

1 **The experience of hospitalization in people with advanced chronic obstructive**
2 **pulmonary disease: A qualitative, phenomenological study**

3 **Abstract**
4

5 Objectives: People with advanced chronic obstructive pulmonary disease (COPD) are frequently
6 hospitalized, reporting high physical, psychological and spiritual suffering. Existing research focused on
7 discrete aspects of hospitalization, such as care or treatment, yet lacks a complete picture of the
8 phenomenon. The aim of this study is to understand the lived experience of hospitalization in people
9 with advanced COPD.

10 Methods: A qualitative, descriptive phenomenological approach was employed to study the
11 phenomenon of hospitalization for people with advanced COPD. Unstructured interviews were
12 conducted during hospitalization at a tertiary care hospital in India, in 2017, audio-recorded, and then
13 transcribed. Giorgi's descriptive phenomenological analysis method guided the analysis.

14 Results: Fifteen people with advanced COPD participated. Emergency admissions were common
15 because of acute breathlessness, leading to repeated hospitalizations. Hospitalization gave a sense of
16 safety but, despite this, people preferred to avoid hospitalization. Care influenced trust in
17 hospitalization and both shaped the experience of hospitalization. Multi-dimensional suffering was
18 central to the experience and was described across physical, psychological and spiritual domains.

19 Discussion: Hospitalization was identified largely as a negative experience due to the perception of
20 continued suffering. Integrating palliative care into the routine care of people with advanced COPD may
21 enable improvements in care.

22 Keywords: advanced COPD; repeated hospitalization; acute breathlessness; phenomenology; qualitative
23 study

24 Introduction

25 Hospitalization is common for those with advanced chronic obstructive airways disease (COPD) ¹.

26 Admission is often related to exacerbations of breathlessness, frequently recurrent, as 27% of
27 exacerbations are followed by a second event within 8 weeks². Readmission to hospital is therefore a
28 regular pattern for people with advanced COPD, with 90 day readmission rates ranging from 16-48%³.

29 Hospital episodes are not only frequent, but also extended, as the mean length of hospital stay can be
30 around 9 days ⁴⁻⁶. People experience being hospitalized in different ways, but generally, while people
31 appreciate treatment, they can also associate hospitalization with uncertainty, distress and loss of
32 control ⁷⁻⁹. Also people have a high symptom burden that affects the physical, psychological, social and
33 spiritual aspects of individuals during hospitalization ¹⁰. Prolonged symptom burden causes high
34 healthcare utilization and contributes considerable financial burden ¹¹. It is critically important that
35 there is a full understanding of the experience of hospitalization to facilitate high quality, holistic care.

36 A qualitative research approach can facilitate an understanding of individual experiences such as
37 hospitalization. Qualitative studies have examined hospitalization in people with mixed stages of COPD,
38 mainly from symptom burden, breathlessness, anxiety, and treatment perspectives ¹²⁻¹⁵. These studies
39 provide some insight into the experience of hospitalization, however, not in the context of advanced
40 COPD. Currently, there is more evidence from this perspective of the lived experience of people with
41 advanced COPD in community settings, and their care needs¹⁶. Studies on the experience of
42 hospitalization in people with advanced COPD has mainly focused on elements of care and treatment ¹⁷.
43 Therefore, it is important to study the experience of hospitalization from admission to discharge, to
44 enable an understanding of the complete picture of the phenomenon.

45 A phenomenological approach, in particular, offers a rich account of the phenomenon being studied,
46 such as the individual experience, to expound and present the essence of the phenomenon ¹⁸. Studies
47 have adopted phenomenology as an approach to find the essence of a particular experience, such as the

48 acute care experience, which indicates that this could be a valuable approach to study the experience of
49 hospitalization⁹. A phenomenological approach presents the phenomenon as it appears in its context,
50 which can facilitate studying the experiences while preserving the individual culture and context¹⁹.
51 Current studies of hospitalization in advanced COPD are conducted in the Western context, which could
52 have influenced the presentation of the phenomenon¹⁷. Asian countries are not well-represented in
53 previous studies on hospitalization; therefore, utilizing a phenomenological approach could be valuable
54 in studying hospitalization in the Indian context. This study aims to explore the phenomenon of
55 hospitalization in people with advanced COPD in India. Additionally, in the light of a lack of evidence
56 focusing on the whole experience of hospitalization, the research question asked was: ‘what is the lived
57 experience of hospitalization in people with advanced COPD?’

58 **Methods**

59 *Study design*

60 Qualitative, descriptive phenomenology following Giorgi’s method was employed, as it provides in-
61 depth exploration of the phenomenon²⁰. This study was reported following COREQ guidelines²¹.

62 *Philosophical underpinning*

63 The epistemological underpinnings of descriptive phenomenology emphasizes consciousness of
64 intentionality and phenomenological reduction or bracketing, which enable the study of a phenomenon
65 ^{22, 23}. In this research, intentionally directing the researchers’ consciousness to the phenomenon as
66 described by the participants facilitated studying the experience of hospitalization, as it appears in the
67 context. Bracketing the researcher’s assumptions related to hospitalization helped approach the
68 phenomenon fresh to present the essence of the phenomenon.

69

70 *Population*

71 Adults over the age of eighteen years with advanced COPD according to the Global Initiative for Chronic
72 Obstructive Lung Disease stage III and IV²⁴ and /or with clinical staging, and those who were currently
73 hospitalized were the population of interest (Table 1).

74 Insert table 1 here

75 *Setting*

76 This study was conducted in a tertiary care hospital in south India, which caters to the wider population
77 of the city, as well as for people from the neighboring states. This is a private, Christian, religious
78 hospital, which provides care for people from various religious and socio-economic backgrounds.

79 *Sample*

80 A purposive, homogenous sampling method was employed, as this helped identify the potential
81 participants who shared similar characteristics to study the experience ²⁵. According to Giorgi's
82 phenomenological method the adequacy of sample size is determined by saturation of themes²⁶. Data
83 collection was stopped when themes were saturated.

84 *Recruitment*

85 Potential participants were identified from the admission records of pulmonary and geriatric medicine
86 wards by the hospital staff. Participants indicated their willingness to participate to either staff or the
87 first author (BB). Then, BB took written consent from willing participants, after explaining the voluntary
88 nature of participation and potential to withdraw from the study. Fifteen participants were approached
89 and all agreed to participate in the study.

90 *Data collection*

91 To explore the phenomenon in depth, descriptive and structural questions were used ²⁷⁻²⁹. Descriptive
92 questions were used to understand the overall experience of hospitalization, and structural questions to

93 clarify the phenomenon of hospitalization. Individual, face-to-face, unstructured interviews were
94 conducted in the Tamil language, employing open-ended questions (appendix 1). All the interviews were
95 conducted at the hospital either at the bedside or in the adjacent counselling room by BB. Participants'
96 family members were allowed to be present during the interview but it was explained that they could
97 not participate in the interview, given the idiographic focus on the person with COPD. Interviews were
98 recorded with one or two temporary pauses of a few minutes, allowing time to manage any
99 breathlessness or cough. In case of emotional upset, the first author BB provided initial support by
100 active listening, and visited them next day in the ward to find out whether further psychological support
101 was required. None of the participants requested this further psychological support.

102 Interviews were audio-recorded on an encrypted digital voice recorder then, transferred to a password
103 protected computer. Data collection and coding were done simultaneously, so any new topics found
104 from the analysis could be added to the next interview. The author's (BB) previous knowledge about
105 advanced COPD including textual and experiential knowledge was bracketed to avoid subjectivity, in
106 order to get a fresh view of the phenomenon³⁰. The process of bracketing was followed from the time
107 of data collection until data analysis.

108 Data Analysis

109 BB transcribed all the audio recordings verbatim into the Tamil language and then, translated these into
110 English. They were back-translated into Tamil by a bilingual expert to check the accuracy of the
111 translation. Employing back-translation ensured that the meaning of the translated text in English stayed
112 close to the original language; back-translation not only reduces translation errors, but also ensures the
113 validity of translation^{31, 32}. Any challenges in translation were discussed with the translator and resolved
114 before the final version of the transcript was prepared and this final, verified transcript was used for
115 analysis.

116 Data analysis followed Giorgi's five step phenomenological analysis method²⁰. Transcriptions were
117 imported into the NVivo 11 software to enable data management and analysis. Data were coded by BB
118 and checked by CW, for the consistency of coding. Firstly, the text was read to understand its
119 wholeness. 'Bracketing' was used to suspend presuppositions by writing down (BB's) thoughts related to
120 hospitalization and COPD³³. Then, the text was re-read to capture the 'meaning units', which are parts
121 of the text relevant to hospitalization. Thirdly, meaning units were segregated and coded. The fourth
122 step was to transform the meaning units into a scientific expression, which involved changing the
123 participants' description from the first person to the third person expression, and to a formal, scientific
124 language, in order to integrate a similar description across all the transcripts. Finally, themes were
125 developed from the transformed meaning units; 'eidetic reduction' was employed to include only the
126 essential elements of the phenomenon by eliminating the non-essentials and repetitions. Identifying
127 redundant elements through this process determined data saturation²⁰. The description of the
128 phenomenon of hospitalization was written from the transformed meaning units of the main themes.

129 *Trustworthiness*

130 Trustworthiness in qualitative studies refers to transferability, credibility, dependability and
131 confirmability^{34,35}. Transferability is determined by giving a thick and rigorous description of the
132 findings of the phenomenon of hospitalization which enables the transferability of the findings to a
133 similar context³⁴. Credibility refers to the researcher's ability to produce an accurate data which is
134 facilitated by employing 'eidetic reduction' to eliminate the irrelevant constituents; also the sufficiency
135 of description, which is indicated by absence of repetitions in the description of the findings, indicated
136 credibility²³. Dependability relates to the replicability of findings, which is facilitated by meticulously
137 employing the steps of Giorgi's phenomenological analysis for analysing the data²³. Confirmability refers
138 to the measures taken to ensure neutrality. Employing bracketing to avoid the researcher's previous

139 experiences and assumptions from interpreting the data facilitated neutrality. Writing down and
140 updating the researcher's thoughts related to the phenomenon and consciously avoiding these thoughts
141 during data analysis helped practise the process of bracketing.

142 *Study team*

143 This study was undertaken as part of a completed PhD by the first author (BB). The other authors are
144 researchers with PhDs, with extensive experience in research in palliative care and psychology,
145 respectively. The first author had earlier worked as a palliative care physician in the research setting;
146 however, participants were not aware about her previous employment in the hospital and no
147 participants had received clinical care from her.

148 *Ethics*

149 Ethics approval was obtained from the authors' host institution, Lancaster University Ethics Committee,
150 (ID: FHMREC17006), the Indian Ethics committee (ID: IEC/169/2016), and from the Indian Council for
151 Medical Research (ID: 5/8/4-31).

152 **Findings**

153 Fifteen participants were interviewed from August to December 2017. Five women and ten men were
154 interviewed and their ages ranged from 61-83 years (see table 2). The mean interview time was 26.06
155 minutes with a range of 20.2 – 30.5 minutes.

156 Insert table 2 here

157 Four key constituents were developed: repeated hospitalization, perception of care, trust in
158 hospitalization and multi-dimensional suffering. The essence of the phenomenon is presented in the
159 following sections. The sub-constituents are organized under each main constituent.

160 Repeated hospitalization

161 Emergency admissions

162 Emergency admissions were common in the advanced stage of COPD due to the immediate treatment
163 required for acute breathlessness. Although quick attention and immediate relief of breathlessness was
164 appreciated, delays were reported both in deciding admissions and transfer to the ward. The delays
165 were either due to the unavailability of a bed or a long queue of other patients waiting to be admitted:

166 *"I came morning 9am to the emergency department, evening 8pm only I got a bed."* (P8)

167 At times, emergency department physicians were not aware of participants' medical history, which
168 caused confusion in treatment decisions:

169 *"No. Nobody explained...my son called up and asked the doctor to know why I needed ICU
170 treatment."* (P13).

171 Emergency admissions often involved quick medical decisions and immediate treatment, which, at
172 times, could be overwhelming and anxiety provoking.

173 Familiarity and reluctance towards hospitalization

174 A sense of familiarity with the treating staff and the routine procedures of hospital were perceived,
175 during the course of repeated hospitalization. Familiarity with staff created a sense of safety and control
176 with the belief that their problem would managed, which reduced anxiety:

177 *"They [doctors] give good treatment during emergencies...now I get the confidence that I will
178 survive for some more days."* (P6)

179 Feeling safe and being cared for helped the development of trust with staff. Having gone through the
180 routine hospital procedures did create a sense of familiarity but, at times, complying with hospital
181 routines was also perceived as troublesome despite an acceptance of their necessity:

182 *"They take blood tests and wake me up at 4 am in the morning; again some other staff comes
183 and asks for tests. But they have to do their duty, I can't complain about it."* (P3).

184 But the noisy and dirty hospital environment caused a negative impression about hospitalization.
185 Particularly, noise from neighboring patients and medical equipments caused sleep disturbance during
186 hospitalization:

187 *“When neighbour patients snore like tearing the whole building apart; I try to tie a towel around*
188 *my head; I even thought of plugging my ears with cotton...” (P12)*

189 Apart from this, a sense of being a burden was perceived as the family provided care, spending both
190 their money and time. Repeated hospitalization was perceived to cause an inability to fulfil family
191 responsibilities, such as being able to cook for the family and look after grandchildren. However,
192 participants seemed to understand the necessity of hospitalization and, therefore, accepted its
193 inevitability:

194 *“What can I say...shall I remain at the hospital thinking that I will be fine if I go to hospital or*
195 *shall I remain at home thinking that I would become alright at home?” (P11)*

196 Familiarity and a sense of safety created a positive impact on hospitalization but an unclean hospital
197 environment and care burdens caused a negative impression.

198 Perception of care

199 Rewards and burdens of treatment

200 Immediate medical attention was perceived to help restore normal breathing and relieved the fear of
201 imminent death. Both timely treatment and the expertise of the staff were considered to be
202 components of efficient treatment, which enabled independence to be regained in a short time and
203 then, a return to usual life:

204 *“...they [staff] give immediate treatment... just two days are sufficient for them... they change me*
205 *to a normal man...” (P15)*

206 This also facilitated developing trust with staff, as well as trust in this particular hospital. While
207 treatment brought immediate relief, participants were aware that the effect of treatment would not last
208 for a long time, and understood the need for repeated treatment due to the nature of the illness:

209 *"I am OK now... within two days I will go home; but it may come again. I know that also."* (P3)

210 Particularly, intensive care unit treatment was perceived as difficult; having tubes inserted all around
211 the body and being hooked on to the oxygen machine created a sense of isolation. On occasions, not
212 being aware of the reason for the intensive care unit admission was overwhelming:

213 *"No... nothing they [staff] said... just for nebulization, why should I be in the ICU?"* (P15).

214 While treatment was regarded as beneficial, at the same time, it was also perceived as burdensome.

215

216 The attitude of the staff
217 The caring attitude of staff providing immediate attention, dedicated care by taking account of every
218 small detail, listening and a good explanation of the treatment plan facilitated both a good relationship
219 and development of trust with staff. Participants felt that staff provided good care, despite being busy
220 and did everything to restore their health to normal:

221 *"The way the doctors treat us and the quick response, that itself makes me feel happy."* (P3)

222 The caring attitude of staff encouraged individuals both to engage actively in the treatment and develop
223 trust with them.

224 On some occasions, an unpleasant attitude from a member of staff, such as not paying attention,
225 ignoring emotional concerns and failing to explain treatment plans caused emotional upset to the
226 participants. Being direct and abrupt was felt unpleasant when communicating the prognosis. On
227 occasions, doctors did not seem to be concerned about the presence of others and did not ask for the
228 consent of the participant before discussing the prognosis more publicly:

229 *"A doctor told me that 98% of your lungs are dead [laughs]; my wife cried. He [doctor] is saying*
230 *right to my face while my wife was with me."* (P8)

231 Being insensitive to participants' emotions and failing to discuss future treatment plans were perceived
232 as being indicative of an uncaring attitude.

233 Most individuals did not completely understand their prognosis. However, individuals felt that the
234 doctors should know when to initiate the conversations about prognosis, and to explain the treatment
235 plan:

236 *"I don't ask usually; they [doctors] are here to tell me, if there is anything that I should know."*
237 (P9)

238 Insufficient information about prognosis and future treatment plan often caused a perception of
239 inadequate care during hospitalization.

240 Trust in hospitalization

241 Immediate symptom relief improved independence and participants' ability to carry out daily activities
242 during hospitalization, which established trust in hospitalization for continued care. Decisions about
243 choosing a hospital were informed by good impressions from past experiences and the opinion of family
244 and others. Individuals' previous, good experience in this particular hospital shaped their trust in
245 hospitalization:

246 *"Here, they make sure that the patients get relief. I came to this hospital because I had hope in*
247 *them."* (P6)

248 Further, an unreasonably high healthcare cost and poor quality of treatment was reported in other
249 private hospitals, which reduced trust in hospitalization. Facilities available in the hospital, and expertise
250 of the staff also influenced the decision of the choice of hospital:

251 *"No, it is neatly done here...all equipments are available and drawing blood is pretty smooth."*
252 (P8)

253 The opinion of family members and friends also played a role in choosing this particular hospital. The
254 belief that this hospital held the value of Christian religion, which suggested good care and a high chance
255 of getting well, seemed to influence the decision:

256 *"...that belief that this is a Christian hospital. Also my mother-in-law has confidence in this*
257 *hospital."* (P12)

258 Both individuals' experience and their family's opinion about the hospital, which relates to the perceived
259 moral and religious values of the hospital, seemed to be important in developing trust in hospitalization.

260 Multi-dimensional suffering

261 Suffering was reported as multi-dimensional and affected the physical, psychological and spiritual
262 aspects of the individuals.

263 The experience of breathlessness was described in many different ways: a choking sensation in the
264 throat, a pulling sensation in the chest, a sensation of heaviness and/or tightness, perception of a rock-
265 like chest or extreme difficulty in inhaling air. For some it was an intense struggle just to take a breath:

266 *"I feel as if it is blocked [breath]; air is not getting inside; it keeps coming outside."* (P7)

267 The unpredictable nature of breathlessness and its severity devastated participants' daily life. Getting
268 breathlessness in the toilet or in similar situations seemed to impact their dignity:

269 *"... it [breathlessness] comes suddenly. What am I supposed to do then? As if I am going to pee*
270 *or poop now [without control]."* (P1)

271 Fatigue accompanied with breathlessness restricted participants' ability to do simple daily tasks, such as
272 eating, which caused dependency on others. Feelings of low self-esteem and being a burden to others
273 due to dependency were at times overwhelming:

274 *"Why am I like this? How long will my children take care of me?"* (P2);

275 *"Now I know for sure that this [illness] will not leave my body...isn't it?"* (P13)

276 Fatigue with dependency both indicated incurability and contributed to high symptom burden which
277 caused a negative impact on the experience of hospitalization.

278 Psychological and spiritual distress

279 Anxiety was experienced during breathlessness due to varied reasons. Some thought that it was natural
280 to get scared during breathlessness. Being alone in the hospital bed during breathlessness caused fear,
281 which was relieved by someone's presence or immediate medical attention. However, participants felt
282 that they could not express their fear to anybody during hospitalization, as they felt staff were primarily
283 there to take care of physical symptoms. Sensation of imminent death during acute breathlessness
284 caused considerable spiritual distress.

285 Perceiving life was purposeless created a sense of emptiness in life and caused death wishes during
286 hospitalization. Some participants perceived that death was better than living with suffering every day,
287 while others expressed that they were not afraid of dying:

288 *"...when the time comes, I will go; if my time is good, I will be alive for some more time."* (P9)

289 Nevertheless, reflecting fulfilment in life encouraged hope for the future, and to find meaning in life.

290 Being able to complete family duties, such as raising children, providing education and seeing children
291 married were regarded as important duties in the Indian culture, which gave a sense of fulfilment in life
292 and hope around the future:

293 *"...whether it becomes cured or not, I need to be alive now; I have to get my son married..."* (P2)

294 In general, religious belief helped people accept suffering and death as part of life and participants
295 continued to trust God, despite suffering, to provide a peaceful death and eternal life. However,
296 participants did not seem to have had an opportunity to discuss death and dying concerns with staff
297 during hospitalization. The depth of multi-dimensional suffering indicated persistent suffering despite
298 frequent hospitalization.

299 Discussion

300 This is the first study to take a holistic approach to understanding the lived experience of hospitalization
301 in people with advanced COPD. Phenomenological analysis yielded four key constituents: repeated
302 hospitalization, perception of care, trust in hospitalization and multi-dimensional suffering. This study
303 found that the essence of the phenomenon of hospitalization had both positive and negative aspects;
304 however, the overall experience was negative due to persistent, multi-dimensional suffering.

305 Both positive and negative views of hospitalization could be held simultaneously, which depending on
306 the expectations about hospitalization and healthcare delivery. Studies conducted in cancer and other
307 chronic illnesses report that hospitalization is a continuum of positive and negative experience, which is
308 influenced by the seriousness of illness, expectations from hospitalization and interpersonal
309 relationships with staff^{36,37}. The experience of hospitalization can see a co-existence of positive and
310 negative, confirming the balance between expectations versus healthcare delivery¹⁷. This empirical
311 study found that care and treatment and communication were expressed as both positive and negative,
312 which indicates that the phenomenon of hospitalization could be complex and variable.

313 Persistent, multi-dimensional suffering included physical, psychological and spiritual aspects, which
314 caused a negative impact on the experience of hospitalization. This present study found that
315 breathlessness was relieved with treatment, but it kept recurring during the course of hospitalization,
316 which caused continuing suffering. While breathlessness was given immediate attention, other
317 psychological and spiritual issues were neglected. Participants in this study were hesitant to discuss their
318 anxiety during hospitalization, as they thought that staff were trained to treat only physical symptoms,
319 which led to prolonged distress. Studies report that persistent psychological distress after discharge
320 could be one of the causes for readmission in people with advanced COPD, which also contributed to a
321 negative experience of hospitalization^{38,39}. Death and dying concerns were the main spiritual issues
322 reported that remained unaddressed during repeated hospitalization. Previous studies conducted in

323 people with advanced COPD do not report spiritual concerns, despite their connection with symptom
324 burden and impact on quality of life^{40, 41}. Studies which have examined hospitalization in both acute and
325 non-acute settings identified that high symptom burden is the main contributor for a negative
326 perception of hospitalization; however, these studies do not take account of psychological and spiritual
327 issues into the conceptualization of symptom burden^{36, 37, 42}. Continuing physical, psychological and
328 spiritual suffering could have contributed to a largely negative perception of hospitalization in this study.

329 This empirical study also found that poor communication and staff attitudes caused a predominantly
330 negative perception. Studies confirm that communication and staff attitude are the major reasons for
331 negative experience of hospitalization in individuals with other chronic illnesses⁴²⁻⁴⁴. Poor explanation
332 of treatment and inadequate explanation of disease prognosis caused uncertainty around the future
333 which, in turn, had a negative impact on the experience. Discussing prognosis is known to be particularly
334 challenging in acute care settings and the unpredictable disease journey of COPD further complicates
335 the identification of advanced stage⁴⁵. However, utilizing effective communication skills, avoiding
336 confrontations and setting realistic short-term goals could help in communicating disease prognosis⁴⁶,
337⁴⁷. Staff attitude is another major influencing factor for patient satisfaction with hospital care which also
338 determines the experience of hospitalization^{48, 49}. This empirical study showed that attitudes such as not
339 paying attention and ignoring emotional concerns caused a negative perception. Unclear disease
340 prognosis compounded by poor communication seemed to impact the experience more negatively.

341 *Conceptualization of hospitalization*

342 Limited evidence exists on what constitutes the concept of hospitalization. Hospitalization has been
343 studied both in varied chronic illness conditions and in various hospital settings, from acute care to
344 ordinary inpatient care, but mainly from a care and treatment perspective^{44, 50, 51}. From this research,
345 the conceptualization of hospitalization seems to include two main elements: firstly, the hospital as a

346 physical place and a facility for the sick; secondly, being hospitalized which includes the multi-faceted
347 aspects of administration, treatment and care, and communication. These two main elements are
348 integral parts of each other but their sub-elements may be varied and together they contribute to the
349 experience of hospitalization (figure 1). This study identified trust in hospitalization as one of the
350 contributing sub-elements along with other sub-elements. Care and communication, and trust seemed
351 to have a contrasting perception of both positive and negative elements, which indicates the dynamic
352 nature and complexity of these sub-elements.

353 Insert figure 1 here

354 The complexity of these elements mainly depend on the nature and depth of care required, the
355 expectation of the individuals and the competency of the staff involved^{44, 51}. This conceptualization of
356 hospitalization should, therefore, be understood from the specific context of this research, such as
357 varied socio-cultural and religious backgrounds of the participants, and from the perspective of repeated
358 and often emergency hospitalizations for a chronic and advanced stage of illness (figure 1). These
359 dimensions in themselves are not complete, as hospitalization is a broad, varied and complex
360 phenomenon and could be conceptualized differently in other contexts and cultures.

361 **Strengths and limitations**

362 This is the first qualitative study to capture the experience of hospitalization in people with advanced
363 COPD. Previous studies on hospitalization have mostly been from a Western perspective, hence those
364 findings may not be transferable to countries with a different socio-cultural context, such as India, which
365 has a high prevalence rate of COPD and hospitalization⁵². This is the first study on the experience of
366 hospitalization in the Asian/Indian setting, where research on COPD care is scarce. This study included
367 participants with varied socio-cultural backgrounds that enriched the experience of hospitalization.

368 Interviews were conducted in the hospital, to capture the phenomenon afresh, which helped overcome
369 the challenge of relying on the memory of participants⁵³. Interviewing at the hospital facilitated the
370 exploration of real-time experience capturing the time-space dynamics in hospitalization, which helped
371 narrating all the nuanced aspects of the experience⁵⁴.

372 Limitations

373 The sample had more male participants than female, although it does reflect the prevalence of COPD in
374 India⁵². Nonetheless, this could mean that important aspects of the COPD experience which some
375 research has shown might be more pertinent to women (such as loss of role as a home-maker, altered
376 physical appearance, and a lack of confidence to cope with the illness alone), could also have influenced
377 the experience⁵⁵. The relatively short interview length ($M = 26$ minutes) was likely due to the inherent
378 challenges of interviewing participants with breathlessness and extreme physical weakness, but could
379 have limited the depth of exploration of certain aspect of the experience⁵⁶. Finally, as participants were
380 still hospitalized, the discharge aspect did not emerge during the interview.

381 Recommendations for practice and policy

382 Practice

383 Poor communication, especially during emergency admissions, has been identified as an area that
384 requires improvement. Communication training for staff, specifically in discussing end-of-life care, could
385 enable staff to be more effective in communicating sensitive topics⁵⁷⁻⁶⁰. Emergency staff could also take
386 support from palliative care professionals when required. Staff should be able to identify psychological
387 distress and access help from a psychologist when required. Screening of spiritual concerns should be
388 included in the routine care of people with advanced COPD to identify spiritual distress.

389 Policy

390 The preference to discussing advance care planning needs to be addressed, as this might vary in other
391 international settings that some people want less or more information. This aspect needs to be
392 considered by the policy developers and clinicians to provide tailored information^{53, 61}.

393 Future research

394 The feasibility of adopting an integrated care plan to ensure continuity of care, as patients often require
395 a transfer between pulmonary and palliative care, and the benefits and challenges in implementing this
396 plan, needs to be researched in the Indian context⁶².

397 This research captured the experience of hospitalization as a snapshot, which may not be adequate to
398 understand the varying perception of hospitalization. Since hospitalization is a complex and dynamic
399 experience, a longitudinal, qualitative study should be considered to understand the experience of
400 repeated hospitalization over time⁶³.

401 Conclusion

402 This study found that the phenomenon of hospitalization included both positive and negative aspects,
403 depending on the individuals' context-specific needs and expectations. However, the overall experience
404 of hospitalization was perceived predominantly as negative due to persistent, multi-dimensional
405 suffering, despite repeated hospitalizations. This indicates a lack of a holistic approach to people
406 hospitalized with advanced COPD. A palliative care approach could help providing a holistic care for
407 individuals with multi-dimensional suffering during hospitalization¹⁰. Early integration of palliative care
408 into the routine care of COPD is required to improve the care of individuals with advanced COPD.

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Appendix

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Appendix 1- Interview guide

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597 The interview will use a broad, open question to begin the interview. It will use indicators to extract the
598 information from the participant. Some of the indicators that might be used in the interview are stated
599 below.

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601 *Opening question*

602 Can you please tell me about your experience of being hospitalized?

603 *Indicators/Prompts*

604

605 1. Can you tell me more about it?

606

607 2. How does that make you feel?

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609 3. Could you describe it in little more detail?

610

611 4. How exactly does that affect you?

612

613 5. What made you feel like that?

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Tables

616 **Table 1 Inclusion and exclusion criteria**

Inclusion criteria	Exclusion criteria
COPD patients with GOLD stage III and IV ²⁴ ; clinical symptoms such as worsening breathlessness, acute exacerbations with frequent hospitalization, use of a non-invasive ventilator and/or long term oxygen-dependency were also considered to identify the advanced stage. Adult patients > 18 years of age. Admitted to the pulmonary and geriatric medicine wards for a minimum of 24 hours. Able to communicate fluently in Tamil and/or English.	Acutely ill participants who were unable to communicate and with cognitive impairment.

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639 **Table 2 Demographic characteristics**

Baseline characteristics	
Gender (n)	
Female	5
Male	10
Age	61-83 (years) Mean 66.2
Religion (n)	
Hindu	11
Christian	4
Time since diagnosis of COPD (years)	7-15 (range)
Oxygen therapy (n)	
Non-invasive ventilation	4
Nasal oxygen	1
Intermittent oxygen	10
Co-morbidities (n)	
Hypertension	7
Diabetes	3
Heart disease	2
Dyslipidemia	10
Number of days admitted	2-18 Mean 4.73
Hospitalization in past one year	1-5 Mean 2.26
Route of admission (n)	
Emergency department	10
Outpatient department	5

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