

1 **Day-to-day living with severe chronic obstructive pulmonary disease: Towards a family-**
2 **based approach to the illness impacts**

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31 **Abstract**

32 Objective: This study explores the perspectives of both patients and family members
33 regarding the impact of chronic obstructive pulmonary disease (COPD) in their family life.

34 Design: An exploratory qualitative study was conducted with patients and their family
35 members in the chronic phase of COPD. Individual interviews were performed to explore
36 participants' perspectives and submitted to thematic analysis.

37 Results: Six major themes emerged from patients' perspective: (1) impact of COPD symptoms
38 on personal and family daily life; (2) (over)protective family support; (3) difficulties in couple
39 communication; (4) sense of identity loss; (5) fear of COPD progression; and (6) coping
40 resources. Five main themes emerged from the family members' perspective: (1) restrictions
41 in family's social life; (2) emotional distress related to COPD exacerbations; (3) tension in
42 couple relationship; (4) financial strain of COPD and (5) coping resources.

43 Conclusions: The overall findings illustrate the complex interaction between the experience of
44 living with COPD and communication patterns, emotional states, social support and social
45 roles within the family. The results highlight the need to develop family-based interventions
46 to facilitate a functional adjustment to COPD. However, these interventions in COPD remain
47 undeveloped and empirical evidence is needed.

48 **Key-words:** chronic obstructive pulmonary disease; family; impact; family-systems illness
49 model; family-based interventions

50 **Introduction**

51 According to the World Health Organization, 210 million people throughout the world are
52 affected by chronic obstructive pulmonary disease (COPD) (World Health Organization,
53 2007). This incapacitating disease is estimated to become the seventh leading cause of years
54 lived with disability by 2030 (Mathers & Loncar, 2006). COPD is characterised by persistent
55 airflow limitation (Vestbo et al., 2013) and it is frequently associated with the occurrence of
56 exacerbations, progressive loss of independence and poor quality of life. These aspects
57 increase patients' dependence on family members, mainly on the carer who represents the
58 primary source of support (Spence et al., 2008). Thus, a growing number of families have
59 been dealing with the challenges imposed by COPD.

60 The associations between adult chronic diseases and family functioning are well-documented.
61 It is known that a chronic illness has profound effects on close family members and on the
62 family as a whole (Campbell, 2003; Knafl & Gilliss, 2002; Rolland, 1999). In addition, a
63 growing body of research evidenced that families can have a beneficial or harmful influence
64 on patient's psychological adjustment and illness management (Campbell, 2003; Martire,
65 Lustig, Schulz, Miller, & Helgeson, 2004; Rolland, 2003). Most research on COPD, however,
66 has investigated its impacts solely on the patient (Barnett, 2005; Gardiner et al., 2010;
67 Williams, Bruton, Ellis-Hill, & McPherson, 2007). Only a few number of studies have
68 attempted to understand the nature and extent of the COPD impacts on family members,
69 particularly, on those providing care (Bergs, 2002; Cain & Wicks, 2000; Pinto, Holanda,
70 Medeiros, Mota, & Pereira, 2007; Simpson, Young, Donahue, & Rocker, 2010). However,
71 according to our knowledge, no study has investigated the impacts of COPD on family life
72 considering both the patient's and close family member's perceptions. The availability of this
73 information is fundamental given the importance of family relationships in the management
74 of chronic diseases and the bidirectional links between patient and family member outcomes.

75 Moreover, each chronic disease poses distinct challenges to families, and research needs to
76 demarcate the disease's specificities (e.g., COPD) from the general aspects of chronic
77 illnesses. Therefore, this study aimed to explore the perspectives of both patients and family
78 members regarding the impact of COPD in their family life.

79 **The Family Systems Illness Framework**

80 The Family Systems Illness (FSI) model (Rolland, 1984, 1987, 1999) can provide a useful
81 framework to understand the experiences of families dealing with COPD. Rolland's
82 framework has been used to explain the interactions between chronic diseases such as cancer,
83 stroke, multiple sclerosis and pediatric chronic conditions and family functioning (Herzer et
84 al., 2010; Rolland, 2005; Sieh, Dikkers, Visser-Meily, & Meijer, 2012). According to the FSI
85 model, each family is affected by and influences the course of a chronic disease (Rolland,
86 1999). The model is grounded in a strength-oriented perspective, emphasising the possibilities
87 for resilience and development of the family, instead of just considering their difficulties and
88 risks (Walsh, 1996, 2003).

89 Rolland's FSI model postulates that family adjustment to chronic illness depends on the
90 interplay of three dimensions: key family system variables; psychosocial typology of illness;
91 and time phases of illness (Rolland, 1987, 1994). The model addresses how each type of
92 disorder, with its pattern of emotional, practical and relational challenges over time, fits with
93 the patterns, strengths and vulnerabilities of a family unit. It emphasises that family responses
94 to chronic illness vary according to communication patterns, individual and family
95 development, multigenerational patterns of coping with illness and loss and belief systems
96 (Rolland, 2003, 2005).

97 The psychosocial typology of illness defines meaningful and useful categories with similar
98 psychosocial demands for a wide set of chronic conditions affecting patients and families. It
99 conceptualises broad distinctions of disease onset (acute or gradual), course (progressive,

100 constant or episodic), outcome (fatal or shorted life span, or possible sudden death vs. no
101 effect on longevity), incapacitation (non-disabling vs. disabling) and the level of uncertainty
102 about its trajectory. According to this psychosocial typology, COPD has a gradual onset,
103 progressive course (with acute episodes), a possible fatal outcome and it is disabling (Rolland,
104 1987). To understand the natural history of chronic disease as a dynamic process, three time
105 phases can be described (Rolland, 1994, 1999): crisis, chronic and terminal. The crisis phase
106 comprises any symptomatic period before diagnosis and the initial contact with illness
107 symptoms, treatments and institutional settings. The chronic phase, whether long or short, can
108 be marked by constancy, progression or episodic change. It has been reported as “the day-to-
109 day living with chronic illness”. The terminal phase includes the preterminal stage of the
110 disease, where the inevitability of death becomes apparent and dominates the family life.
111 Different phases require different tasks from the family, to facilitate a functional and healthy
112 adjustment to the disease (Rolland, 1999).

113 Chronic diseases, such as COPD, are long-lasting conditions that require ongoing
114 management over a period of years or decades (World Health Organization, 2005), becoming
115 a part of the family identity (Larsen, 2009). Indeed, the chronic phase of the disease has been
116 reported as the long haul, the time span between the initial diagnosis and readjustment period
117 and the terminal phase (Rolland, 1999). The family perceives how the disease affects their
118 life, and the task of keeping the balance between personal/family needs and illness constraints
119 assumes significant importance. Family members reallocate roles and efforts on maintaining
120 individual autonomy in the family system, to preserve a semblance of normality (Rolland,
121 1994). Considering that each time phase of an illness poses unique challenges to family
122 functioning (Rolland, 1987, 1999, 2003), the FSI framework was used in this study to
123 understand the psychosocial impacts of COPD on family life, during the chronic phase.

124 **Methods**

125 ***Design***

126 An exploratory qualitative study, with a cross-sectional design, was conducted with patients
127 and family members in the chronic phase of COPD. Patients were included if they presented a
128 COPD diagnosis for more than two years, according to the Global Initiative for Chronic
129 Obstructive Lung Disease (GOLD) criteria (Vestbo et al., 2013). The family member was
130 identified by the patient as being the spouse, a child or a significant other. To participate,
131 patients and family members had to meet the following criteria: age \geq 18 years old; able to
132 understand the purpose of the study and agree to participate voluntarily. Patients and family
133 members were excluded if one of them presented severe psychiatric conditions and/or
134 inability to understand and engage in the study.

135 The recruitment was performed in a primary care centre and in a district hospital in the central
136 region of Portugal, between October 2011 and February 2012. Potentially eligible patients
137 were identified by clinicians of the institutions involved in the study, who were then contacted
138 via telephone by a clinician's assistance, who informed them about the study and asked for
139 their willingness to be contacted by the researchers. Then, interested patients received a
140 telephone call from the researchers, were informed in detail about the study objectives and
141 were asked to identify eligible family members. For those who agreed to participate, a
142 meeting was scheduled in the primary care centre or hospital, according to families'
143 convenience. A total of 32 patients and their respective family members were contacted and
144 informed about the study. All agreed to participate, however, 12 families failed the scheduled
145 meeting due to deterioration of patients' health condition (e.g., COPD exacerbation). The
146 final sample was composed of 40 participants, 20 patients and 20 family members.

147 ***Data Collection***

148 A structured questionnaire was used to collect socio-demographic data from patients and
149 family members (gender, age, academic qualifications, marital and work status). Additional

150 questions were included for family members to collect data related to the caregiving period
151 (duration in years and hours per week) and kinship to the patient.

152 Spirometry was performed using a portable spirometer (MicroLab 3500, CareFusion, Kent,
153 UK) to assess patients' lung function (Miller et al., 2005). The classification of COPD severity
154 was carried out in accordance with the GOLD criteria (Vestbo et al., 2013). Patients were
155 asked to report their disability resulting from breathlessness using the modified British
156 Medical Research Council questionnaire (mMRC) (Doherty, 2006). The mMRC
157 questionnaire comprises five grades (range 0–4), with higher grades indicating greater
158 perceived respiratory disability.

159 Individual interviews were conducted to explore the perspectives of patients with COPD and
160 their family members. The interview schedule comprised open-ended questions that were
161 formulated around the impact of COPD in family life; specifically, patients and family
162 members were asked: “*Which are the main changes that COPD brought to your personal and*
163 *family life?*”; “*What are the main difficulties/concerns?*”; and “*How have you been coping*
164 *with COPD?*”. The interviews were conducted at the same time but in different physical
165 spaces, by two trained gerontologists, so patients and family members could talk openly and
166 the confidentiality guaranteed. Participants were informed that they could interrupt the
167 interview at any time. On average, the interviews with patients lasted 46.7 ± 4.8 minutes and
168 with family members 50.7 ± 5.3 minutes. All interviews were digitally audio-recorded for
169 further transcription and analysis.

170 ***Ethical issues***

171 The study received full approval from the Institutional Ethics Committee. All participants in
172 this study were unpaid volunteers. Written consent forms were obtained prior to any data
173 collection. Some ethical concerns were considered regarding the nature of the interviews. It
174 was expected that participants could be emotionally challenged during the interview, since

175 painful feelings about the COPD experience and how it constraints personal and family life
176 are likely to arise in such context. For this reason, researchers informed participants that, in
177 primary care centre and in the hospital, where the interviews were conducted, a psychologist
178 was available to provide support in case of need. However, none of the participants gave a
179 negative feedback about the interview nor expressed the wish to talk to the psychologist.

180 ***Data Analysis***

181 Descriptive statistics were performed to characterise the sample, using PASW Statistics
182 (Predictive Analytics Software) version 19.0 for Windows (SPSS Inc., Chicago, Illinois).

183 The interviews were transcribed verbatim. The transcripts were analysed using thematic
184 analysis (Miles & Huberman, 1994). Two independent researchers (gerontologists) coded and
185 categorised data into themes in three phases: data reduction; data display; and conclusion
186 drawing/verification (Miles & Huberman, 1994). The data reduction intended to simplify the
187 data by extracted themes. In this phase all transcripts were read, notes made, codes assigned,
188 meanings grouped together and themes/subthemes generated. The data display allowed
189 drawing conclusions. In this second phase, each researcher used maps of themes and
190 quotations to facilitate data analysis. Conclusion drawing and verification implied reviewing
191 the meaning of the analysed data and verifying emergent conclusions as a means of testing the
192 validity of the findings (Miles & Huberman, 1994). After the three phases, check-coding was
193 conducted between the two researchers to compare and discuss the themes generated. They
194 subsequently registered their agreements and disagreements. Inter-judgment agreement was
195 80%, which may be considered high (Miles & Huberman, 1994). After discussing,
196 researchers reached a consensus on the major themes and subthemes that emerged from the
197 data. To assure credibility of qualitative data the *peer debriefing* technique was also
198 performed (Lincoln & Guba, 1985). This technique consists of reviewing the methodology
199 procedures and the data by an independent researcher to the study, who challenges the

200 researchers' assumptions and ask questions about the method and interpretations. This
201 procedure allowed the research team to become more aware of their own views and helped
202 limiting the potential influence of preconceptions regarding the data (Creswell & Miller,
203 2000; Lincoln & Guba, 1985).

204 To ensure reflexivity (Meyrick, 2006), the researchers held regular group meetings to reflect
205 and discuss issues related to the study. All research team members had experience in working
206 with families living with chronic illness, but none had personally experienced a COPD
207 diagnosis or lived with a family member with this condition.

208 **Findings**

209 *Participants*

210 Patients were mostly male (n=16; 80%), with a mean age of 74.1±8.5 years old. Patients'
211 mean forced expiratory volume in one second (FEV₁) was 37.3±8.4% of the predicted.
212 According to the GOLD criteria, 14 patients had severe COPD (70%) and 6 very severe
213 (30%) (Vestbo et al., 2013). Patients with very severe COPD were on long-term oxygen
214 therapy. Most patients (n=12; 60%) had a mMRC grade of 3 ("*Stops for breath after walking*
215 *about 100 meters or after a few minutes on level ground*").

216 Family members were twelve spouses and eight adult children, with a mean age of 61.5±13.1
217 years old. Most were female (n=18; 90%), lived with the patients (n=16; 80%) and half
218 provided more than 20 hours of care per week.

219 Table 1 provides the socio-demographic, clinical and caregiving characteristics of
220 participants.

221 [Table 1 near here]

222 From the 40 transcripts, different significant themes and subthemes were identified regarding
223 the impact of the chronic phase of COPD on personal and family life, according to patients'

224 and family members' perspectives (table 2). Participants' identification was coded (p-patients;
225 fm-family members) to preserve anonymity and ensure confidentiality.

226 [Table 2 near here]

227 *Patients' perspectives*

228 *Impact of COPD symptoms on personal and family daily life*

229 All patients (n=20) reported negative impacts of the COPD symptoms (e.g., breathlessness,
230 fatigue) in their daily life, namely: restriction in leisure and social activities, such as walking
231 or dancing; constraints in mobility; sleep disturbance and restrictions in professional activity,
232 forcing them to retire from their employment. These impacts were reflected in the following
233 statements: "*I used to enjoy going out dancing. Nowadays I go, but I am not the same person,*
234 *I feel tired, I can only watch the others dancing.*" [p₁, female, 73yrs]; "*I wish I could do more*
235 *things, I wish I could go to work but I know that this [disease] will end up with me.*" [p₂, male,
236 58yrs]

237 Moreover, negative impacts on family activities, such as going on holidays or visiting other
238 family members, were also reported by patients. Due to these changes, patients felt restricted
239 to their home: "*I don't go to my relatives' house, I don't go on vacations, I'm restricted to my*
240 *home.*" [p₃, male, 80yrs] These restrictions were often accompanied by patients' feelings of
241 sadness and loneliness: "*There are some days that I prefer to be alone, in those days, I have*
242 *no joy to go out.*" [p₄, male, 66yrs]

243 *(Over)Protective family support*

244 Most patients stated that their family members were a source of support, either instrumental
245 or emotional, and were responsive to their needs (n=16): "*She [wife] is always by my side for*
246 *everything that happens.*" [p₂, male, 58yrs] Nevertheless, patients felt that their family

247 members were excessively focused on their disease and permanently concerned with their
248 health behaviours. This type of family support was sometimes perceived by patients as
249 overprotective: *"The care and concern are excessive; she [wife] is extremely concerned with*
250 *me."* [p5, male, 66yrs]

251 *Difficulties in couple communication*

252 Patients considered that COPD had an impact on marital relationship, affecting couple's
253 communication (n=7). Most male patients expressed embarrassment when asking their wives
254 for help in activities of daily living: *"She [wife] helps me with everything, but most of the*
255 *times I do not ask for help because I feel embarrassed."* [p7, male, 77yrs] Feelings of not
256 being understood by the partner were also present: *"I feel that sometimes I am a little bit*
257 *aggressive in my answers, but she [wife] needs to understand my problems. She doesn't*
258 *understand me!"* [p6, male, 60yrs]

259 *Sense of identity loss*

260 The difficulty to accept the disease led to a sense of identity loss in some patients (n=6): *"I*
261 *used to do everything and now I can't do any of those things, I'm reduced to nothing."* [p8,
262 male, 70yrs] Patients' loss of identity was associated with feelings of powerlessness and
263 difficulty to redefine their role in the family, expressed by difficulties in being reciprocal:
264 *"Now I can't do a thing for them [family], my wife is the leader and she is responsible for*
265 *everything."* [p9, male, 79yrs] Patients were also concerned about the family reactions to their
266 losses: *"I'm not the person I used to be (...) my family feels sad to see me this way."* [p10,
267 female, 60yrs]

268 *Fear of COPD progression*

269 Patients expressed their fear about the progression of the disease, mainly due to the worsening
270 of symptoms, like breathlessness (n=12): *"(...) with the disease progression, this shortness of*

271 *breath gets worse and now, I think a lot about tomorrow, the pain that it might cause.” [p11,*
272 *male, 64yrs]*

273 *Coping resources*

274 Patients relied on several coping strategies to deal with COPD and their constraints, namely
275 positive reappraisal, search for meaning and problem-solving strategies. Reminding
276 themselves that things could be worse and they were well-off compared to other people were
277 some of the coping skills used by patients (n=4): *“We have to think about our day-to-day*
278 *lives and think that there is always someone else that is worse than us.” [p13, female, 88yrs]*

279 Patients also searched for logical causes of COPD, attributing it to past experiences (e.g.,
280 childhood illness) (n=2): *“I have realised that this [disease] was due to having bronchitis*
281 *when I was young, and then smoking (...) I was born and raised next to the lagoon and I am*
282 *starting to realise that probably this affected me as well.” [p12, male, 77yrs]*

283 Problem-solving strategies were also used by patients. Maintaining a healthy lifestyle through
284 protective behaviours and exercising regularly were two of the most widely used strategies
285 (n=6): *“I need to get vaccinated. Vaccines have already prevented me from catching the flu”*
286 *[p13, female, 88yrs]; “I started swimming again, I hope it is the best for my disease” [p14,*
287 *male, 69yrs]*

288 ***Family members’ perspectives***

289 *Restrictions in family’s social life*

290 Given the demands of the disease, family members felt that the patient required more
291 attention and care, leading to restrictions in their social life (n=18): *“I gave up things that*
292 *could make me happy outside the home.” [fm2, wife, 66yrs]* Specifically, the spouses reported
293 an increased interaction with the patient but a reduction in personal contacts with other family
294 members: *“I stay at home instead of going out with my sisters. Now we talk more on the*

295 *phone, I'm living a very isolated life.*" [fm₁, wife, 66yrs] Moreover, some spouses also
296 revealed that they felt limited to home due to patient's dependence of oxygen therapy: "*I tell*
297 *you, my house is my prison.*" [fm₆, wife, 65yrs]; "*Walking down the street with him is quite*
298 *problematic! We end up staying at home, so my life turned upside down. He doesn't feel*
299 *good*" [fm₂, wife, 66yrs] COPD also changed family routines, causing a restriction in their
300 leisure activities: "*We don't go for a walk, on vacations, family reunions have ended. We are*
301 *very isolated.*" [fm₇, wife, 75yrs]

302 *Emotional distress related to COPD exacerbations*

303 The progressive trajectory of COPD, combined with episodes of acute exacerbation, was a
304 major cause of emotional distress for family members (n=15): "*Everything changes, our lives*
305 *turned upside down in all aspects, all! In terms of emotional states (...) our lives stopped!*"
306 [fm₁, wife, 66yrs]

307 Emotional distress was mainly related to the worsening of patients' symptoms and the
308 perceived possibility of patients to have a very painful death associated to asphyxia: "*I get*
309 *always frightened when she is short of breath, and then I fear that she might die.*" [fm₅,
310 daughter, 43yrs] In the former, family members shared their permanent concerns regarding
311 the patient's health condition, leading to an extreme attention to environmental factors, such
312 as climate, but also with patients' proper clothing: "*It is a constant concern, I'm always afraid*
313 *that he gets the flu. I know that it is the beginning of a respiratory infection, and it all just*
314 *gets worse.*" [fm₂, wife, 66yrs] The fear of a painful death due to asphyxia led family
315 members to be permanently close to the patient, avoiding leaving her/him alone: "*I feel*
316 *worried all the time, I cannot let him at home by himself, because something can happen.*"
317 [fm₄, daughter, 50yrs]

318 *Tension in couple relationship*

319 Similarly to patients, spouses also reported constraints in the couple relationship (n=5).
320 Spouses blamed the patient for the COPD diagnosis due to life-cycle smoking habits, causing
321 disagreement and tension between the couple: *"In relation to his addictions [smoking], he is*
322 *a weak-minded person."* [fm9, wife, 75yrs]

323 Marital tensions were also caused by patient's resistance to use portable oxygen therapy: *"He*
324 *is embarrassed to go out with a bottle of oxygen, this situation has been discussed. He always*
325 *upsets me (...) then he begins: this is heavy, this is heavy"* [fm1, wife, 66yrs]

326 Family members believed that patients' attitudes and negative emotional reactions to the
327 disease caused tensions in daily life: *"He continues to do things, but his behaviour has*
328 *changed. I think he is more aggressive, because he cannot deal with the situation."* [fm8,
329 wife, 78yrs]

330 *Financial strain of COPD*

331 Two family members reported that COPD had limited patients' ability to work and forced
332 their retirement, affecting the family's financial resources: *"He stopped working, so our*
333 *economic situation got a lot worse."* [fm2, wife, 66yrs] Financial strain was also caused by the
334 need of expensive medications (e.g., bronchodilators) with no support from social and health
335 services: *"These medications are expensive and there is no support from the services."* [fm10,
336 husband, 62yrs]

337 *Coping resources*

338 Similarly to patients, family members used a number of coping strategies to handle with the
339 difficulties imposed by COPD. Family members dealt with COPD through positive
340 reappraisal (n=9). Living with and caring for a patient with COPD allowed family members to
341 find meaning in their experience, as they considered it as an opportunity for personal growth
342 from adversity: *"I changed as a person (...) the disease makes me feel more mature, more*

343 *prepared and responsible for other people.*" [fm₁₀, husband, 62yrs]; *"Certainly we grow up*
344 *with these difficulties; perhaps we look more at what surrounds us, is a way for us to grow*
345 *spiritually.*" [fm₁₁, wife, 79yrs]

346 Getting help and support from family, friends and professional networks were some of the
347 mechanisms used to manage COPD constraints (n=17): *"When my wife was hospitalised, he*
348 *helped me [grandson]! 'Grandpa, don't worry, I will cook something'"* [fm₁₀, husband,
349 62yrs]; *"I have too many friends that call me, that give me support and say: 'keep calm, you*
350 *know, it is going to be alright'"* [fm₆, wife, 65yrs]

351 Family members applied other problem-solving strategies, such as seeking for relevant
352 information about COPD and treatment procedures (n=4), or reorganising family routines to
353 minimise the effects of potentially adverse COPD effects for the patient (e.g., change the
354 place of family meetings) (n=6): *"I know what is like, she gets tired and I try to avoid her*
355 *doing things, I do them instead. Like bed-making, lift the mattress, she has difficulties and I*
356 *help her.*" [fm₁₀, husband, 62yrs]

357 **Discussion**

358 The overall findings illustrate the complex interaction between the experience of living with
359 COPD and communication patterns, emotional states, social support and social role within the
360 family. Although some different reactions to COPD were identified, patients and family
361 members shared similar and interrelated difficulties and concerns that seemed to affect family
362 functioning.

363 Restraints in family social life represented a significant lifestyle change for both patients and
364 family members as a result of the spiral of worsening COPD symptoms. Patients felt deprived
365 from family and social activities as a consequence of the progressive COPD-related fatigue,
366 sleep disturbance, breathlessness and difficulty in mobility. Hence, it is known that patients

367 become socially isolated and do not share experiences with family and friends, which
368 frequently lead to feelings of sadness, loneliness or even abandonment (Ek & Ternstedt,
369 2008; Gardiner et al., 2010). But the confining/isolating nature of COPD was also extended to
370 their family members. This result is not surprising, as while the dependency of the ill person
371 increases, the caring demands from close family members also intensify (e.g., monitoring
372 breathlessness, long-term oxygen therapy and treatment regimen adherence) forcing them to
373 give up from social contacts and activities (Bergs, 2002; Booth, Silvester, & Todd, 2003).
374 Consistent with previous research (Boyle, 2009; Gullick, 2012; Simpson et al., 2010), the
375 patient's need for oxygen therapy was pointed out as a particular reason for family members'
376 restrictions in social life. Moreover, for family members, the majority of social interactions
377 were limited to the ill person. Due to time constraints and COPD care demands, family
378 members may perceive little opportunity to maintain or develop new social relationships. It
379 has been widely recognised that the loss of social participation of family members,
380 particularly the carers, contribute to high levels of perceived burden and other negative
381 health-related outcomes (Croog, Burleson, Sudilovsky, & Baume, 2006; Pearlin, Mullan,
382 Semple, & Skaff, 1990; Thommessen et al., 2002). Moreover, families exposed to long-term
383 illness demands tend to define themselves based almost exclusively in that experience; this
384 reorganisation of family dynamics around the illness and the difficult emotional landscape
385 that surrounds it, can rigidify the family functioning and development as a chronically ill
386 family (Patterson & Garwick, 1994). Thus, as recommended by the FSI Model, interventions
387 should be implemented to help family members coping with the developmental demands of
388 the disease, without sacrificing their own or family's development as a system over time
389 (Rolland, 2003). Moreover, raising community awareness for the availability of respite
390 services is fundamental for family members to maintain and nurture personal social networks,
391 enhance social support, preserve personal freedom and enable self-care.

392 The couple relationship appears to have been affected by the disease. According to the
393 patients' views, the poor supportive attitudes of spouses, such as lack of validation for the
394 patient's negative emotional reactions, overprotection or criticism, can suggest marital-
395 strained relationships (Bergs, 2002; Grant, Cavanagh, & Yorke, 2012; Simpson et al., 2010).
396 A significant amount of research across different chronic illnesses (e.g., heart disease, cancer
397 or chronic kidney disease) has demonstrated that poor quality spousal support, like critical,
398 blaming and controlling behaviours, are predictors of patients' poor physical and mental
399 health outcomes and reduce the ability to cope with the disease (Campbell, 2003; Martire et
400 al., 2004). In the present study, beliefs about the causes of COPD were particularly significant
401 for family members. Some spouses tended to blame the partners for their disease, as a result
402 of long years of cigarette smoking. Perceiving COPD as a self-inflicted disease may create
403 tension in the couple relationship that might lead to marital conflict and turn the caring
404 responsibility harder to accept (Gullick, 2012).

405 In addition, empirical evidence suggests that those who feel burdened by caregiving tend to
406 behave overprotectively (Kuijjer et al., 2000; Thompson & Sobolew-Shubin, 1993). This is
407 particularly the case of female carers who tend to be more overprotective than male carers
408 (Edwards & Noller, 1998; Holtzman, Abbey, Singer, Ross, & Stewart, 2011). Spouses'
409 overprotection however, has been shown to undermine patients' self-efficacy in dealing with
410 the disease and patients' feelings of control over their lives (Hagedoorn et al., 2000; Martire,
411 Stephens, Druley, & Wojno, 2002). Such evidence might explain a sense of loss of identity
412 and the feelings of powerlessness expressed by patients, particularly men, who had also
413 difficulties in redefining their roles within the family. Therefore, it is essential to improve
414 open communication between patients and family members about the support that is needed,
415 perceived and provided. Professionals should inform families about the possible maladaptive
416 effects of blaming, controlling and overprotecting and help them to redefine relationships

417 with others, as well as, to preserve the concept of personal and family identity (Rolland, 1999,
418 2003).

419 The likelihood and severity of COPD-related crisis was particularly distressful for family
420 members who were often too worried to leave the patient in case of an acute breathlessness
421 episode occur in their absence. Fears about this illness-related crisis are often considered a
422 major source of a family's undercurrent of anxiety (Boyle, 2009; Grant et al., 2012; Pinto et
423 al., 2007; Spence et al., 2008). Concerns related to the disease progression and worsening of
424 symptoms were also expressed by patients. Family feelings of anticipatory loss were
425 associated with the uncertainty about COPD prognosis. These findings are consistent with
426 previous studies reporting that patients with COPD tend to be poorly informed about the long-
427 term prognosis of their disease and about what to expect toward the end of life, especially
428 when compared with other diseases such as cancer or acquired immunodeficiency syndrome
429 (Curtis et al., 2002; Gardiner et al., 2010). According to the FSI model, learning to live with
430 anticipatory loss and uncertainty, as for the case of COPD trajectory, is a fundamental task for
431 families in the chronic phase (Rolland, 1999). Thus, family-based interventions should seek
432 suitable ways of normalising emotions related to threatened or impending loss, strengthening
433 the families' capacities to cope with emotional distress. In addition, developing viable and
434 flexible plans is crucial for families to cope with possible crises, highlighting the need to be
435 offered with useful information and guidelines about the COPD course and symptom
436 management (Rolland, 1994).

437 Despite the adverse effects of COPD, patients and family members mobilised their resources
438 and strengths to cope with the difficulties of everyday life. Some of them were able to find
439 meaning in COPD experience, using positive reappraisal. Problem-solving strategies were
440 also reported from both sides. In other chronic conditions, evidence has shown that the use of
441 positive reappraisal, seek guidance and support, and problem-solving strategies were

442 positively related to psychological growth and development (Kramer, 1997; Rohrbaugh et al.,
443 2004; Urcuyo, Boyers, Carver, & Antoni, 2005; Widows, Jacobsen, Booth-Jones, & Fields,
444 2005). As such, family-based interventions in the COPD context should be focused on family
445 coping and adaptational pathways, to reduce vulnerability and facilitate a positive adaptation
446 (e.g. psychoeducational multifamily groups) (Rolland, 1994; Walsh, 2002). Moreover,
447 professionals should give families positive feedback from successful experiences of coping,
448 since it strengthens the COPD family resources (Moos & Holahan, 2007). The FSI model
449 acknowledges the importance of these resources to a functional adjustment to the disease
450 (Rolland, 2003).

451 *Limitations and future research perspectives*

452 Some limitations need to be acknowledged. This study was conducted with families in the
453 chronic phase of the disease. However, the different time-phases in COPD - crisis and
454 terminal - might involve different specific impacts on COPD families that need to be further
455 explored. Moreover, the cross-sectional design is limited to provide an understanding of the
456 changing nature of COPD impacts and challenges for families. Specifically, it does not allow
457 an understanding of how the transition periods between the three time phases might be
458 experienced. Future longitudinal studies need to be conducted to examine changes throughout
459 the course of the disease. Analysing patient and family member's experiences together and
460 relating these with their history of family functioning should also be further explored. It
461 would help to identify high risk families that, shaped by unresolved issues and past
462 dysfunctional patterns, might not functionally cope with the challenges imposed by a severe
463 chronic condition such as COPD (Rolland, 1994). Moreover, the sample recruitment might
464 have resulted in an over-representation of distressed families, as clinicians might have
465 identified those participants who could somehow benefit from a "psychosocial-oriented
466 interview". Finally, the findings were also limited by cohort and contextual factors.

467 Participants were mostly older adults and the study was conducted in Portugal, where health
468 and support services for patients with COPD and their families (e.g., pulmonary
469 rehabilitation, respite care or psychoeducational support) are not widespread (Figueiredo,
470 Gabriel, Jácome, & Marques, 2013). Thus, cross-cultural studies with samples including
471 younger cohorts should also be conducted to explore the extent of these findings.

472 Nevertheless, the current study provides relevant and unique knowledge about the
473 difficulties, constraints and resources experienced by families in the presence of COPD. The
474 overall findings highlight the need for developing supportive family-based interventions in
475 the context of COPD. Priority goals should include: helping families to cope with and manage
476 the stresses inherent to COPD; increasing mutually supportive interactions between members;
477 nurturing the current support system and build additional extra familial support; and
478 minimising intrafamilial hostility and criticism (Fisher & Weihs, 2000; Weihs, Fisher, &
479 Baird, 2002). Family-focused approaches to the management of chronic diseases have been
480 shown promising results in a number of patient and family member outcomes (Martire et al.,
481 2004; Shields, Finley, Chawla, & Meadors, 2012). However, the effects of family-based
482 interventions targeted to the management of COPD remains unknown (Fisher & Weihs, 2000)
483 and empirical evidence is needed.

484 **Conclusion**

485 The presence of a chronic illness like COPD can deeply affect not only the patient, but also
486 the family. The overall results showed that COPD families face a number of difficulties
487 related to relationships tension, social isolation, a sense of powerlessness, emotional strain
488 and uncertainty towards the future. In the light of the FSI model (Rolland, 1987, 1999) it
489 becomes clear that there are a number of challenges that families need to pursuit in order to
490 “put the illness in its place” and keep going with their individual and familiar lives throughout

491 the “long haul” (Rolland, 1999). Therefore, the results highlight the need to develop family-
492 based interventions to facilitate a functional adjustment to the COPD.

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666

667 **Table 1** - Socio-demographic, clinical and caregiving characteristics of participants (n=40).

Characteristics	Patients (n=20)	Family members (n=20)
Gender		
Female, n(%)	4(20%)	18(90%)
Male, n(%)	16(80%)	2(10%)
Age (years), M±SD	74.1±8.5(58-88)	61.5±13.0(38-81)
Academic qualifications, n(%)		
No qualifications	2(10%)	2(10%)
Primary School	13(65%)	12(60%)
Secondary School	5(25%)	5(25%)
High school	0	1(5%)
Marital Status, n(%)		
Married	15(75%)	19(95%)
Divorced	1(5%)	1(5%)
Widowed	4(20%)	0
Work status, n(%)		
Retirement	19(95%)	11(55%)
Full-time employment	1(5%)	5(25%)
Unemployment	0	2(10%)
Domestic	0	2(10%)
FEV₁ (% predicted), M±SD	37.3±8.4%	-
mMRC, n(%)		
Grade 1	4(20%)	-
Grade 2	4(20%)	-
Grade 3	12(60%)	-
Caregiving hours (weekly hours), n(%)		
8-20	-	10(50%)
20-40	-	4(20%)
>40	-	6(30%)

668 Abbreviations: FEV₁, forced expiratory volume in one second; mMRC, modified British Medical Research Council
 669 questionnaire.

670

671 **Table 2** - Living in the chronic phase of COPD: emerging themes and subthemes from the patients' and family members'
 672 perspectives.

Psychosocial typology of COPD, according to the FSI Model	Gradual onset, progressive course (with acute episodes), a possible fatal outcome and incapacitating.	
Time phase of COPD	Chronic phase	
	Themes	Subthemes
<i>Patients' perspectives</i>	Impact of COPD symptoms on personal and family daily life	Restrictions in leisure and social activities
		Constraints in mobility
		Sleep disturbance
	(Over)Protective family support	Restrictions in professional activity
		Family as a source of support (Over)Protective care
	Difficulties in couple communication	Embarrassment of asking for help
		Feelings of not being understood
	Sense of identity loss	Feelings of powerlessness
	Fear of COPD progression	Difficulties in being reciprocal
		Worsening of symptoms
Coping resources	Positive reappraisal	
	Search for meaning	
	Exercising regularly	
	Protective health behaviours	
<i>Family members' perspectives</i>	Restrictions in family's social life	Reduction of contacts with other family members
		Restriction to home due to the patient dependence on oxygen therapy
	Emotional distress related to COPD exacerbations	Concerns related to the worsening of patients' symptoms
		Fear that patient has a painful death associated to asphyxia
	Tension in couple relationship	Spouses blamed the patient for the COPD diagnosis
		Patients' attitudes and negative emotional reactions
	Financial strain of COPD	Limited patients' ability to work
		Expensive medications with no support from social and health services
	Coping resources	Positive reappraisal
		Getting help and support from family, friends and professional networks
Seeking for relevant information about COPD		
		Reorganising family routines

673