

BMJ Open PANDORA dyadic project: hope, spiritual well-being and quality of life of dyads of patients with chronic obstructive pulmonary disease in Switzerland – a multicentre longitudinal mixed-methods protocol study

Filipa Baptista Peixoto Befecadu ^{1,2,3}, Jerome Stirnemann,² Ivan Guerreiro,^{4,5} Tanja Fusi-Schmidhauser,^{6,7} Cyril Jaksic,² Philip J Larkin,^{1,3} Gora da Rocha Rodrigues ⁸, Sophie Pautex⁹

To cite: Baptista Peixoto Befecadu F, Stirnemann J, Guerreiro I, *et al.* PANDORA dyadic project: hope, spiritual well-being and quality of life of dyads of patients with chronic obstructive pulmonary disease in Switzerland – a multicentre longitudinal mixed-methods protocol study. *BMJ Open* 2023;**13**:e068340. doi:10.1136/bmjopen-2022-068340

► Prepublication history for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-068340>).

Received 15 September 2022
Accepted 26 April 2023



© Author(s) (or their employer(s)) 2023. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

Correspondence to

Mrs Filipa Baptista Peixoto Befecadu; fabp30@gmail.com

ABSTRACT

Introduction Chronic obstructive pulmonary disease (COPD) is responsible for 2.9 million deaths annually in Europe. Symptom burden and functional decline rise as patients reach advanced stages of the disease enhancing risk of vulnerability and dependency on informal caregivers (ICs).

Evidence shows that hope is an important psycho-social-spiritual construct that humans use to cope with symptom burden and adversity. Hope is associated with increased quality of life (QoL) comfort and well-being for patients and ICs. A better understanding of the meaning and experience of hope over time as patients transition through chronic illness may help healthcare professionals to plan and deliver care more appropriately.

Methods and analysis This is a longitudinal multicentre mixed-methods study with a convergent design. Quantitative and qualitative data will be collected from dyads of advanced COPD patients and their ICs in two university hospitals at two points in time. The Herth Hope Index, WHO Quality of Life BREF, Functional Assessment of Chronic Illness Therapy-Spiritual Well-being and the French version of the Edmonton Symptom Assessment Scale will be used to collect data. Dyadic interviews will be conducted using a semi-structured interview guide with five questions about hope and their relationship with QoL.

Statistical analysis of data will be carried out using R V.4.1.0. To test whether our theoretical model as a whole is supported by the data, structural equation modelling will be used. The comparison between T1 and T2 for level of hope, symptom burden, QoL and spiritual well-being, will be carried out using paired t-tests. The association between symptom burden, QoL, spiritual well-being and hope will be tested using Pearson correlation.

Ethics and dissemination This study protocol received ethical approval on 24 May 2022 from the *Commission cantonale d'éthique de la recherche sur l'être humain*—Canton of Vaud. The identification number is 2021-02477.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Combining quantitative and qualitative methods offers the potential to better understand the experience and meaning of hope for patients and informal caregivers (ICs).
- ⇒ A longitudinal approach to the study will capture change and illuminate the place of hope as a dynamic aspect of negotiating chronic and life-limiting illness.
- ⇒ Research with dyads offers a novel approach to understanding the global experience of chronic and life limiting illness.
- ⇒ The relatively heterogeneous nature of the population and the focus of the study in one region may impact on the generalisability of results to chronic obstructive pulmonary disease patients and ICs in the wider context.

INTRODUCTION

Chronic obstructive pulmonary disease (COPD), one of the most prominent causes of chronic conditions in high-income countries, is responsible for 2.9 million deaths annually in Europe. COPD is the third leading cause of death in the world.^{1–3} Symptom burden and functional decline rise as patients reach advanced stages of their disease enhancing vulnerability and dependency on family or informal caregivers (ICs). Common symptoms associated with COPD include severe breathlessness (47.3%),⁴ depression (40%, range from 8%–80%), anxiety (36%, range from 6%–74%),⁵ recurrent acute exacerbations and hospitalisations⁶ resulting in poor quality of life (QoL).⁷ As disease progresses, patients increasingly need ICs for assistance with care and activities.^{8–10}

ICs are the main providers of care at home comparative to healthcare professionals (HCPs) providing largely consultation services.¹⁰ The burden of care leads frequently to psychological sequelae such as anxiety, depression, emotional distress and poor QoL.^{8–10} ICs are at risk of increased personal vulnerability especially when there is an imbalance between burden and coping capacity.¹⁰ A 2015 literature review examining existing knowledge about informal caregiving in patients with COPD, concluded that ICs were mostly female spouses still contributing to the work force, 34% of whom took time off from work to help their partner.¹⁰ Caregivers reported lack of information, emotional and practical support, moments of anxiety, helplessness, depression, worries, uncertainty about the future, loss of mobility and social isolation with a concomitant impact on patient life quality and distress for both patient and caregiver.¹⁰

Hope is a dynamic basic human response essential to life, health and illness that changes over time.^{11–14} An important psycho-social-spiritual construct that humans use to cope with symptom burden and adversity,¹⁵ it is associated with finding meaning through determining ones' own inner resources^{16–19} and contributes to comfort, QoL and well-being for patients and families.^{20–23} Conversely, hopelessness is associated with symptom burden including pain, anxiety, depression, fatigue, spiritual suffering and suicidal ideation.^{16 21 24} Common threats to hope comprise demoralisation, psychological, spiritual and existential distress, lack of social support and symptom burden.²⁵ Symptom burden, particularly depression can detrimentally affect hope, resulting in poor well-being in patients and their ICs.²⁴ Hope studies in other clinical populations consider hope as a predictor of mood states and QoL within recipients of heart transplant.¹⁴ A Dutch qualitative longitudinal study, including, severe COPD population saw an association between hope and a change in the nature of hope as their physical condition changed.¹¹ Such changes were paramount in the dynamics of hope, hopelessness and despair.¹¹ Spiritual well-being, like hope, is seen as a positive resource that patients and ICs use to cope with health deficits.²⁶ A cross-sectional study of 500 patients with cardiovascular disease concluded that hope and spiritual well-being are positively related. Gender (in favour of females), religious belief (0.99, 95% CI 0.17 to 1.80, $p=0.018$) and hope (0.90, 95% CI 0.68 to 1.13, $p<0.001$) were predictors of spiritual well-being.²⁷ Spirituality and hope seemingly connect and both are important resources for patients and ICs, yet sparsely explored in the context of dyads of COPD patients and their ICs. A further qualitative study in palliative care suggested that developing a spiritual connection was an important factor that contributed to maintaining hope for both patient and IC.²⁸ However, to date no study has been identified which investigated patient and IC as a single unit—the dyad.

A dyad is defined as 'an interactive relationship between a pair of individuals'²⁹ (p315). Working at a dyadic level

enables a relationship-based understanding of how dyadic behaviours and coping strategies impact simultaneously illness management, health and well-being.³⁰ A recent Jordanian dyadic cross-sectional study into hope in end stage renal disease concluded that higher levels of hope in patients' were associated with a better ICs' environment domain of QoL.³¹ The use of the Herth Hope Index (HHI) demonstrated that both patients and ICs had a moderate level of hope (scores 24–35). ICs had a significantly higher level of hope scores than patients (33.47 ± 4.06 vs 32.06 ± 3.81 , $p=0.002$), and ICs had significantly higher scores in all domains of QoL than patients.³¹ Patients' and ICs scores on the HHI had a significant positive correlation with their own scores in all QoL domains (physical, psychological, social relationships and environment) as well as with some of their ICs' domain of QoL.³¹ Since hope impacts on both in equal measure and opportunities, both patient and IC should be considered as a single unit in terms of care and research.³² This may be particularly beneficial in under-researched dyadic populations such as COPD.^{33 34}

Overall, evidence suggests that hope is a complex personal phenomenon requiring individualised hope-enhancing strategies for effectiveness. However, there is a lack of data on how hope is experienced in the context of COPD. Greater understanding of patient and caregiver QoL, symptom burden, hope and spiritual well-being in this complex and life-limiting disease as well as deeper understanding of their dyadic experience over time would aid in the planning and management of care.^{33 34} Understanding dyadic hope expression as a transitional pattern over time may also help HCPs to address and recognise patterns of hope as they change, constructing new models of care focused on the needs of both patients and ICs.

METHODS AND ANALYSIS

Mixed-methods convergent design

This study comprises a longitudinal mixed-methods convergent design as described by Creswell and Plano Clark.³⁵ Qualitative and quantitative data are collected at the same time with the intent to merge results and bring together both results, so they can be compared or combined, to give a more complete understanding of the problem.³⁵ Quantitative and qualitative data will be collected from dyads of advanced COPD patients and their ICs in two university hospitals of French-speaking Switzerland at two points in time. In this study, comparisons of the quantitative (HHI scores) and qualitative results (verbatim extracts from the dyadic interviews) will be made through a side-by-side joint display with meta-inferences. Quantitative data from HHI scores of dyads in T1 and T2 will be compared with their experience to provide comprehensive results, and/or validate and confirm results.

Hypothesis and primary objective

- ▶ The primary objective tests the relationship between advanced COPD patients and their ICs' level of hope and QoL.
- ▶ Secondary objectives are to:
 - Describe the experience of hope in advanced COPD patients and their ICs across two points in time.
 - Test the associations between hope, symptom burden, QoL and spiritual well-being of patients suffering from advanced COPD.
 - Test the associations between hope, QoL and spiritual well-being of ICs of advanced COPD patients.
 - Test the effect of time on hope, symptom burden, QoL and spiritual well-being of patients suffering from advanced COPD and their ICs.
 - Describe to what extent do the quantitative and qualitative results converge.
 - Merge quantitative and qualitative data on hope to gather a broader understanding of dyad's experience over time.

We consider that the dynamics of patients and ICs can be seen through an Actor-Partner Interdependence Model (APIM). With this in mind, our main hypothesis is that both the patient's and their IC's QoL influence each other's level of hope. As secondary hypotheses, we hypothesise that lower levels of hope are negatively associated with symptom burden in patients with advanced COPD. Further, higher levels of hope will be positively associated with better QoL, and higher levels of spiritual well-being. Over time, we expect symptom burden to increase and levels of hope to decrease for both patients and their ICs.

Primary and secondary endpoints

Hope: primary outcome

The HHI is a 12-item self-reported scale (4-point Likert scale ranging from 1—strongly disagree to 4—strongly agree) used to assess the overall hope level of the participants (score ranging between 12 and 48). Higher scores indicate higher levels of hope.³⁶ Translated into several languages, it has been validated in different populations, including both chronic and terminally ill adult patients.³⁷ The original English version was translated by our research team using Wild's method and pretested in a sample of six persons (two elders, two adults, one teenager and one person with chronic disease).³⁸ Of the 12 items, four questions in each of three subscales of the HHI include: factor 1—temporality and future; factor 2—positive readiness and expectancy, factor 3—interconnectedness with self and others. Internal consistency reliability ranges from $\alpha=0.89$ to 0.97 and a test–retest reliability of $r=0.91$ for different patient populations including ICs.^{31 39}

Quality of life

The WHO Quality of Life BREF (WHOQoL-BREF)⁴⁰ is a self-administrated 26-item instrument measuring four domains of the QoL: physical health (seven items),

psychological health (six items), social relationships (three items) and environmental health (eight items), plus two global health-related QoL items measuring individual's overall satisfaction with life and overall sense of self well-being.⁴⁰ Responses range from 1 to 5 on a 5-point scale. Domain scores are calculated by taking the mean of all items included in each domain and multiplying by a factor of four. These scores are then transformed to a 0–100 scale with higher scores indicating better QoL.^{40 41} This instrument has been used widely in research with various populations. The WHOQoL-BREF was translated and validated in French using a sample of 2102 patients with neuromuscular disease.⁴² The WHOQoL-BREF has good to excellent psychometric properties of reliability and the domain scores show good discriminant validity, content validity, internal consistency (Cronbach's alpha: physical health, 0.80; psychological health, 0.76; social relationships, 0.66 and environment, 0.80) and test–retest reliability.⁴³

Symptom burden

Edmonton Symptom Assessment Scale - revised version (ESAS-r) is a 10-item patient rated symptoms scale and a numerical rating for symptom severity (0–10) translated and adapted to French (F-ESAS Cronbach's alpha 0.77).⁴⁴ The F-ESAS-r scale assess the intensity of pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath and a supplementary symptom added by the patient if necessary. The severity of each symptom is rated from 0 'absence of symptom' to 10 'worst possible intensity'. Each numerical scale is interpreted independently from the other scales; however, it is also possible to calculate the total sum of all symptoms. The sum of the severity scores corresponds to the measure of symptom burden. Total scores range from 0 to 90 and higher scores indicate greater symptom burden.

Spiritual well-being

The Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp-12) is a 12-item scale widely used to measure spiritual well-being.²⁶ Responses are scored on a 5-point Likert scale ranging from 0 'not at all' to 4 'very much'. Total scores range from 0 to 48, with higher scores indicating higher spiritual well-being. High spiritual well-being was defined as a FACIT-Sp total score ≥ 36 .⁴⁵ The 12 items comprise two subscales; one measuring sense of meaning and peace and the other measuring the role of faith in illness. The validation of the French version in elderly patients show good psychometric properties (Cronbach's alpha: 0.85).²⁶

Sociodemographic data

Sociodemographic data will provide information regarding age, gender, family circumstances, background, level of education, professional status and religious affiliations. The degree of the relationship between the patient and the IC will be collected. This questionnaire will be administered to both, patient and IC.

Medical data

Following ethical approval and under clinical supervision of the medical team, medical records will be screened to ensure that patients meeting eligibility criteria for the study, using the Palliative Performance Scale (PPS).⁴⁶

Project population, inclusion and exclusion criteria

A multicentre study is proposed to include a larger number of participants living with and caring for COPD from different geographic locations. There is no consensus on the appropriate method for determining adequate sample size in structural equation modelling (SEM).^{47–49} Taking into account the number of variables to be tested (in this case four), some authors recommend at least 10 subjects per variable. Because the unit of interest in the present study is a dyad, we plan on not having fewer than 40 dyads.

The main hypothesis is concerned with the association between hope and QoL. Its corresponding null hypothesis (H_0) is that the correlation coefficients between hope and QoL (whether they be of patients or ICs) are equal to zero. We aim to recruit at least two dyads per week per centre, across 4 months; a total of 64 dyads. This sample size would allow us to detect, with an $\alpha=0.05$ (two-tailed) and $\text{power}=0.80$, an association between hope and QoL corresponding to a correlation coefficient of at least $r=0.336$ (calculated with G*Power 3.1.9.7). This applies to all four correlations between hope (patients and ICs) and QoL (patients and ICs). This value is satisfactory with regards to our expectation since any true correlation coefficients below 0.336 would be deemed too low to be of interest. This value is also below most correlation coefficients found in literature between measures of hope and measures of QoL (or dimensions of them), with ranges of 0.39–0.72,⁵⁰ 0.43–0.60,⁵¹ 0.57,⁵² 0.31–0.44,⁵³ 0.49,⁵⁴ making it a realistic to expect a value above 0.336. Therefore, we aim to include 64 dyads of advanced COPD patients and their ICs across the two centres. Although we expect drop-out, our main hypothesis relates on the measurements made at baseline. Our secondary hypothesis pertaining to repeated measures will only be carried out if the sample allows it. Furthermore, this decision takes in consideration the difficulties in recruiting in this context.

Qualitative data will be collected from a purposeful sample of dyads using a pre-prepared interview guide. Questions will invite the participant to share their experience of living with COPD and the place and perception of hope in navigating the illness from the perspective of both patient and IC. Attention will be paid to the benefit of having as heterogeneous a sample as possible to reflect a range of age, ethnicity, marital status and stage of disease.

Inclusion criteria

- ▶ Adult patients (≥ 18 years old) with capacity for discernment, able to provide informed consent.

- Diagnosed with severe COPD (global initiative for chronic obstructive lung disease III or IV) group B, C and D⁵⁵
- or COPD at any disease stage with use of oxygen therapy at home
- or non-staged COPD and hospitalisation in intensive care unit (ICU)/intermediate care unit (IMCU)
- or non-staged COPD and hospitalisation for non-invasive ventilation in ICU/IMCU.
- ▶ Negative answer from a clinician to the ‘surprise question’: ‘Would you be surprised if this patient died in the next 12 months?’⁵⁶
- ▶ General physical decline, increasing dependency and need for support (PPS score between 30% and 70%⁵⁷).
- ▶ ICs considered by the patient as the person most involved in their care (adult age ≥ 18 years old), being able to speak, read and understand French, capacity of discernment and being able to provide informed consent.

Exclusion criteria

- ▶ Patient or IC not sufficiently literate in French language to understand written information or take part in an interview
- ▶ Patients with an anticipated prognosis of less than 3 months
- ▶ Patients and/or ICs with existing diagnosis of dementia, cognitive disorder, memory loss or disturbances of speech that would not allow to conduct an interview.
- ▶ Patient diagnosed with active cancer, receiving curative or palliative cancer therapies.

Recruitment, screening and informed consent procedure

Participants will be recruited by the research team, in collaboration with the clinical team in charge of the patients, from the internal medicine departments of the two hospitals. Eligible patients will be identified through patient records to confirm the inclusion criteria documented and kept in a secured file. In addition, the clinical team will be required to give a negative response to the surprise question (‘Would you be surprised if this patient died in the next 12 months?’). For inpatients, a member of the research team will visit the wards to recruit eligible participants. For each potentially eligible patient, the researcher will calculate the PPS.⁴⁶ People with a score below 30% will be excluded (too ill to participate in the study), as will those with a score $>70\%$ (not in physical decline). The score of 70% is defined as the minimum score to indicate need of specialised palliative care.⁴⁶ At that point, the research team will consult the patient record and clinical team to ensure that inclusion criteria are met, ascertain stability of clinical condition, and note diagnoses of dementia, cognitive disorder, memory loss or disturbances of speech and oncological disease under treatment which would render them ineligible. Once

collated, the research team will meet with eligible patients and invite them to participate, explaining the study and sharing the participant information letter. Patients will be given at least 24 hours to make their decision. Those who agree will be invited to choose the IC to participate with them in the study (who will also receive a participant's information letter and at least 24 hours to make their decision). Both will receive a consent form, to be signed and dated by the investigator or designee at the time of participant agreement/signature. The consent form will be stored securely as part of the study records. If necessary, the research team will mail the information letter and the consent to the patient/IC. In all cases, before mailing the information letter, the research team will call the patient and the designed IC to present and explain the study.

Following consent, a research team member will arrange an appointment with the dyad. If in the discharge phase with a preference to answer questionnaires at home, the patient's email address will be requested so that the questionnaires can be sent directly to the participant to avoid attrition due to discharge.

For respiratory outpatients, the research team will consult the list of patients with the collaboration of the clinical team and include/exclude them according to the criteria. Finally, the research team will call the patients, present the study, answer their questions and invite them to participate and to identify an IC. If they accept to participate an information letter and consent will be mailed to them.

Study procedures

The overall duration of the study is 16 months. Recruitment will take place over 12 months (started in May 2022). Data will be collected at two points in time: T1—baseline and T2—4 months after baseline. In an earlier qualitative longitudinal study in Portugal (publication in preparation), testing of timelines demonstrated good adherence to the protocol. In a sample of eight dyads, only one dyad was lost to the study because of hospitalisation and clinical decline at T2.

The questionnaires will be answered via an electronic tablet supplied to the participants with a link to a Research Electronic Data Capture system (REDCap). Face to face interviews will be audio-recorded, transcribed verbatim

and coded. Interviews can also take place virtually. The choice will be given to the participants. All recruited participants will be asked to complete the list of assessments noted in [table 1](#).

When possible, quantitative and qualitative data collection will occur concurrently. It may be separated to reduce burden to the patient and IC and accommodate routine care and treatment. Quantitative data will be always collected first to ensure the interview does not affect the quantitative data. Quantitative data will be collected using tools listed in [table 1](#) and the sociodemographic questionnaire. The PPS will be used to determine patient ability to participate.

Qualitative data will be collected through face-to-face semi-structured interviews with patient and IC together (duration 30–40 min). The semi-structured interview guide was developed and inspired by Dufault and Martocchio's six dimensions of hope and the three subscales of the HHI, involving a committee of experts who revised and validated the guide.^{13 36} The interview guide has five main questions addressing the experience of hope and QoL. The first question is 'When I mention the word 'hope', what are the first thoughts that come to mind?'. At the beginning of each interview, the research team members will encourage participants to mention if the interview is perceived as too demanding; they will suggest a break, and assess the possibility of continuing. During data collection, if a participant's health deteriorates, the principal investigator will suspend data collection and inform the participant's physician and the clinical team. If participants experience psychological distress, they will be provided with the details of mental health clinicians and asked whether they would like a psychologist to contact them to discuss their distress. Participants will then be asked whether or not they would like to continue their participation in the study.

Withdrawal and discontinuation

Participation is voluntary and participants may withdraw from the study at any time without giving any reason and without further consequence. Participants will be reminded the digital recorder can be switched off and the interview terminated at any time. If consent is revoked, the data collected will be anonymised and analysed not to jeopardise the value of the study. Further data will not

Table 1 Assessments and interviews

		Sociodemographic data	HHI	WHOQoL-BREF	FACIT-Sp-12	ESAS-r	PPS	Semistructured interview
Patients	T1	X	X	X	X	X	X	X
	T2		X	X	X	X	X	X
ICs	T1	X	X	X	X			X
	T2		X	X	X			X

ESAS-r, Edmonton Symptom Assessment Scale - revised version; FACIT-Sp-12, Functional Assessment of Chronic Illness Therapy-Spiritual Well-being; HHI, Herth Hope Index; IC, informal caregiver; PPS, Palliative Performance Scale; WHOQoL-BREF, WHO Quality of Life BREF.

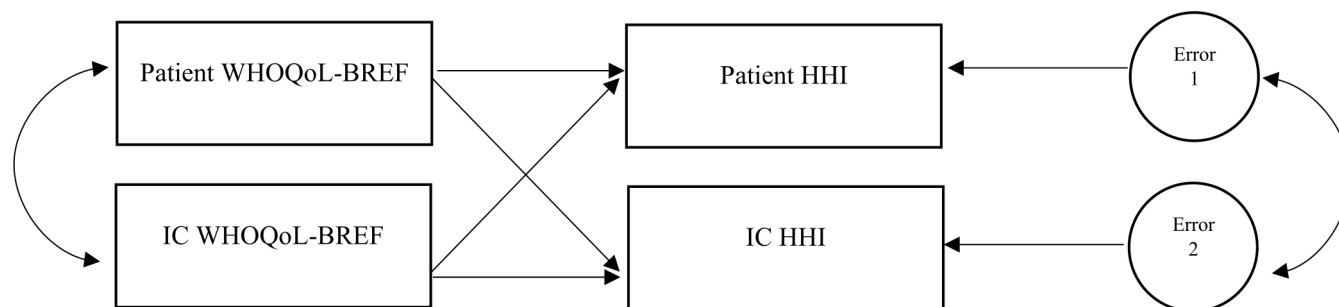


Figure 1 Representation of the structural equation modelling using HHI as a dependent variable and WHOQoL-BREF as independent variable. HHI, Herth Hope Index; IC, informal caregiver; WHOQoL-BREF, WHO Quality of Life BREF.

be collected. The investigator may discontinue a participant in the study at any time if necessary (eg, the patient's health situation declines or changes rapidly and/or participation in the study becomes a burden).

STATISTICS AND METHODOLOGY

Statistical analysis plan

The statistical analysis of the data will be carried out using R V.4.1.0. Descriptive statistics will be used; for nominal variables absolute and relative frequencies, for continuous variables means and SD, or median and IQR when appropriate.

Primary objective

To test in one single model, whether patients' QoL is associated with their own level of hope as well as ICs' level of hope and vice-versa, SEM will be used. This is the method of choice to test an APIM (see figure 1).⁴⁸

The SEM is used to explore how individuals interact.^{29 47} This model assumes 'the fact that the variable scores collected from individuals interacting within dyads are not independent, but are likely to be more correlated than scores from individuals in different dyads'²⁹ (p315).

In order to convey the strength of the associations between WHOQoL and HHI, Pearson correlation for each of the four associations will be calculated. In addition, partial correlations will be conducted to investigate the association between one's WHOQoL score and an HHI score (their own or their partner) while controlling for their partner's WHOQoL score. As a result, four partial correlations (one per association) will be conducted. Because our main hypothesis will be tested with a single test (SEM), and these additional correlation tests will be carried out to inform the direction and strength of association and not to directly answer the main hypothesis, no correction for multiple testing will be applied to their p-values.

Secondary objectives

Comparison between T1 and T2 for level of hope, symptom burden, QoL and spiritual well-being, will be done using paired t-tests. The association between symptom burden, QoL, spiritual well-being and hope will be tested using Pearson correlation tests. Non-parametric alternatives

will be used when appropriate. Alpha threshold of 0.05 will be used to determine statistical significance. Internal consistency of the HHI translated into French will be calculated using Cronbach's alpha.

Handling of missing data

The questionnaires will be automatically submitted into REDcap software by the patient or IC via the tablet. In practice, since all questions will be mandatory (meaning an empty field will block the subsequent one) we expect to have few to no missing data. However, if it is the case, missing data will be treated according to the guidelines provided by the authors of the instruments.

Qualitative data analysis

Semi-structured interviews will be translated verbatim and will be analysed using inductive thematic analysis as described by Braun and Clarke with a pragmatic perspective.⁵⁸ Interviews will be analysed on an ongoing basis to ensure data saturation.

ETHICS AND DISSEMINATION

This study protocol received ethical approval on 24 May 2022 from the *Commission cantonale d'éthique de la recherche sur l'être humain*—Canton of Vaud. The number of identification is 2021-02477.

Project data will be handled sensitively and securely, only accessible to authorised personnel. Quantitative data in Redcap via the online questionnaires and qualitative verbatim transcriptions will be stored in a secure server protected with a password. All persons involved in the study in any way are bound by confidentiality. The names of the participants will not appear in any printed or online reports or publications and any material with the potential to identify a participants, such as direct quotations in interview will be anonymised using a code design (eg, P1/T1/FBPPB), indicating patient, time and interviewer initials.

The results will be the subject of one or more publications.

Patient and public involvement

Patients, ICs and/or the public are not involved in the design, conduct, reporting or dissemination of this study.

Author affiliations

¹Institute of Higher Education and Research in Healthcare, University of Lausanne, Lausanne, Switzerland

²Geneva University Hospitals, Geneva, Switzerland

³Chair of Palliative Care Nursing, Palliative and supportive care service, Lausanne University Hospital, Lausanne, Switzerland

⁴Division of Pneumology, Geneva University Hospitals, Geneva, Switzerland

⁵Faculty of Medicine, University of Geneva, Geneva, Switzerland

⁶Palliative and Supportive Care Clinic and Department of Internal Medicine, Ente Ospedaliero Cantonale, Lugano, Switzerland

⁷University of Geneva, Geneva, Switzerland

⁸HES-SO University of Applied Sciences and Arts Western Switzerland, HESAV School of Health Sciences, Lausanne, Switzerland

⁹Dpt of Readaptation and Geriatrics, Geneva University Hospitals, Geneva, Switzerland

Contributors This project was a collaboration between several authors, each of whom made a significant contribution. FBPB oversaw the project, conceptualised the idea, created the plan and methodology, wrote the first draft of the document and secured the funding. JS, IG and TF-S contributed to the design of the project, while CJ contributed to the methodology and wrote the first draft of the document. GdRR, SP and P.J.L worked on the conceptualisation, methodology and writing of the document. In conclusion, the success of the project is due to the collaborative efforts of all the authors.

Funding This work was supported by the Geneva University Hospitals with a grant from the Care Directorate.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iDs

Filipa Baptista Peixoto Befecadu <http://orcid.org/0000-0003-3252-9657>

Gora da Rocha Rodrigues <http://orcid.org/0000-0001-7136-8345>

REFERENCES

- Siouta N, van Beek K, Preston N, *et al*. Towards integration of palliative care in patients with chronic heart failure and chronic obstructive pulmonary disease: a systematic literature review of European guidelines and pathways. *BMC Palliat Care* 2016;15.
- Sleeman KE, de Brito M, Etkind S, *et al*. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Glob Health* 2019;7:e883–92.
- Organization WH. Chronic obstructive pulmonary disease (COPD). 2021. Available: [https://www.who.int/news-room/fact-sheets/detail/chronic-obstructive-pulmonary-disease-\(copd\)](https://www.who.int/news-room/fact-sheets/detail/chronic-obstructive-pulmonary-disease-(copd)) [Accessed 14 Oct 2021].
- Punekar YS, Mullerova H, Small M, *et al*. Prevalence and burden of dyspnoea among patients with chronic obstructive pulmonary disease in five European countries. *Pulm Ther* 2016;2:59–72.
- Yohannes AM, Willgoss TG, Baldwin RC, *et al*. Depression and anxiety in chronic heart failure and chronic obstructive pulmonary disease: prevalence, relevance, clinical implications and management principles. *Int J Geriatr Psychiatry* 2010;25:1209–21.
- Søgaard M, Madsen M, Løkke A, *et al*. Incidence and outcomes of patients hospitalized with COPD exacerbation with and without pneumonia. *Int J Chron Obstruct Pulmon Dis* 2016;11:455–65.
- Camac ER, Voelker H, Criner GJ. Impact of COPD exacerbations leading to hospitalization on general and disease-specific quality of life. *Respiratory Medicine* 2021;186:106526.
- Soto-Rubio A, Valero-Moreno S, Diaz JL, *et al*. Copd at the end of life: predictors of the emotional distress of patients and their family caregivers. *PLoS One* 2020;15:e0240821.
- Kar S, Zengin N. The relation between self-efficacy in patients with chronic obstructive pulmonary disease and caregiver burden. *Scand J Caring Sci* 2020;34:754–61.
- Nakken N, Janssen DJA, van den Bogaart EHA, *et al*. Informal caregivers of patients with COPD: home sweet home? *Eur Respir Rev* 2015;24:498–504.
- Olsman E, Leget C, Duggleby W, *et al*. A singing choir: understanding the dynamics of hope, hopelessness, and despair in palliative care patients. A longitudinal qualitative study. *Palliat Support Care* 2015;13:1643–50.
- Herth KA, Cutcliffe JR. The concept of hope in nursing 3: hope and palliative care nursing. *Br J Nurs* 2002;11:977–82.
- Dufault K, Martocchio BC. Symposium on compassionate care and the dying experience. hope: its spheres and dimensions. *Nurs Clin North Am* 1985;20:379–91.
- Caboral MF, Evangelista LS, Whetsell MV. Hope in elderly adults with chronic heart failure. concept analysis. *Invest Educ Enferm* 2012;30:406–11.
- Salamanca-Balen N, Merluzzi TV, Chen M. The effectiveness of hope-fostering interventions in palliative care: a systematic review and meta-analysis. *Palliat Med* 2021;35:710–28.
- Best M, Aldridge L, Butow P, *et al*. Assessment of spiritual suffering in the cancer context: a systematic literature review. *Palliat Support Care* 2015;13:1335–61.
- Feuz C. Hoping for the best while preparing for the worst: a literature review of the role of hope in palliative cancer patients. *Journal of Medical Imaging and Radiation Sciences* 2012;43:168–74.
- Nierop-van Baalen C, Grypdonck M, van Hecke A, *et al*. Health professionals' dealing with hope in palliative patients with cancer, an explorative qualitative research. *Eur J Cancer Care (Engl)* 2019;28:e12889.
- Moore RJ. Handbook of pain and palliative care. *Hope in the Context of Pain and Palliative Care*. Cham: Handbook of Pain and Palliative Care 2018:377–98, 2018.
- Querido A. A promoção da esperança em FIM de vida: avaliação da efetividade de um programa de intervenção em pessoas CoM doença crónica avançada E progressiva. In: *Hope promotion at the end-of-life: Effectiveness of na intervention program in palliative patients*. Universidade Católica Portuguesa, 2013.
- Broadhurst K, Harrington A. A mixed method thematic review: the importance of hope to the dying patient. *J Adv Nurs* 2016;72:18–32.
- Daneault S, Lussier V, Mongeau S, *et al*. Ultimate journey of the terminally ill: ways and pathways of hope. *Can Fam Physician* 2016;62:648–56.
- Moree S de, Smets EM, Visser LN, *et al*. Silver linings: the experience of hope in dyads with motor neuron disease. An explorative study. *J Palliat Care Med* 2019;09:01.
- Davis MP, Lagman R, Parala A, *et al*. Hope, symptoms, and palliative care. *Am J Hosp Palliat Care* 2017;34:223–32.
- Bovero A, Opezzo M, Botto R, *et al*. Hope in end-of-life cancer patients: a cross-sectional analysis. *Palliat Support Care* 2021;19:563–9.
- Monod S, Lécurveux E, Rochat E, *et al*. Validity of the FACIT-sp to assess spiritual well-being in elderly patients. *PSYCH* 2015;06:1311–22.
- Yaghoobzadeh A, Soleimani MA, Allen KA, *et al*. Relationship between spiritual well-being and hope in patients with cardiovascular disease. *J Relig Health* 2018;57:938–50.
- Holtslander LF, Duggleby W, Williams AM, *et al*. The experience of hope for informal caregivers of palliative patients. *J Palliat Care* 2005;21:285–91.
- Peugh JL, DiLillo D, Panuzio J. Analyzing mixed-dyadic data using structural equation models. *Structural Equation Modeling: A Multidisciplinary Journal* 2013;20:314–37.
- Lyons KS, Lee CS. The theory of dyadic illness management. *J Fam Nurs* 2018;24:8–28.
- Al-Rawashdeh S, Alshraifeen A, Rababa M, *et al*. Hope predicted quality of life in dyads of community-dwelling patients receiving hemodialysis and their family caregivers. *Qual Life Res* 2020;29:81–9.
- Benzein EG, Berg AC. The level of and relation between hope, hopelessness and fatigue in patients and family members in palliative care. *Palliat Med* 2005;19:234–40.
- Sullivan DR, Iyer AS, Enguidanos S, *et al*. Palliative care early in the care continuum among patients with serious respiratory illness: an official ATS/AAHPM/HPNA/SWHPN policy statement. *Am J Respir Crit Care Med* 2022;206:e44–69.
- Schroedl CJ, Yount SE, Szmulowicz E, *et al*. A qualitative study of unmet healthcare needs in chronic obstructive pulmonary disease. A potential role for specialist palliative care? *Ann Am Thorac Soc* 2014;11:1433–8.

- 35 Creswell JW, Plano Clark VL. Designing and conducting mixed methods research. 2018.
- 36 Herth K. Abbreviated instrument to measure hope: development and psychometric evaluation. *J Adv Nurs* 1992;17:1251–9.
- 37 Herth K. Fostering hope in terminally-ill people. *J Adv Nurs* 1990;15:1250–9.
- 38 Wild D, Grove A, Martin M, *et al.* Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (pro) measures: report of the ISPOR Task force for translation and cultural adaptation. *Value Health* 2005;8:94–104.
- 39 Herth K. Hope in the family caregiver of terminally ill people. *J Adv Nurs* 1993;18:538–48.
- 40 Skevington SM, Lotfy M, O'Connell KA, *et al.* The world Health organization's whoqol-bref quality of life assessment: psychometric properties and results of the International field trial. A report from the WHOQOL group. *Qual Life Res* 2004;13:299–310.
- 41 WHO. *WHOQOL User Manual*. 1998.
- 42 Leplège A, Réveillère C, Ecosse E, *et al.* Psychometric properties of a new instrument for evaluating quality of life, the WHOQOL-26, in a population of patients with neuromuscular diseases. *Encephale* 2000;26:13–22.
- 43 Baumann C, Erpelding M-L, Régat S, *et al.* The WHOQOL-BREF questionnaire: French adult population norms for the physical health, psychological health and social relationship dimensions. *Rev Epidemiol Sante Publique* 2010;58:33–9.
- 44 Pautex S, Vayne-Bossert P, Bernard M, *et al.* Validation of the French version of the Edmonton symptom assessment system. *J Pain Symptom Manage* 2017;54:721–6.
- 45 McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. *Lancet* 2003;361:1603–7.
- 46 Prompantakorn P, Angkurawaranon C, Pinyopornpanish K, *et al.* Palliative performance scale and survival in patients with cancer and non-cancer diagnoses needing a palliative care consultation: a retrospective cohort study. *BMC Palliat Care* 2021;20:74.
- 47 Kenny DA, Cook WL, Kashy DA. *Dyadic data analysis*. New York, NY: Guilford Press, 2006.
- 48 Hong S, Kim S. Comparisons of multilevel modeling and structural equation modeling approaches to actor-partner interdependence model. *Psychol Rep* 2019;122:558–74.
- 49 Ullman JB. Structural equation modeling: reviewing the basics and moving forward. *J Pers Assess* 2006;87:35–50.
- 50 Lucas AG, Chang EC, Morris LE, *et al.* Relationship between hope and quality of life in primary care patients: vitality as a mechanism. *Soc Work* 2019;64:233–41.
- 51 Wippold GM, Roncoroni J. Hope and health-related quality of life among chronically ill uninsured/underinsured adults. *J Community Psychol* 2020;48:576–89.
- 52 Kim M, Kim K, Kim J-S. Impact of resilience on the health-related quality of life of adolescents with a chronic health problem: a structural equation approach. *J Adv Nurs* 2019;75:801–11.
- 53 Yadav S. Perceived social support, hope, and quality of life of persons living with HIV/AIDS: a case study from Nepal. *Qual Life Res* 2010;19:157–66.
- 54 Li M-Y, Yang Y-L, Liu L, *et al.* Effects of social support, hope and resilience on quality of life among Chinese bladder cancer patients: a cross-sectional study. *Health Qual Life Outcomes* 2016;14:73.
- 55 Disease GfCOL. Pocket guide to COPD diagnosis, management, and prevention a guide for health care professionals. In: *Global Initiative for Chronic Obstructive Lung Disease*. 2020.
- 56 Downar J, Goldman R, Pinto R, *et al.* The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis. *CMAJ* 2017;189:E484–93.
- 57 Ho F, Lau F, Downing MG, *et al.* A reliability and validity study of the palliative performance scale. *BMC Palliat Care* 2008;7:10.
- 58 Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3:77–101.