the different interview techniques we have used, participants appear to have difficulties defining goals. Despite the different possible hypotheses on why patients would not define personal goals, we still tend to believe that multimorbidity asks for a goal-oriented care approach. In general it seems most important to differentiate between whether patients really don’t have the need to set goals or whether they are hampered by external (reversible) factors. Providers should become increasingly attentive to patients personal goals especially in a healthcare system that is increasingly dominated by disease management programs and biomedical outcomes.

**ETHICAL APPROVAL**

The study was approved by the Ethics Committee of the Ghent University Hospital.

**COMPETING INTERESTS**

None of the authors have a conflict of interests to declare in relation to this work.

**AUTHORS CONTRIBUTIONS**

PB was responsible for the coordination of the overall study, conception and design. PB, MG, PV, CD, and ML collected the data. PB and ML analyzed and interpret the data and prepared the final report. PB, ML, SW and ADS made critical revisions to the paper. PB and ML wrote the article.

**ACKNOWLEDGEMENTS**

The authors would like to gratefully acknowledge Mrs. Leen Deconinck for sharing her expertise about use of the COPM. Additionally, the authors thank the community nursing organization ‘Wit-Gele Kruis West-Vlaanderen’ for their cooperation to the recruitment of participants.

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Table 1. Problem-oriented versus Goal-oriented care

<table>
<thead>
<tr>
<th></th>
<th>Problem-oriented care</th>
<th>Goal-oriented care</th>
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<tbody>
<tr>
<td><strong>Definition of Health</strong></td>
<td>Absence of disease as defined by the health care system</td>
<td>Maximum desirable and achievable quality and/or quantity of life as defined by each individual</td>
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<tr>
<td><strong>Purposes of Health Care</strong></td>
<td>Eradication of disease, prevention of death</td>
<td>Assistance in achieving a maximum individual health potential</td>
</tr>
<tr>
<td><strong>Measures of success</strong></td>
<td>Accuracy of diagnosis, appropriateness of treatment, eradication of disease, prevention of death</td>
<td>Achievement of individual goals</td>
</tr>
<tr>
<td><strong>Evaluator of success</strong></td>
<td>Physician</td>
<td>Patient</td>
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Appendix B: The Canadian Occupational Performance Measure

CANADIAN OCCUPATIONAL PERFORMANCE MEASURE

Authors:
Mary Law, Sue Baptiste, Anne Carswell,
Mary Ann McColl, Helene Polatajko, Nancy Pollock

The Canadian Occupational Performance Measure (COPM) is an individualized measure designed for use by occupational therapists to detect self-perceived change in occupational performance problems over time.

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<th>Client Name:</th>
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<th>Respondent (if not client):</th>
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**STEP 1: IDENTIFICATION OF OCCUPATIONAL PERFORMANCE ISSUES**

To identify occupational performance problems, concerns and issues, interview the client, asking about daily activities in self-care, productivity and leisure. Ask clients to identify daily activities which they want to do, need to do or are expected to do by encouraging them to think about a typical day. Then ask the client to identify which of these activities are difficult for them to do now to their satisfaction. Record these activity problems in Steps 1A, 1B, or 1C.

**STEP 1A: Self-care**

<table>
<thead>
<tr>
<th>Activity Type</th>
<th>Importance</th>
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<tbody>
<tr>
<td>Personal Care (e.g., dressing, bathing, feeding, hygiene)</td>
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<tr>
<td>Functional Mobility (e.g., transfers, indoor, outdoor)</td>
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<tr>
<td>Community Management (e.g., transportation, shopping, finances)</td>
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**STEP 2: RATING IMPORTANCE**

Using the scoring card provided, ask the client to rate, on a scale of 1 to 10, the importance of each activity. Place the ratings in the corresponding boxes in Steps 1A, 1B, or 1C.

**STEP 1B: Productivity**

<table>
<thead>
<tr>
<th>Activity Type</th>
<th>Importance</th>
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<tr>
<td>Paid/Unpaid Work (e.g., finding/keeping a job, volunteering)</td>
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<tr>
<td>Household Management (e.g., cleaning, laundry, cooking)</td>
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<td>Play/School (e.g., play skills, homework)</td>
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### STEP 1C: Leisure

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<tr>
<th>Quiet Recreation (e.g., hobbies, crafts, reading)</th>
<th>IMPORANCE</th>
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<th>Active Recreation (e.g., sports, outings, travel)</th>
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<th>Socialization (e.g., visiting, phone calls, parties, correspondence)</th>
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### STEPS 3 & 4: SCORING - INITIAL ASSESSMENT and REASSESSMENT

Confirm with the client the 5 most important problems and record them below. Using the scoring cards, ask the client to rate each problem on performance and satisfaction, then calculate the total scores. Total scores are calculated by adding together the performance or satisfaction scores for all problems and dividing by the number of problems. At reassessment, the client scores each problem again for performance and satisfaction. Calculate the new scores and the change score.

#### Initial Assessment:

<table>
<thead>
<tr>
<th>OCCUPATIONAL PERFORMANCE PROBLEMS</th>
<th>PERFORMANCE 1</th>
<th>SATISFACTION 1</th>
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<th>SATISFACTION 1</th>
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#### SCORING:

\[
\text{Total score} = \frac{\text{Total performance or satisfaction scores}}{\# \text{ of problems}}
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<table>
<thead>
<tr>
<th>PERFORMANCE SCORE 1</th>
<th>SATISFACTION SCORE 1</th>
<th>PERFORMANCE SCORE 2</th>
<th>SATISFACTION SCORE 2</th>
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#### CHANGE IN PERFORMANCE = Performance Score 2 \[\square\] - Performance Score 1 \[\square\] = \[\square\]

#### CHANGE IN SATISFACTION = Satisfaction Score 2 \[\square\] - Satisfaction Score 1 \[\square\] = \[\square\]
ADDITIONAL NOTES AND BACKGROUND INFORMATION

Initial Assessment:

Reassessment:
Appendix C: Informed consent document attn. the management of ‘Wit-Gele Kruis West-Vlaanderen’

Informatiebrief voor het Wit-Gele Kruis (directie)

Titel van de studie:
Hoe kunnen de individuele doelstellingen van de patiënt met multimorbiditeit in de thuiszorg geïdentificeerd en geregistreerd worden?

Doel van de studie:
Deze studie richt zich op patiënten met multimorbiditeit die nog thuis verblijven maar beroep doen op thuisverpleging. Dit onderzoek richt zich op personen met COPD en die daarnaast nog een of multiple chronische aandoeningen hebben. Dit vraagt voor de patiënten een uitgebreide en soms ingewikkelde zorg. Vaak is de zorgverlening niet afgestemd op de individuele en persoonlijke noden van de patiënt. Via deze studie willen we meer inzicht krijgen in het dagdagelijks functioneren van de patiënt om zo de verwachtingen van de patiënt in kaart te brengen. Er wordt gepeild naar de functionele beperkingen van de patiënt en naar de individuele doelstellingen gerelateerd aan deze beperkingen. Zo kan de complexe verpleegkundige zorg in de toekomst meer richten op wat de patiënt zelf belangrijk vindt.

Beschrijving van de studie:
Bij de deelnemende patiënten worden interviews afgenomen om de persoonlijke doelstellingen te verhelderen. Het dagdagelijks leven van de patiënt wordt ook via interviews in kaart gebracht.

Het gaat om een kwalitatieve benadering aan de hand van diepe-interviews. Zowel het functioneren van de patiënt als de individuele prioriteiten van de participanten wordt in kaart gebracht met behulp van de COPM (Canadian Occupational Performance Measure). Dit instrument wordt als leidraad gebruikt voor de interviews.

Bij elke patiënt wordt hetzelfde interview tweemaal afgenomen. Tussen de twee interviews wordt een periode voorzien die ruimte biedt aan de participant om te reflecteren over zijn antwoorden. Daaruit kan afgeleid worden welke doelstellingen patiënten over het algemeen belangrijk vinden.

Naast de interviews wordt ook medische data verzameld bij de huisarts. Het gaat om de spirometriedata, de medicatie van de patiënt en de aandoeningen van de patiënt. Hiervoor neemt de onderzoeker zelf contact op met de betrokken huisarts.

Wat wordt verwacht van de deelnemer?
Indien u toestemming geeft voor het onderzoek wordt persoonlijk contact opgenomen met de organisatie door de onderzoeker. Er werd reeds afgesproken met de verpleegkundig directeur (Dhr. Jo Logghe) dat de onderzoeker samen met het Wit-Gele Kruis potentiële participanten zal selecteren op basis van de in- en exclusiecriteria.

XX
Als organisatie heeft u de mogelijkheid om patiënten aan te bevelen of te onthouden van de studie.

De organisatie heeft recht op transparantie van het onderzoek en kan op elk ogenblik van het proces om duidelijkheid vragen.

Naast uw toestemming, is ook de goedkeuring van de betrokken huisarts alsook van de participant vereist om opgenomen te kunnen worden in de studie.

**Deelname en beëindiging:**

De deelname aan deze studie vindt plaats op vrijwillige basis. U kan weigeren om deel te nemen aan de studie, en u kunt zich op elk ogenblik terugtrekken uit de studie zonder dat u hiervoor een reden moet opgeven en zonder dat dit op enigerlei wijze een invloed zal hebben op uw verdere relatie en/of behandeling met de onderzoeker. Als u deelneemt, wordt u gevraagd het toestemmingsformulier te tekenen.

**Studieverloop:**

U zal door de onderzoeker gecontacteerd worden om een afspraak te maken voor het selecteren van mogelijke participanten op een voor U passend moment.

De duur van het onderzoek wordt geschat op een jaar: vanaf goedkeuring Ethisch Comité tot juni 2013.

**Risico’s en voordelen:**

Er zijn geen risico’s voor de deelnemers aan deze studie.

Het belangrijkste voordeel is dat u bijdraagt aan de ontwikkeling van een betere verpleegkundige zorg dat meer gericht is op de prioriteiten van de patiënten. Uw deelname zal de zorg voor patiënten met multimorbiditeit binnen de thuisverpleging ten goede komen.

**Kosten:**

Uw deelname aan deze studie brengt geen extra kosten mee voor U.

**Vergoeding:**

Er wordt geen vergoeding voorzien voor deelname aan deze studie.

**Vertrouwelijkheid:**

**Contactpersoon:**

Als er een probleem optreedt tijdens de studie of als U aanvullende informatie wenst over de studie of over uw rechten en plichten, kunt U in de loop van de studie op elk ogenblik contact opnemen met:

Mieke Lanssens

Mieke.Lanssens@UGent.be

09 3322747

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**Toestemmingsformulier**


Ik heb een kopij gekregen van dit ondertekende en gedateerde formulier. Ik heb uitleg gekregen over de aard, het doel, de duur van de studie en over wat men van mij verwacht. Men heeft me de gelegenheid en voldoende tijd gegeven om vragen te stellen over de studie, en ik heb op al mijn vragen een bevredigend antwoord gekregen.

Indien ik toegang wil tot mijn gegevens, zal ik mij richten tot de toezijnde onderzoeker die verantwoordelijk is voor de verwerking.

Ik ben me ervan bewust dat deze studie werd goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het UZ Gent en dat deze studie zal uitgevoerd worden volgens de richtlijnen voor de goede klinische praktijk (ICH/GCP) en de verklaring van Helsinki, opgesteld ter bescherming van mensen deelnemend aan experimenten. Deze goedkeuring was in geen geval de aanzet om te beslissen om deel te nemen aan deze studie.

Men heeft mij ingelicht over het bestaan van een verzekeringspolis in geval er letsel zou ontstaan dat aan de studieprocedures is toe te schrijven.

Ik mag me op elk ogenblik uit de studie terugtrekken zonder een reden voor deze beslissing op te geven en zonder dat dit op enigerlei wijze een invloed zal hebben op mijn verdere relatie met de onderzoeker.

Ik ben bereid op vrijwillige basis deel te nemen aan deze studie

Naam van de vrijwilliger:

__________________________

Datum:_____________________
Handtekening:

Ik bevestig dat ik de aard, het doel, en de te voorziene effecten van de studie heb uitgelegd aan de bovenvermelde vrijwilliger. De vrijwilliger stemde toe om deel te nemen door zijn/haar persoonlijk gedateerde handtekening te plaatsen.
Naam van de persoon die de voorgaande uitleg heeft gegeven:
______________________________

Datum:________________________

Handtekening:
Appendix D: Informed consent document attn. the nurses of ‘Wit-Gele Kruis West-Vlaanderen’

Informatiebrief voor het Wit-Gele Kruis (vpk).

Titel van de studie:
Hoe kunnen de individuele doelstellingen van de patiënt met multimorbiditeit in de thuiszorg geïdentificeerd en geregistreerd worden?

Doel van de studie:
Deze studie richt zich op patiënten met multimorbiditeit die nog thuis verblijven maar beroep doen op thuisverpleging. Dit onderzoek richt zich op personen met COPD en die daarnaast nog een of multiple chronische aandoeningen hebben. Dit vraagt voor de patiënten een uitgebreide en soms ingewikkelde zorg. Vaak is de zorgverlening niet afgestemd op de individuele en persoonlijke noden van de patiënt. Via deze studie willen we meer inzicht krijgen in het dagdagelijks functioneren van de patiënt om zo de verwachtingen van de patiënt in kaart te brengen. Er wordt gepeild naar de functionele beperkingen van de patiënt en naar de individuele doelstellingen gerelateerd aan deze beperkingen. Zo kan de complexe verpleegkundige zorg in de toekomst meer richten op wat de patiënt zelf belangrijk vindt.

Beschrijving van de studie:
Bij de deelnemende patiënten worden interviews afgenomen om de persoonlijke doelstellingen te verhelderen. Het dagdagelijks leven van de patiënt wordt ook via interviews in kaart gebracht.

Het gaat om een kwalitatieve benadering aan de hand van diepe-interviews. Zowel het functioneren van de patiënten als de individuele prioriteiten van de participanten wordt in kaart gebracht met behulp van de COPM (Canadian Occupational Performance Measure). Dit instrument wordt als leidraad gebruikt voor de interviews.

Bij elke patiënt wordt hetzelfde interview tweemaal afgenomen. Tussen de twee interviews wordt een periode voorzien die ruimte biedt aan de participant om te reflecteren over zijn antwoorden. Daaruit kan afgeleid worden welke doelstellingen patiënten over het algemeen belangrijk vinden.

Naast de interviews wordt ook medische data verzameld bij de huisarts. Het gaat om de spirometriedata, de medicatie en de aandoeningen van de patiënt. Hiervoor neemt de onderzoeker zelf contact op met de betrokken huisarts.

Wat wordt verwacht van de deelnemer?
Indien u toestemming geeft voor het onderzoek wordt persoonlijk contact opgenomen met de organisatie door de onderzoeker. Er werd reeds afgesproken met de verpleegkundig directeur (Dhr. Jo Logghe) dat de onderzoeker samen met het Wit-Gele Kruis potentiële participanten zal selecteren op basis van de in- en exclusiecriteria.
Als verpleegkundige bent u een vertrouwenspersoon voor de patiënt. U bent dus geschikt om de patiënt te vragen of hij wenst deel te nemen en om eventueel te antwoorden op vragen. Pas nadat u met de patiënt zijn mogelijke participatie tot de studie heeft besproken, zal de onderzoeker contact opnemen met de patiënt.

U heeft recht op transparantie van het onderzoek en kan op elk ogenblik van het proces om duidelijkheid vragen.

**Deelname en beëindiging:**

De deelname aan deze studie vindt plaats op vrijwillige basis. U kan weigeren om deel te nemen aan de studie, en u kunt zich op elk ogenblik terugtrekken uit de studie zonder dat u hiervoor een reden moet opgeven en zonder dat dit op enigerlei wijze een invloed zal hebben op uw verdere relatie en/of behandeling met de onderzoeker. Als u deelneemt, wordt u gevraagd het toestemmingsformulier te tekenen.

**Studieverloop:**

U zal door de onderzoeker of door de nursingbegeleider gecontacteerd worden in verband met een patiënt die in aanmerking komt.

De duur van het onderzoek wordt geschat op een jaar: vanaf goedkeuring Ethisch Comité tot juni 2013.

**Risico’s en voordelen:**

Er zijn geen risico’s voor de deelnemers aan deze studie.

Het belangrijkste voordeel is dat u bijdraagt aan de ontwikkeling van een betere verpleegkundige zorg dat meer gericht is op de prioriteiten van de patiënten. Uw deelname zal de zorg voor patiënten met multimorbiditeit binnen de thuisverpleging ten goede komen.

**Kosten:**

Uw deelname aan deze studie brengt geen extra kosten mee voor U.

**Vergoeding:**

Er wordt geen vergoeding voorzien voor deelname aan deze studie.

**Vertrouwelijkheid:**

Contactpersoon:

Als er een probleem optreedt tijdens de studie of als U aanvullende informatie wenst over de studie of over uw rechten en plichten, kunt U in de loop van de studie op elk ogenblik contact opnemen met:

Mieke Lanssens
Mieke.Lanssens@UGent.be
09 3322747

Toestemmingsformulier

Ik, _________________________________________ heb het document “Informatiebrief voor het Wit-Gele Kruis (vpk)” gelezen Ik stem in met de inhoud van het document en stem ook in deel te nemen aan de studie. Ik geef hierbij ook de toestemming aan de onderzoeker om bestaande gegevens vanuit de patiëntendossiers van het Wit-Gele Kruis West-Vlaanderen op te zoeken en om de nodige gegevens te verzamelen en te verwerken.

Ik heb een kopij gekregen van dit ondertekende en gedateerde formulier. Ik heb uitleg gekregen over de aard, het doel, de duur van de studie en over wat men van mij verwacht. Men heeft me de gelegenheid en voldoende tijd gegeven om vragen te stellen over de studie, en ik heb op al mijn vragen een bevredigend antwoord gekregen.

Indien ik toegang wil tot mijn gegevens, zal ik mij richten tot de toezende onderzoeker die verantwoordelijk is voor de verwerking.

Ik ben me ervan bewust dat deze studie werd goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het UZ Gent en dat deze studie zal uitgevoerd worden volgens de richtlijnen voor de goede klinische praktijk (ICH/GCP) en de verklaring van Helsinki, opgesteld ter bescherming van mensen deelnemend aan experimenten. Deze goedkeuring was in geen geval de aanzet om te beslissen om deel te nemen aan deze studie.

Men heeft mij ingelicht over het bestaan van een verzekering polis in geval er letsel zou ontstaan dat aan de studie procedures is toe te schrijven.

Ik mag me op elk ogenblik uit de studie terugtrekken zonder een reden voor deze beslissing op te geven en zonder dat dit op enigerlei wijze een invloed zal hebben op mijn verdere relatie met de onderzoeker.

Ik ben bereid op vrijwillige basis deel te nemen aan deze studie

Naam van de vrijwilliger:

______________________________

Datum:______________________
Handtekening:

Ik bevestig dat ik de aard, het doel, en de te voorziene effecten van de studie heb uitgelegd aan de bovenvermelde vrijwilliger. De vrijwilliger stemde toe om deel te nemen door zijn/haar persoonlijk gedateerde handtekening te plaatsen.
Naam van de persoon die de voorgaande uitleg heeft gegeven:

________________________

Datum:________________________

Handtekening:
Appendix E: Informed consent document attn. the GP

Informatiebrief voor de huisarts

Titel van de studie:
Hoe kunnen de individuele doelstellingen van de patiënt met multimorbiditeit in de thuiszorg geïdentificeerd en geregistreerd worden?

Doel van de studie:
Deze studie richt zich op patiënten met multimorbiditeit die nog thuis verblijven maar beroep doen op thuisverpleging. Dit onderzoek richt zich op personen met COPD en die daarnaast nog een of multiple chronische aandoeningen hebben. Dit vraagt voor de patiënten een uitgebreide en soms ingewikkelde zorg. Vaak is de zorgverlening niet afgestemd op de individuele en persoonlijke noden van de patiënt. Via deze studie willen we meer inzicht krijgen in het dagdagelijks functioneren van de patiënt om zo de verwachtingen van de patiënt in kaart te brengen. Er wordt gepeild naar de functionele beperkingen van de patiënt en naar de individuele doelstellingen gerelateerd aan deze beperkingen. Zo kan de complexe verpleegkundige zorg in de toekomst meer richten op wat de patiënt zelf belangrijk vindt.

Beschrijving van de studie:
Bij de deelnemende patiënten worden interviews afgenomen om de persoonlijke doelstellingen te verhelderen. Het dagdagelijks leven van de patiënt wordt ook via interviews in kaart gebracht.

Het gaat om een kwalitatieve benadering aan de hand van diepte-interviews. Zowel het functioneren van de patiënten als de individuele prioriteiten van de participaten wordt in kaart gebracht met behulp van de COPM (Canadian Occupational Performance Measure). Dit instrument wordt als leidraad gebruikt voor de interviews.

Bij elke patiënt wordt hetzelfde interview tweemaal afgenomen. Tussen de twee interviews wordt een periode voorzien die ruimte biedt aan de participant om te reflecteren over zijn antwoorden. Daaruit kan afgeleid worden welke doelstellingen patiënten over het algemeen belangrijk vinden.

Wat wordt verwacht van de deelnemer?
Indien u toestemming geeft voor het onderzoek wordt persoonlijk contact opgenomen met u door de onderzoeker. Er werden reeds potentiële deelnemers geselecteerd in samenspraak met het Wit-Gele Kruis, waaronder patiënten uit uw bestand.

Als huisarts heeft u de mogelijkheid om patiënten te onthouden van de studie (of eventueel nieuwe patiënten aan te bevelen).

Uw toestemming is essentieel omdat we inzicht vragen in bepaalde medische data van de participant. Zodat een demografische analyse uitgevoerd kan worden. Het gaat over de aanwezige aandoeningen die wijzen op multimorbiditeit en de medicatie die genomen wordt.
Daarnaast zijn -voor dit onderzoek- gegevens gerelateerd aan COPD vereist: het jaar waarin de COPD werd vastgesteld en de spirometriewaarden.

Als huisarts heeft u recht op transparantie van het onderzoek en kan op elk ogenblik van het proces om duidelijkheid vragen.

Naast uw toestemming, is ook de goedkeuring van de betrokken thuisverplegingsorganisatie alsook van de participant vereist om opgenomen te kunnen worden in de studie.

**Deelname en beëindiging:**

De deelname aan deze studie vindt plaats op vrijwillige basis. U kan weigeren om deel te nemen aan de studie, en u kunt zich op elk ogenblik terugtrekken uit de studie zonder dat u hiervoor een reden moet opgeven en zonder dat dit op enigerlei wijze een invloed zal hebben op uw verdere relatie en/of behandeling met de onderzoeker of het Wit-Gele Kruis. Als u deelneemt, wordt u gevraagd het toestemmingsformulier te tekenen.

**Studieverloop:**

U zal door de onderzoeker gecontacteerd worden om een afspraak te maken voor het selecteren van mogelijke participanten op een voor U passend moment.

De duur van het onderzoek wordt geschat op een jaar: vanaf goedkeuring Ethisch Comité tot juni 2013.

**Risico’s en voordelen:**

Er zijn geen risico’s voor de deelnemers aan deze studie.

Het belangrijkste voordeel is dat u bijdraagt aan de ontwikkeling van een betere verpleegkundige zorg dat meer gericht is op de prioriteiten van de patiënten. Uw deelname zal de zorg voor patiënten met multimorbiditeit binnen de thuisverpleging ten goede komen.

**Kosten:**

Uw deelname aan deze studie brengt geen extra kosten mee voor U.

**Vergoeding:**

Er wordt geen vergoeding voorzien voor deelname aan deze studie.

**Vertrouwelijkheid:**

Contactpersoon:

Als er een probleem optreedt tijdens de studie of als U aanvullende informatie wenst over de studie of over uw rechten en plichten, kunt U in de loop van de studie op elk ogenblik contact opnemen met:

Mieke Lanssens
Mieke.Lanssens@UGent.be
09 3322747

Toestemmingsformulier

Ik, _________________________________________ heb het document “Informatiebrief voor de huisarts” gelezen Ik stem in met de inhoud van het document en stem ook in deel te nemen aan de studie. Ik geef hierbij ook de toestemming aan de onderzoeker om bestaande gegevens vanuit de patiëntendossiers op te zoeken en om de nodige gegevens te verzamelen en te verwerken.

Ik heb een kopij gekregen van dit ondertekende en gedateerde formulier. Ik heb uitleg gekregen over de aard, het doel, de duur van de studie en over wat men van mij verwacht. Men heeft me de gelegenheid en voldoende tijd gegeven om vragen te stellen over de studie, en ik heb op al mijn vragen een bevredigend antwoord gekregen.
Indien ik toegang wil tot mijn gegevens, zal ik mij richten tot de toeziende onderzoeker die verantwoordelijk is voor de verwerking.
Ik ben me ervan bewust dat deze studie werd goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het UZ Gent en dat deze studie zal uitgevoerd worden volgens de richtlijnen voor de goede klinische praktijk (ICH/GCP) en de verklaring van Helsinki, opgesteld ter bescherming van mensen deelnemend aan experimenten. Deze goedkeuring was in geen geval de aanzet om te beslissen om deel te nemen aan deze studie.

Men heeft mij ingelicht over het bestaan van een verzekering polis in geval er letsel zou ontstaan dat aan de studie procedures is toe te schrijven.

Ik mag me op elk ogenblik uit de studie terugtrekken zonder een reden voor deze beslissing op te geven en zonder dat dit op enigerlei wijze een invloed zal hebben op mijn verdere relatie met de onderzoeker.

Ik ben bereid op vrijwillige basis deel te nemen aan deze studie
Naam van de vrijwilliger:
_____________________________________

Datum:______________________________
Handtekening:

Ik bevestig dat ik de aard, het doel, en de te voorziene effecten van de studie heb uitgelegd aan de bovenvermelde vrijwilliger. De arts stemde toe om deel te nemen door zijn/haar persoonlijk gedateerde handtekening te plaatsen.

Naam van de persoon die de voorgaande uitleg heeft gegeven:

______________________________

Datum:________________________

Handtekening:
Appendix F: Informed consent document attn. the participant

Informatiebrief voor de deelnemers

Titel van de studie:

Hoe kunnen de individuele doelstellingen van de patiënt met multimorbiditeit in de thuiszorg geïdentificeerd en geregistreerd worden?

Doel van de studie:

Deze studie richt zich op patiënten met multimorbiditeit die nog thuis verblijven maar beroep doen op thuisverpleging. Multimorbiditeit is een term voor het hebben van meerdere chronische aandoeningen of ziektes tegelijkertijd. Bijvoorbeeld suikerziekte, artrose, hart- en vaatziekten,.... Dit onderzoek richt zich op personen die een longziekte hebben en daarnaast nog een of meerdere chronische aandoeningen. Dit vraagt voor de patiënten een uitgebreide en soms ingewikkelde zorg. Vaak is de zorgverlening niet afgestemd op de individuele en persoonlijke noden van de patiënt. Via deze studie willen we meer inzicht krijgen in het dagdagelijks functioneren van de patiënt om zo de verwachtingen van de patiënt ik kaart te brengen. Zo kan de complexe verpleegkundige zorg in de toekomst meer richten op wat de patiënt zelf belangrijk vindt.

Beschrijving van de studie:

Bij de deelnemende patiënten worden interviews afgenomen om de persoonlijke doelstellingen te verhelderen. Het dagdagelijks leven van de patiënt wordt ook via interviews in kaart gebracht.

In totaal worden ongeveer 20 interviews afgenomen bij verschillende patiënten. Daaruit kan afgeleid worden welke doelstellingen patiënten over het algemeen belangrijk vinden.

Wat wordt verwacht van de deelnemer?

Indien u toestemming geeft voor het onderzoek wordt persoonlijk contact opgenomen met u door de onderzoeker. Samen wordt gezocht naar een datum waarop de onderzoeker -zelf verpleegkundige- kan langskomen om een interview af te nemen.

Voor een afspraak voorzien wij 2 uur. Dit lijkt lang, en vaak duurt de afspraak inderdaad korter, maar we willen vermijden dat we door tijdsdruk het contact voortijdig moeten afbreken.

Nadien volgt een uitgebreid interview waarin er gevraagd wordt naar uw dagdagelijks functioneren en de problemen die u daarin ervaart. Op het einde van dit gesprek definitieert u, samen met de onderzoeker, uw eigen prioriteiten of belangrijkste doelstellingen voor uw persoonlijke zorg.

Bij afloop van het gesprek zal de onderzoeker vragen om een nieuwe afspraak te plannen voor een tweede gesprek. Er zal een periode voorzien worden tussen de twee interviews waarin u tijd en ruimte krijgt om te reflecteren over uw prioriteiten. Het tweede gesprek verloopt identiek aan het eerste, ook de vraagstelling blijft dezelfde.
Het gesprek wordt opgenomen op audiotape zodat er geen informatie verloren gaat. De tapes zullen enkel geanalyseerd worden door de onderzoeker en zullen niet rechtstreeks gebruikt worden voor publicatie. U kan als deelnemer ten allen tijde de tape van het interview en/of een uitgetikte versie opvragen bij de onderzoeker. Na afloop van de studie zullen de audiotapes worden vernietigd.

De onderzoeker is gebonden aan het beroepsgeheim. Alle gegevens worden gecodeerd bij het analyseren van het interview. In geen enkel geval wordt melding gemaakt van namen of contactgegevens van de deelnemers.

Deelname en beëindiging:

De deelname aan deze studie vindt plaats op vrijwillige basis. U kan weigeren om deel te nemen aan de studie, en u kunt zich op elk ogenblik terugtrekken uit de studie zonder dat u hiervoor een reden moet geven en zonder dat dit op enigerlei wijze een invloed zal hebben op uw verdere relatie en/of behandeling met de onderzoeker of de behandelende arts. Als u deelneemt, wordt u gevraagd het toestemmingsformulier te tekenen.

Studieverloop:

U zal door de onderzoeker gecontacteerd worden om een afspraak te maken voor het interview op een voor U passend moment. Het interview zal worden opgenomen op audiotape. U kan ten allen tijde het gesprek onderbreken voor een pauze. Indien U niet wenst door te gaan met het gesprek of een bepaald onderwerp wil overslaan wordt dit ten allen tijde gerespecteerd.

Risico’s en voordelen:

Er zijn geen risico’s voor de deelnemers aan deze studie.

Het belangrijkste voordeel is dat u bijdraagt aan de ontwikkeling van een betere verpleegkundige zorg dat meer gericht is op de prioriteiten van de patiënten. Uw deelname zal de zorg voor patiënten met multimorbiditeit binnen de thuisverpleging ten goede komen. Bovendien stelt deze studie de deelnemer in staat om stil te staan bij zijn eigen functioneren en na te denken over individuele noden en prioriteiten.

Kosten:

Uw deelname aan deze studie brengt geen extra kosten mee voor U.

Vergoeding:

Er wordt geen vergoeding voorzien voor deelname aan deze studie.

Vertrouwelijkheid:

In overeenstemming met de Belgische wet van 8 december 1992 en de Belgische wet van 22 augustus 2002, zal u persoonlijke levenssfeer worden gerespecteerd en zal u toegang krijgen tot de verzamelde gegevens. Elk onjuist gegeven kan op uw verzoek verbeterd worden. Als u akkoord gaat om aan deze studie deel te nemen, zullen uw persoonlijke en klinische gegevens
tijdens deze studie worden verzameld en gecodeerd. Verslagen waarin U wordt geïdentificeerd, zullen niet openlijk beschikbaar zijn. Als de resultaten van de studie worden gepubliceerd, zal uw identiteit vertrouwelijke informatie blijven.

**Letsels ten gevolge van deelname aan de studie:**

Alhoewel het onwaarschijnlijk is dat u schade zal oplopen door mee te doen aan deze studie, heeft de onderzoeker voorzien in een vergoeding en/of medische behandeling in het geval van schade en/of letsel tengevolge van deelname aan de studie. Voor dit doeleinde is een verzekering afgesloten met foutloze aansprakelijkheid conform de wet inzake experimenten op de menselijke persoon van 7 mei 2004. Op dat ogenblik kunnen uw gegevens doorgegeven worden aan de verzekeraar.

**Contactpersoon:**

Als er een probleem optreedt tijdens de studie of als U aanvullende informatie wenst over de studie of over uw rechten en plichten, kunt U in de loop van de studie op elk ogenblik contact opnemen met:

Mieke Lanssens

Mieke.Lanssens@UGent.be

09 3322747

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**Toestemmingsformulier**

Ik, _________________________________________ heb het document “Informatiebrief voor de deelnemers” gelezen. Ik stem in met de inhoud van het document en stem ook in deel te nemen aan de studie. Ik geef hierbij ook de toestemming aan de onderzoeker om bestaande gegevens uit mijn patiëntendossier op te zoeken en de nodige gegevens te verzamelen en te verwerken.

Ik heb een kopij gekregen van dit ondertekende en gedateerde formulier. Ik heb uitleg gekregen over de aard, het doel, de duur van de studie en over wat men van mij verwacht. Men heeft me de gelegenheid en voldoende tijd gegeven om vragen te stellen over de studie, en ik heb op al mijn vragen een bevredigend antwoord gekregen.

Indien ik toegang wil tot mijn gegevens, zal ik mij richten tot de toezichthouder die verantwoordelijk is voor de verwerking gekregen.

Ik ben er ervan bewust dat deze studie werd goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het UZ Gent en dat deze studie zal uitgevoerd worden volgens de richtlijnen voor de goede klinische praktijk (ICH/GCP) en de verklaring van Helsinki, opgesteld ter bescherming van mensen deelnemend aan experimenten. Deze goedkeuring was in geen geval de aanzet om te beslissen om deel te nemen aan deze studie.
Men heeft mij ingelicht over het bestaan van een verzekeringspolis in geval er letsel zou ontstaan dat aan de studieprocedures is toe te schrijven.

Ik mag me op elk ogenblik uit de studie terugtrekken zonder een reden voor deze beslissing op te geven en zonder dat dit op enigerlei wijze een invloed zal hebben op mijn verdere relatie met mijn behandelend arts of de onderzoeker.

Ik ben bereid op vrijwillige basis deel te nemen aan deze studie.

Naam van de vrijwilliger:

__________________________

Datum:_____________________

Handtekening:

Ik bevestig dat ik de aard, het doel, en de te voorziene effecten van de studie heb uitgelegd aan de bovenvermelde vrijwilliger. De vrijwilliger stemde toe om deel te nemen door zijn/haar persoonlijk gedateerde handtekening te plaatsen.

Naam van de persoon die de voorgaande uitleg heeft gegeven:

__________________________

Datum:_____________________

Handtekening:
Appendix G: Patients’ Characteristics

<table>
<thead>
<tr>
<th>Name</th>
<th>Sex</th>
<th>Age</th>
<th>Civil class</th>
<th>Comorbidities</th>
<th>Health care network</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Male</td>
<td>70</td>
<td>Widower</td>
<td>Obesitas, Prostate cancer, Anemia, Recidivist angor, Depression, Cataract</td>
<td>GP, Oftalmologist, Cardiologist, Gynaecologist, Urologist, Pneumologist, Home assistance, Community nursing, Informal care by sister and niece</td>
</tr>
<tr>
<td>P2</td>
<td>Female</td>
<td>88</td>
<td>Widow</td>
<td>Obesitas, Diabetes II, Recidivist Lumbago, Lipid disorder, Cataract, Refluxoesofagitis, Dyspnoe, Coronary Artery disease, Chronic Gastritis, Tachycardia, Hypertension</td>
<td>GP, Endocrinologist, Podologist, Home assistance, Community nursing, informal care by children</td>
</tr>
<tr>
<td>P3</td>
<td>Female</td>
<td>79</td>
<td>Widow</td>
<td>Obesitas, Alzheimer disease, Heart failure, Severe Hypertension, TBC, Generalized Osteoarthritis, Lumbago</td>
<td>GP, Reumatologist, Cardiologist, Pneumologist, Orthopedist, Home assistance, Community Nursing, Informal care by children</td>
</tr>
<tr>
<td>P4</td>
<td>Female</td>
<td>85</td>
<td>Single</td>
<td>Hypertension, Osteoporosis, Oesofagitis, Cardiorespiratoire insufficientie</td>
<td>Gp, Pneumologist, Community Nursing</td>
</tr>
<tr>
<td>P5</td>
<td>Male</td>
<td>71</td>
<td>Married</td>
<td>Claudicatio intermittens, Prostate hypertrophy</td>
<td>GP, Community Nursing, Home assistance</td>
</tr>
<tr>
<td>P6</td>
<td>Female</td>
<td>57</td>
<td>Married</td>
<td>Sleep disorder, Hysterectomy</td>
<td>GP</td>
</tr>
<tr>
<td>P7</td>
<td>Female</td>
<td>88</td>
<td>Widow</td>
<td>Depression, Carpale-tunnel syndrome, hyperthyroidism, Lipid disorder, Hypertension, Refluxoesofagitis, Obesitas, Pancreatitis</td>
<td>GP, Lives in a nursing home</td>
</tr>
<tr>
<td>P8</td>
<td>Male</td>
<td>69</td>
<td>Married</td>
<td>Prostate hypertrophy, Otitis Media, Vocal Cord cancer, Lipid disorder</td>
<td>GP, Home assistance, Pedicure</td>
</tr>
<tr>
<td>P9</td>
<td>Male</td>
<td>72</td>
<td>Married</td>
<td>Osteoarthritis, Appendicitis, Recidivist</td>
<td>GP, Physical therapist,</td>
</tr>
<tr>
<td>ID</td>
<td>Gender</td>
<td>Age</td>
<td>Marital Status</td>
<td>Medical Conditions</td>
<td>Healthcare Providers</td>
</tr>
<tr>
<td>-----</td>
<td>--------</td>
<td>------</td>
<td>----------------</td>
<td>------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------</td>
</tr>
<tr>
<td>P10</td>
<td>Female</td>
<td>56</td>
<td>Divorced</td>
<td>Pneumonia, Arrhythmia, Alcohol abuse</td>
<td>Cardiologist, Chiropractor.</td>
</tr>
<tr>
<td>P11</td>
<td>Male</td>
<td>76</td>
<td>Married</td>
<td>Atrial fibrillation, Prostate cancer, Hypertension, Angina Pectoris, Claudication Intermittens, Refluxoesophagitis, Cataract</td>
<td>Cardiologist, Pneumologist, Urologist, Nurse daily, Informal care by partner.</td>
</tr>
<tr>
<td>P12</td>
<td>Male</td>
<td>84</td>
<td>Widower</td>
<td>Abdominal Aneurism, Atrial Fibrillation, Cardiac Failure, Radiculopathy, Prostate cancer, Hypercholesterolemia, Osteoporosis, Ulcus Duodenii, Cerebrovascular Accident, Atherosclerosis, Cataract</td>
<td>Cardiologist, Pneumologist, Ophthalmologist, Informal care by son</td>
</tr>
<tr>
<td>P13</td>
<td>Male</td>
<td>51</td>
<td>Married</td>
<td>Social problem(financial), Drug abuse, Alcohol abuse.</td>
<td>GP</td>
</tr>
<tr>
<td>P14</td>
<td>Male</td>
<td>68</td>
<td>In a relationship</td>
<td>Diabetes type II, Visual impairment, Hearing impairment, Peripheral arterial disease, Balance disorder, Osteoarthritis.</td>
<td>GP, Home assistance, Vascular surgeon</td>
</tr>
<tr>
<td>P15</td>
<td>Female</td>
<td>50</td>
<td>In a relationship</td>
<td>Breastcancer, Gastric ulcer, Osteoarthritis, General Tiredness, Social problem (relational)</td>
<td>Oncologist, Gynecologist, Physical therapist, Informal care by daughter</td>
</tr>
<tr>
<td>P16</td>
<td>Male</td>
<td>70</td>
<td>Married</td>
<td>Minières disease, Diabetes II, Macular degeneration, Generalised arthritis, Lipid disorder, Hypertension</td>
<td>Pneumologist, Ophthalmologist, Informal care</td>
</tr>
<tr>
<td>P17</td>
<td>Female</td>
<td>65</td>
<td>Married</td>
<td>Chronic Kidney Disease, Gout, Refluxoesofagitis, Hypertension, Lipid disorder</td>
<td>Pneumologist</td>
</tr>
<tr>
<td>P18</td>
<td>Male</td>
<td>77</td>
<td>Married</td>
<td>Lipid Disorder, Prostate cancer, Hypertension, Osteoporosis</td>
<td>Pneumologist, Urologist</td>
</tr>
<tr>
<td>P19</td>
<td>Male</td>
<td>82</td>
<td>Married</td>
<td>Generalised osteoarthritis, Refluxoesofagitis, Atrial Fibrillation, Cataract</td>
<td>Pneumologist, Cardiologist, Informal care by partner</td>
</tr>
</tbody>
</table>
Appendix H: Summary in Dutch

Probleemstelling

De vergrijzing brengt een stijgende prevalentie chronische ziekten met zich mee. Bovendien komen steeds vaker twee of meer chronische ziekten voor bij eenzelfde patiënt. Multimorbiditeit heeft echter een grote impact op het functioneren en op de kwaliteit van leven van een patiënt. De noden en behoeften van patiënten worden complexer doordat ze samenhangen aan verschillende chronische ziekten. Nu krijgen patiënten een behandeling voor elke ziekte afzonderlijk (een ‘problem-oriented approach’) met een focus op ziekte specifieke uitkomstmaten zoals bloeddruk, longinhoud, glycemie, etc. Een behandeling kan dan wel effectief zijn voor een bepaalde ziekte, maar de combinatie van meerdere aandoeningen zorgt ervoor dat de ziekte specifieke richtlijnen vaak tegenstrijdig zijn. Bovendien zijn de behandelingen onvoldoende aangepast aan de individuele behoeften van de patiënt. Er is nood aan een integrale aanpak die verder kijkt dan de biomedische indicatoren, waarbij patiënt gerichtheid een grotere rol speelt. Deze thesis moedigt de introductie van de ‘goal-oriented approach’ aan om deze problematiek te minimaliseren. De aanpak biedt patiënten de mogelijkheid zorg te sturen aan de hand van hun individuele doelen. De wetenschappelijke literatuur bewijst dat aan de implementatie van een ‘goal-oriented approach’ binnen de eerstelijns gezondheidszorg theoretische en conceptuele voordelen verbonden zijn, die een grotere kwaliteit van zorg kunnen betekenen.

COPD is een chronische aandoening dat in aanmerking komt voor een ‘goal-oriented approach’. Bij COPD worden objectieve en ziekte specifieke uitkomstmaten gehanteerd om te beoordelen of een behandeling effectief is. Maar, longinhoud metingen en inhalatie therapieën blijken geen effect te hebben op mortaliteit, longfunctie, functionaliteit of kwaliteit van leven bij patiënten. Bovendien lijden COPD patiënten vaak aan meerdere additionele chronische ziekten.

Doelstelling

Aan de hand van de verzamelde gegevens tracht deze studie te beschrijven welke prioriteiten patiënten voor zichzelf opstellen om zo het proces van doelen stellen door
patiënten te verhelderen. Daarenboven, ondernemt dit onderzoek een poging om onderliggende mechanismen te definiëren die het proces van doelen stellen verhinderen.

**Methode**

Er werd een kwalitatieve onderzoeksmethode gehanteerd waarbij 19 participanten geïnterviewd werden.

**Rekrutering van de participanten**


**Datacollectie**

Het ging om semi-gestructureerde interviews, gebaseerd op de COPM. De COPM (Canadian Occupational Performance Measure) wordt als leidraad gebruikt voor dit diepte-interview omdat het een methodiek biedt om de individuele prioriteiten van deze patiënten te bepalen. Eerst werd het dagelijks leven en functioneren van de deelnemer uitgebreid besproken. Naarmate het interview vorderde, vernauwde de onderzoeker de focus van het gesprek richting de prioriteiten en om de inherente doelen te bepalen. Op het einde van het gesprek, stimuleerde de onderzoeker de participant om persoonlijke doelen te verwoorden door expliciet te vragen om 5 huidige doelen in hun leven op te sommen. Alle interviews werden integraal uitgetypt en geanalyseerd.

**Data-analyse**

De analyse gebeurde op een systematische manier. Eerst werden 3 interviews afzonderlijk gelezen door de onderzoekers. Daarbij selecteerden de onderzoekers onafhankelijk van elkaar tekstfragmenten met betrekking tot een doelstelling. Daarna
kwamen de onderzoekers samen om de geselecteerde tekstfragmenten te vergelijken en te bediscussiëren tot er consensus gevormd werd over de selectie van tekstfragmenten. Dit proces werd meermaals herhaald, zodat alle interviews behandeld werden. Later, werden alle tekstfragmenten in een nieuw document verzameld. Dit gaf de aanleiding tot open codering waarbij meerdere tekstfragmenten gecategoriseerd werden onder een code. Opnieuw kwamen de onderzoekers samen om de codes te bediscussiëren totdat consensus bereikt werd. Vervolgens werden de codes gegroepeerd in grotere categorieën. Uiteindelijk werden de eerste analyses en bevindingen voorgelegd aan een panel van methodologische experts. Dit leidde in een intensieve, uitgebreide discussie en resulteerde in een eerste interpretatie van de opgestelde doelen en in de identificatie van vier hypotheses die verklaren waarom het stellen van doelen moeilijk gaat bij patiënten.

**Resultaten en discussie**

De hoofdbevinding van deze studie is dat het proces van doelen stellen door de participant als moeilijk wordt ervaren. Concrete, specifieke en haalbare doelen werden weinig gedefinieerd.

Aanvullend op deze bevinding, zochten de onderzoekers naar mogelijk mechanismen die kunnen verklaren waarom dit proces zo moeilijk verloopt. Vier hypotheses werden opgesteld:


2. Het stellen van doelen wordt verhinderd doordat patiënten hun situatie aanvaard hebben. We kunnen aannemen dat patiënten hun situatie zodanig aanvaard
hebben, waardoor dat ze geen behoefte meer hebben om te streven naar ambitieuze doelen. Opmerkelijk, vanuit de interviews kon geïnterpreteerd worden dat patiënten geen doelen meer stellen omdat ze geen of onvoldoende perspectief hebben. Vaak in deze gevallen uiten participanten toch acceptatie, maar eigenlijk geven ze het op om doelen te stellen.

3. Ander stressoren verdringen het proces van stellen van doelen. Angst, pijn en vermoeidheid kunnen zodanig prominent aanwezig zijn in het leven van patiënten met COPD en comorbiditeiten dat het stellen van doelen geen prioriteit meer heeft.

4. Patiënten beschouwen persoonlijke doelen als egoïstisch. Participanten ervaren afhankelijk zijn van anderen als een van de grootste problemen en proberen dit zoveel mogelijk te vermijden. Ze voelen zich ongemakkelijk wanneer ze persoonlijke doelen stellen, omdat ze de belangen van anderen voor hun persoonlijke prioriteiten plaatsen.

Deze vier hypotheses verduidelijken welke factoren het proces van doelen stellen in eerstelijnsgezondheidszorg kunnen verhinderen. Een goede communicatie tussen patiënt en hulpverlener is van essentieel belang om te onderscheiden of de patiënt de behoefte heeft om doelen te stellen of niet. Daarnaast moeten hulpverleners aandachtig worden voor een ‘goal-oriented approach’ in eerstelijnsgezondheidszorg door patiënten te engageren en te ondersteunen in het proces van doelen stellen. Bovendien is onze huidige gezondheidszorg onvoldoende gevormd om een ‘goal-oriented approach’ te kunnen integreren. Dit vereist namelijk meer tijd en financiële middelen.