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## Self-care styles of patients with chronic obstructive pulmonary disease: A mixed methods case study

Marco Clari, RN, PhD<sup>a,\*</sup>, Federica Riva-Rovedda, RN, MNS<sup>a</sup>, Valerio Dimonte, RN, MNS<sup>a</sup>, Maria Matarese, RN, MNS<sup>b</sup>

<sup>a</sup> Department of Public Health and Pediatrics, University of Torino, via Santena 5bis, 10126 Turin, Italy

<sup>b</sup> Department of Medicine and Surgery, Campus Bio-Medico University of Rome, 00128 Rome, Italy

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## ABSTRACT

**Background:** In people affected by chronic obstructive pulmonary disease (COPD), self-care is crucial for improving quality of life, decreasing symptom burden, and reducing health care-related costs. Unlike other chronic conditions, little is known about the factors that influence different self-care styles in COPD patients.

**Objectives:** To explore the factors that could influence the self-care styles of patients with COPD.

**Methods:** A mixed methods case study design was used. Quantitative and qualitative data were collected at the same stage in a purposive sample of patients with COPD through questionnaires, interviews, and focus groups. Data were analyzed separately and then integrated to compare the cases.

**Results:** Thirty-seven patients with COPD were recruited from an outpatient clinic, pulmonary rehabilitation unit and online in a patient support group. On average, participants scored below the level of adequacy in all self-care dimensions. Self-care maintenance was influenced by patient age, education level, and economic status. Most participants reported performing self-care behaviors, while some did not because they found it difficult or because they did not recognize their importance. When the quantitative and qualitative data of patients with higher and lower levels of self-care were integrated, four different styles of self-care were identified according to COPD severity, psychological distress and level of self-efficacy: proactive, inactive, reactive, and hypoactive.

**Conclusions:** Personal, clinical, psychological, and social factors not only influence the level of self-care performed by COPD patients but also contribute to the understanding of different self-care styles. This knowledge could support health care professionals in tailoring educational interventions.

### Introduction

The complexity of chronic obstructive pulmonary disease (COPD), which results from various clinical manifestations of the disease, various therapeutic regimens, and the frequency of exacerbations, requires that patients with COPD take care of themselves daily.<sup>1</sup> The process of maintaining health through health-promoting practices and managing illnesses is defined as self-care.<sup>2</sup> According to the middle range theory of self-care for chronic illness, self-care comprises three separate but connected dimensions: self-care maintenance, which includes behaviors that people with chronic diseases perform to maintain clinical and emotional stability; self-care monitoring, which includes behaviors aimed at monitoring the occurrence of symptoms; and self-care management, which consists of behaviors performed to react to symptoms or treatment medication side effects.<sup>3</sup> Effective self-care can reduce

symptom burden, improve patient health-related quality of life, and reduce COPD related hospital admissions and the utilization of health care services.<sup>3</sup>

In COPD, self-care performance can be influenced by various personal, clinical, psychological, and social factors. Among personal factors, younger age and higher education have been positively correlated with greater self-care behaviors,<sup>4</sup> whereas the influence of gender remains unclear.<sup>5</sup> Clinical factors, such as the number of comorbidities and the severity of dyspnea, may lead to fear and reduced confidence in patients' ability to perform everyday activities, contributing to a sedentary lifestyle.<sup>6</sup> Furthermore, higher levels of self-care are reported in advanced disease stages, although they may not always lead to improved health outcomes.<sup>5</sup>

Psychological factors also play a significant role in self-care among COPD patients; anxiety, depression, and a negative perception of the

\* Corresponding author at: University of Torino, Department of Public Health and Pediatrics, Via Santena 5bis, 10126, Turin, Italy.

E-mail address: [marco.clari@unito.it](mailto:marco.clari@unito.it) (M. Clari).

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disease are negatively associated with self-care.<sup>6,7</sup> Self-efficacy is another crucial psychological factor influencing self-care, acting as a predictor of mediator of self-care behaviors.<sup>8</sup> Self-efficacy provides patients with the confidence needed to initiate and maintain self-care behaviors despite potential obstacles.<sup>6</sup>

Among social factors, isolation, loss of personal social roles, and economic burdens seem to reduce patients' ability to independently manage COPD effectively, while the presence of a partner and good relationships with informal and formal caregivers could improve self-care behaviors.<sup>6</sup> Although family support is fundamental, it can elicit a sense of guilt and frustration in patients.<sup>9</sup> Despite the numerous studies, there is still no definitive agreement on factors that can promote or hinder the performance of adequate levels of self-care for patients with COPD, which is often reported to be suboptimal.<sup>10</sup>

Few qualitative studies have been conducted to explore the self-care behaviors of patients with COPD, which include all the actions that patients can take to promote their health and manage COPD.<sup>11</sup> Among them, adapting activities to accommodate breathlessness and conserve energy, using walking aids, engaging in physical exercise, fighting smoking addiction, receiving annual flu vaccination, and adjusting

therapy in response to symptoms as prescribed by health care professionals (HCPs) have been described.<sup>12</sup> Some patients with COPD reported difficulties in performing their self-care behaviors whereas others easily integrated them in their daily routine showing different approaches.<sup>13</sup>

The approaches, methods, or strategies adopted by patients to manage their health, cope with symptoms, and enhance their overall well-being reflecting their attitudes toward self-care could be defined as self-care styles. To our knowledge, no study has hypothesized the existence of distinct self-care styles among patients with COPD or explored the factors that could define these styles. Knowing what factors influence self-care and the styles adopted by subgroups of patients would allow tailored educational interventions to promote effective self-care. Thus, the aim of our study was to explore how personal, clinical, psychological, and social factors combine to define distinct self-care styles among patients with COPD. The objective of the mixed methods quantitative strand was to identify the level of self-care of patients with COPD and the personal, clinical, psychological, and social factors related to their self-care; the objective of the qualitative strand was to explore the experiences of patients with COPD with different level of self-care.

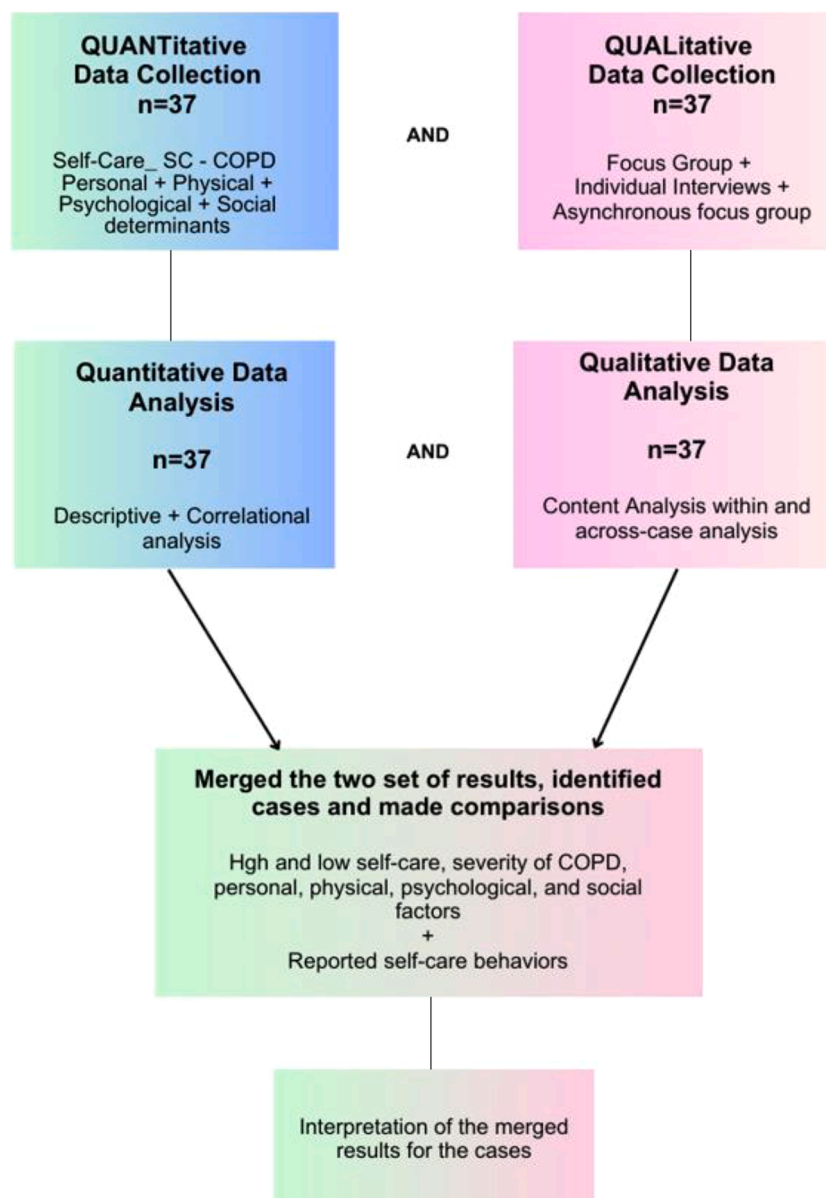


Fig. 1. Mixed method case study diagram.

## Methods

### Study design

A convergent mixed methods-case study design was used<sup>14</sup> (Fig. 1). The rationale for using both types of data is that when used in combination, quantitative and qualitative methods complement each other and can offer a more complete picture of the phenomenon in study.<sup>14</sup> In convergent mixed methods case study, qualitative and quantitative data are collected in a single phase and analyzed separately, and the results are integrated to look for convergence, divergence, contradictions, or relationships to describe and interpret the complexity and theoretical importance of cases.<sup>16</sup> The cases can be derived inductively from quantitative and qualitative data after data collection and analysis, or deductively, before data collection and analysis. In our study, we inductively generated the cases to consider for further analysis.<sup>15</sup>

The study was approved by an Ethics Committee (n. CS/840). Patients who met the inclusion criteria and wanted to participate in the study provided their signed written consent after being informed about the study aim and could withdraw from the study at any time.

### Sample

Participants were recruited from an outpatient pulmonary clinic, a pulmonary rehabilitation unit, and a social media group dedicated to COPD patients. Purposive maximum variation sampling was used to represent a wide range of conditions of interest, including sex, COPD severity, use of oxygen therapy, socioeconomic status, and level of education. The maximum variation sampling ensured inclusion of participants with COPD with diverse characteristics. These differences are expected to influence self-care behaviors and may uncover distinct cases and self-care styles. By including a wide range of cases, we expected to gain a broader understanding of self-care practices among patients with COPD.

The eligibility criteria were a diagnosis of COPD at any stage and the ability to understand and speak Italian. Patients with a diagnosis of dementia or severe cognitive impairment, as documented in their medical records or assessed by the Short Portable Mental Status Questionnaire (SPMSQ)<sup>16</sup> were excluded.

### Quantitative data collection

The 32-item self-care in COPD Inventory (SC-COPDI) was used to measure self-care behaviors. The instrument is composed of three scales that measure the three dimensions of self-care: self-care maintenance (13 items), self-care monitoring (9 items), and self-care management (10 items), and it has showed good validity and reliability in the Italian population.<sup>11</sup> Personal characteristics, including sex, age, education level, and occupation, were collected using a questionnaire developed by the researchers.

The clinical factors evaluated were the disease severity, the grade of airway obstruction, the presence of other chronic conditions, and the use of oxygen. The severity of COPD was evaluated using the ABE assessment tool,<sup>17</sup> which is based on the combination of the magnitude of dyspnea evaluated by the modified Medical Research Council (mMRC) questionnaire<sup>18</sup> or of symptoms evaluated by the 8-item COPD Assessment Test (CAT<sup>TM</sup>).<sup>19</sup> In the mMRC, patients self-reported whether dyspnea influenced their capacity to carry out daily activities, with scores ranging from 0 to 4, where 4 indicates a greater impact of dyspnea on daily activities. In the CAT, patients self-reported the impact of several symptoms on their life, with scores ranging from 0 to 40, where greater values indicate a greater impact of symptoms. CAT reliability, validity and responsiveness have been extensively evaluated in patients with COPD,<sup>20</sup> and demonstrated in the Italian population.<sup>21</sup> The level of airflow obstruction was assessed through the GOLD classification, which classifies obstruction based on spirometric values of forced expiratory

volume in 1 second (FEV1),<sup>17</sup> The GOLD stages were derived from patient medical records. The number of chronic diseases was self-reported by patients by submitting a list of the most common diseases occurring in people with COPD,<sup>17</sup> including cardiovascular disease, muscular and skeletal dysfunctions, metabolic syndrome, osteoporosis, depression, anxiety, and cancer.

The psychological factors considered were self-efficacy, depression, and anxiety. Self-efficacy was measured using the 7-item Self-Care Self-Efficacy Scale in COPD (SCES-COPD),<sup>11</sup> depression was assessed using the 9-item Patient Health Questionnaire (PHQ-9),<sup>22</sup> and anxiety was assessed through the 7-item Generalized Anxiety Disorder (GAD-7).<sup>23</sup> The SCES-COPD scores are standardized to 100 with higher scores indicating greater self-efficacy. It has showed high validity and reliability in the Italian population.<sup>11</sup> The PHQ-9 scores range from 0 to 27 and GAD-7 scores from 0 to 21, with higher scores indicate greater levels of depression and anxiety, respectively.<sup>22,23</sup> Both PHQ-9 and GAD-7 have been widely used in COPD patients, demonstrating good psychometric properties.<sup>24,25</sup>

The social factors considered were perceived income adequacy (evaluated by asking patients to indicate if they believed they had less than needed for a living, enough, or more than needed), living status (living alone or not) and presence of a family caregiver (yes or not).

The set of instruments was administered to patients with COPD in pencil-and-paper format for those recruited in clinical settings, while word files were sent via emails or social media posts to those recruited from social media groups before conducting qualitative interviews.

### Qualitative data collection

Three different methods were used to collect data: individual face-to-face interviews, focus groups, and asynchronous focus groups on social networks. Individual interviews were used to provide in-depth information from individual perspectives, while focus groups were used to provide broader data derived from group interactions.<sup>26</sup> To reach a wider population with different characteristics and to increase the variability of sample characteristics, a virtual asynchronous focus group was conducted on the internet in an online support group. The asynchronous method entails using online discussion boards or forums, allowing participants to read and reply to each other's postings at times of their own choosing.<sup>27</sup> An interview guide was developed and is reported in Supplementary Material Table S1.

### Quantitative data analysis

Descriptive statistics, such as the mean, standard deviation (SD), frequency, and percentage, were calculated. The Pearson correlation coefficient was used to test the relationship between self-care and continuous variables. Correlations were defined as negligible ( $r \leq 0.30$ ), low ( $r = 0.31-0.50$ ), moderate ( $r = 0.51-0.70$ ), high ( $r = 0.71-0.90$ ), and very high ( $r \geq 0.91$ ).<sup>28</sup> One-way analysis of variance (ANOVA) with Tukey's post-test was used to compare means. We defined participants who scored  $\geq 70$  in the SC-COPDI scales as performing high self-care and those who scored  $\leq 30$  as low self-care. Listwise deletion was used to handle missing data. All tests were two-tailed with the level of significance set at  $\leq 0.05$ . The data were analyzed using IBM® SPSS® version 22.0 software.<sup>29</sup>

Power analysis was conducted to determine the sample size for the quantitative component of the study. An effect size of 0.5 was used to achieve significant statistical correlations between variables, with a two-sided alpha of 0.05 and power of 80 %. The estimated sample size required was 26. The G Power software version 3.1.9.3 was used for power analysis.<sup>30</sup>

### Qualitative data analysis

Individual interviews and focus groups were transcribed verbatim,

and the online focus group was exported as text documents. Qualitative data were analyzed using deductive content analysis. Based on knowledge derived from the previous literature, subcategories and categories determined a priori were used to identify first-level codes. The codes were then merged based on their similarity in meaning. A structured categorization matrix was created based on the middle-range theory of self-care for chronic illness.<sup>3</sup> The analysis was performed by two independent researchers; any discrepancies were discussed until a consensus was reached. The report of each participant was considered a unit and analyzed separately. A within-case analysis identified the critical elements of individuals' self-care experiences.<sup>31</sup> The categories identified from this analysis were then compared across cases to highlight commonalities and differences.<sup>31</sup> The data were analyzed with the support of ATLAS.ti 6.2 (ATLAS.ti. Scientific Software Development, Berlin).

To ensure rigor and trustworthiness, field notes, tracking of coding decisions, and periodic discussions between researchers were held.<sup>32</sup> Two participants, one from the outpatient clinic and one from the rehabilitation unit, were contacted by email to validate emergent themes and categories. In addition, emerging themes and categories were posted on the virtual focus group page for further validation.<sup>33</sup> The same sample size determined for the quantitative component of the study was expected to provide sufficient qualitative data; however, consistent with the qualitative approach, this size was also determined through data saturation.<sup>34</sup>

#### Data integration

First, we built an informational matrix in which quantitative results and qualitative accounts of all participants were reported. Second, differences and similarities across self-care levels were searched to uncover possible cases.<sup>14,15</sup> Third, personal, clinical, and psychological factors were compared across and within patients with different levels of self-care to identify differences and similarities in and between cases. Finally, participant narratives were used to interpret and explain differences and similarities in and between cases that described different self-care styles to obtain a wide understanding of the influencing factors.<sup>14,15</sup> The results were summarized in a narrative and graphical representation.

## Results

#### Quantitative results

We recruited 37 participants – 13 (35.1 %) from a pulmonary clinic, 11 (29.7 %) from a pulmonary rehabilitation unit, and 13 (35.2 %) from a social media group. The participants were mainly men (56.8 %), with a mean age of 69.8 years (SD 8.4). Most patients were retired and reported a good economic status and lived with a family caregiver. The characteristics of the participants are reported in Table 1. All stages of COPD were represented. The mean scores for the self-care maintenance, monitoring, and management scales were 56.3 (SD 21.5), 60.1 (SD 26.3) and 43.6 (SD 22.2), respectively, with the self-care management scale presenting the lowest score. Overall, 12 participants (32.4 %) reported adequate scores ( $\geq 70$ ) on the self-care maintenance and monitoring scale, and four (14.8 %) reported adequate scores on the self-care management scale. Four participants scored  $\geq 70$ , and three scored  $\leq 30$  in all dimensions of self-care. Twenty-seven participants (73 %) reported experiencing symptoms of COPD. Patients exhibited symptoms of moderate depression and anxiety (PHQ-9 = 9.0, SD 6.3; GAD-7 = 7.2, SD 5.3) (Table 1).

The self-care maintenance and management scales were moderately correlated ( $r = 0.39$ ,  $p = 0.017$ ,  $r = 0.42$ ,  $p = 0.03$ , respectively) with the self-efficacy scales, while the self-care monitoring scale was strongly correlated ( $r = 0.71$ ,  $p < 0.001$ ). The self-care maintenance, monitoring, and management scales correlated moderately between them (Table 2). The self-care maintenance scale score was negatively correlated with

**Table 1**  
Characteristics of participants ( $n = 37$ ).

Characteristics	
<b>Personal</b>	
Sex (male), n (%)	21 (56.8)
Age, mean (SD); [range]	69.8 (8.4); [52–83]
Level of education, n (%)	
Elementary school	7 (18.9)
Middle school	16 (43.2)
High school	11 (29.7)
University	3 (8.1)
Working status, n (%)	
Retired	32 (86.5)
Employed	5 (13.5)
<b>Clinical</b>	
Years with COPD, mean (SD); [range]	9.3 (8.3); [1–37]
Symptom impact (CAT), mean (SD); [range]	17.8 (8.8); [3–36]*
Severity of dyspnea, n (%)	
mMRC 0	1 (2.7)
mMRC 1	5 (13.5)
mMRC 2	9 (24.3)
mMRC 3	15 (40.5)
mMRC 4	7 (18.9)
COPD GOLD Stage, n (%)	
1	5 (13.5)
2	9 (24.39)
3	16 (43.2)
4	7 (18.9)
ABE assessment, n (%)	
GOLD A	5 (13.5)
GOLD B	17 (45.9)
GOLD E	15 (40.5)
Oxygen therapy (yes), n (%)	15 (40.5)
Other chronic conditions, mean (SD); [range]	2.1 (1.3); [0–5]
<b>Psychological</b>	
Self-efficacy (SCES), mean (SD); [range]	66.8 (21.8); [25–100]‡
Depression (PHQ-9), mean (SD); [range]	9.0 (6.3); [2–23]#
Anxiety (GAD-7), mean (SD); [range]	7.2 (5.3); [0–18]§
<b>Social</b>	
Perceived income adequacy, n (%)	
Not enough for living	5 (13.5)
Enough for living	28 (75.7)
More than enough for living	4 (10.8)
Living status (alone), n (%)	12 (32.4)
Informal caregiver (no), n (%)	16 (43.2)
<b>Self-care of COPD Inventory scales</b>	
Maintenance, mean (SD); [range]	56.3 (21.5); [21.2–94.2]‡
Monitoring, mean (SD); [range]	60.1 (26.3); [9.4–10.0]‡
Management, mean (SD); [range]	43.6 (22.2); [6.3–83.8]‡

SD: Standard Deviation, COPD: Chronic Obstructive Pulmonary Disease, CAT: COPD Assessment Test, mMRC: modified Medical Research Council, GOLD: Global Initiative for Chronic Obstructive Lung Disease, PHQ-9: 9-item Patient Health Questionnaire, GAD-7: 7-item Generalized Anxiety Disorder, SCES: Self-care self-efficacy scale.

\* 0–40 scale.

# 0–27 scale.

§ 0–21 scale.

‡ 0–100 scale.

participant age ( $r = -0.41$ ,  $p = 0.012$ ), and the score was greater when patients had a higher education level ( $p = 0.034$ ) and perceived good income adequacy ( $p = 0.006$ ). No correlations were found between self-care monitoring and management scales or other factors (Table 2). When we analyzed the correlations between factors and self-care scale scores in patients with high self-care ( $\geq 70$ ) and low self-care ( $\leq 30$ ) separately, no significant correlation was identified.

#### Qualitative results

We identified 125 codes grouped into 14 subcategories that described the behaviors performed by participants in the three self-care categories derived from the theoretical framework of self-care for chronic illness: self-care maintenance, monitoring, and management

**Table 2**  
Correlations of variables with self-care scales (n = 37).

Characteristics	Self-care maintenance* Mean (SD)	P-value	Self-care monitoring* Mean (SD)	P-value	Self-care management* Mean (SD), (n = 27)	P-value
Sex		0.062		0.780		0.764
Female	63.8 (24.4)		58.7 (27.4)		44.9 (25.0)	
Male	50.5 (17.5)		61.2 (26.0)		42.3 (20.2)	
Level of education		0.034		0.567		0.620
Elementary school	55.5 (17.8)		65.2 (28.4)		34.2 (14.6)	
Middle school	47.7 (20.6) <sup>a</sup>		54.6 (26.3)		47.1 (21.4)	
High school	61.7 (21.5)		60.51 (27.7)		45.1 (27.2)	
University	84.0 (2.9) <sup>a</sup>		76.4 (15.1)		27.9 (7.7)	
Working status		0.060		0.316		0.254
Retired	53.7 (21.5)		58.4 (26.1)		45.9 (21.2)	
Employed	73.1 (13.9)		71.2 (27.5)		33.2 (26.1)	
Severity of dyspnea		0.063		0.355		0.990
mMRC 0	46.2 (0.0)		75.0 (0.0)		–	
mMRC 1	60.4 (23.4)		53.1 (34.5)		46.2 (35.0)	
mMRC 2	63.5 (21.6)		72.3 (21.2)		44.0 (18.5)	
mMRC 3	45.7 (15.2)		52.1 (25.1)		41.9 (17.9)	
mMRC 4	72.1 (25.8)		66.7 (28.0)		44.6 (34.2)	
COPD GOLD Stage		0.464		0.897		0.965
1	59.2 (22.5)		53.1 (34.5)		46.2 (35.0)	
2	52.8 (18.0)		58.3 (24.2)		40.7 (19.2)	
3	52.5 (21.7)		61.4 (25.7)		42.3 (18.9)	
4	67.3 (25.0)		64.6 (28.8)		46.7 (26.9)	
ABE assessment tool		0.065		0.819		0.754
A	40.4 (21.1)		53.1 (36.2)		35.5 (31.8)	
B	66.4 (19.1)		60.8 (23.5)		45.9 (25.3)	
E	53.1 (21.5)		61.6 (27.1)		43.5 (20.3)	
Oxygen therapy		0.095		0.313		0.868
Yes	51.4 (22.9)		56.5 (29.8)		42.9 (24.5)	
No	63.5 (17.8)		65.5 (19.7)		44.3 (20.5)	
Perceived income adequacy		0.006		0.352		0.063
Not enough for living	41.5 (18.7) <sup>a</sup>		51.9 (35.3)		44.4 (25.1)	
Enough for living	54.9 (20.0) <sup>b</sup>		59.2 (25.8)		39.3 (20.6)	
More than enough for living	84.6 (6.5) <sup>a,b</sup>		76.8 (12.1)		71.1 (10.9)	
Living status		0.152		0.884		0.808
Alone	62.1 (21.9)		60.9 (26.0)		42.3 (20.7)	
With other	51.8 (20.7)		59.6 (27.0)		44.5 (23.8)	
	<b>r</b>	<b>P-value</b>	<b>r</b>	<b>P-value</b>	<b>r</b>	<b>P-value</b>
Self-care maintenance	–		0.56	<0.001	0.38	0.050
Self-care monitoring	0.56	<0.001	–		0.59	<0.001
Self-care management	0.38	0.050	0.59	<0.001	–	
Age	–0.41	0.012	–0.28	0.098	–0.02	0.913
Years with COPD	0.25	0.137	0.06	0.737	–0.18	0.362
Symptom impact (CAT)	0.28	0.094	0.26	0.114	0.12	0.537
Other chronic conditions	–0.10	0.544	–0.07	0.687	–0.17	0.401
Self-efficacy	0.39	0.017	0.71	<0.001	0.42	0.030
Depression (PHQ-9)	–0.15	0.368	–0.04	0.818	–0.08	0.703
Anxiety (GAD-7)	–0.15	0.375	0.04	0.803	–0.76	0.707

Note. Means in a column with different superscript letter are significantly different at  $p \leq 0.05$  level.

SD: Standard Deviation, mMRC: modified Medical Research Council, COPD: Chronic Obstructive Pulmonary Disease, GOLD: Global Initiative for Chronic Obstructive Lung Disease, CAT: COPD Assessment Test, PHQ-9: 9-item Patient Health Questionnaire, GAD-7: 7-item Generalized Anxiety Disorder.

\* 0–100 scale range score.

(Supplementary Table S2). Most participants reported performing several activities to maintain disease stability and monitor and manage symptoms, but a few reported not performing any self-care activities. For example, one participant stated that she did not perform any self-care for COPD prior to hospital admission for exacerbation, as the kidney transplantation she underwent led physicians and the same patient to underestimate the severity of COPD (P13). Four participants struggled to quit smoking, and several attempts to quit smoking were unsuccessful, causing frustration and anger. Additionally, some participants reported that they did not practice respiratory exercises even if they knew how to do them and did not properly manage medications as they modified doses and frequencies. The presence of other chronic conditions challenges patients in recognizing symptoms related to COPD (P24).

### Integration of quantitative and qualitative data

When analyzing and comparing the scores of self-care maintenance, monitoring and management across patients, we observed different levels of self-care performance (see Supplementary Table S3). We identified as cases patients who scored high and low in the three self-care dimensions, employing a positive and negative deviance approach. We integrated quantitative and qualitative data from the paradigmatic cases with high ( $n = 4$ ) and low self-care ( $n = 3$ ) scores on all scales to determine differences and similarities (Table 3). An examination of the quantitative results revealed that the four participants with high self-care presented high self-efficacy, while the three participants with low self-care presented low self-efficacy. The four participants with high self-care differed among them in terms of disease severity and level of psychological distress, as two participants presented moderate symptoms of COPD measured by the ABE assessment

**Table 3**  
Integration of qualitative and quantitative data in cases.

Cases	High self-care - Proactive style		High self-care - Reactive style		Low self-care - Hypoactive style		Low self-care - Inactive style
Participant	P29	P03	P33	P35	P10	P13	P4
<b>Personal factors</b>	Age:68; female Education: high school	Age: 76; male Education: elementary school	Age: 62; female Education: high school	Age: 73; male Education: middle school	Age: 75; female Education: middle school	Age: 67; female Education: high school	Age: 74; male Education: middle school
<b>Clinical factors</b>	Disease severity: B COPD diagnosis: 7 yrs Oxygen therapy: no N. chronic conditions: 1	Disease severity: B COPD diagnosis: 13 yrs Oxygen therapy: no N.chronic conditions: 4	Disease severity: E COPD diagnosis: 5 yrs Oxygen therapy: no N.chronic conditions: 1	Disease severity: E COPD diagnosis: 37 yrs Oxygen therapy: yes N.chronic conditions: 5	Disease severity: E COPD diagnosis: 13 yrs Oxygen therapy: no N.Chronic diseases: 3	Disease severity: E COPD diagnosis: 4 yrs Oxygen therapy: no N. chronic diseases: 4	Disease severity: A COPD diagnosis: 6 yrs Oxygen therapy: no N.chronic diseases: 1
<b>Psychological factors</b>	SCES: 92.9 PHQ-9: 2 GAD-7: 4	SCES: 85.7 PHQ-9: 5 GAD-7: 7	SCES: 92.9 PHQ-9: 23 GAD-7: 17	SCES: 92.9 PHQ-9: 10 GAD-7: 9	SCES: 28.6 PHQ-9: 17 GAD-7: 11	SCES: 25.0 PHQ-9: 20 GAD-7: 14	SCES: 35.7 PHQ-9: 3 GAD-7: 1
<b>Social factors</b>	Income: more than needed	Income: enough for living	Income: less than needed	Income: enough for living	Income: less than needed	Income: enough for living	Income: enough for living
<b>Self-care scales</b>	Maintenance: 94.2 Monitoring: 83.3 Management: 83.3	Maintenance: 90.4 Monitoring: 100.0 Management: -	Maintenance: 71.2 Monitoring: 100.0 Management: 77.5	Maintenance: 76.9 Monitoring: 100.0 Management: 77.5	Maintenance: 25.0 Monitoring: 12.5 Management: 27.5	Maintenance: 23.1 Monitoring: 12.5 Management: 10.0	Maintenance: 23.1 Monitoring: 9.4 Management: -
<b>Comments to transcripts &amp; quotations</b>							
<b>Self-care maintenance category</b>	<ul style="list-style-type: none"> <li>– She regularly goes to visit a pulmonologist and do checkups.</li> <li>– She regularly takes the prescribed medication (bronchodilators) and knows the medicines and their dosages.</li> <li>– She regularly performs physical activities, including yoga, pilates, and long walks on the beach, and performs daily breath exercises.</li> <li>– She follows a healthy diet.</li> <li>– She stopped smoking at the time of the diagnosis.</li> <li>– She decided to spend the winters abroad at the seaside, in a place with a dry climate to avoid lung infections: "Since I no longer spend the winters in Italy, I have never had bronchitis".</li> <li>– She uses the airport assistance service during the flight to avoid overexertion: "I was so scared at airports that this year I solved it by asking the airline for assistance when booking, and it went very well, without stress, without fear of not making it, without anxiety!".</li> <li>– She is socially active and regularly meets her friends.</li> <li>– She has a positive attitude toward life and desires to</li> </ul>	<ul style="list-style-type: none"> <li>– He does regular visits to the pulmonologist.</li> <li>– He changed pulmonary services until finding the best for him: "I first went to X [an old pulmonary service], then they closed, and sent me to hospital Y; they were not satisfactory there and I moved here [referring to the hospital where he is in outpatient care]. I see that here things are much better".</li> <li>– The participant quit smoking promptly after having the diagnosis.</li> <li>– He has learnt to regulate his physical activities to prevent breathlessness: "If I have to go to take the bus and I have to run, it's better that I don't do it because I get out of breath... So I walk slowly, inhale and throw out".</li> <li>– He maintains a social life regularly meeting his friends.</li> <li>– He lives alone and does the housework by himself, regulating his efforts: "I cook myself, I wash the floor; it's not that I make an effort, I slowly clean everything, furniture and everything".</li> </ul>	<ul style="list-style-type: none"> <li>– She is being treated by a pulmonologist she trusts: "After various exacerbations I met a very good pulmonologist who is accompanying me on my journey".</li> </ul>	<ul style="list-style-type: none"> <li>– He has been affected by COPD for many years, he refers to a pulmonary service and has been in oxygen therapy for 6 years after having several exacerbations: "COPD was diagnosed in 1980 at the X hospital in Rome; then I had exacerbations in 2001, 2013, 2017. Since 2003, I have been treated at the pulmonary service of the city Y and then at the hospital's pulmonary service of Z. From 2013, I got worse and had three hospitalizations for exacerbations. I am now at peak disease with emphysema and chronic pulmonary disease".</li> <li>– He recognizes the importance of living in an environment with good air quality and dry climate; for this reason during the summer he moves to the beach: "This year I rented a house to the beach, and I must say that despite the fact that it was very hot it was fine because it was very windy and there were other people in oxygen therapy who could do</li> </ul>	<ul style="list-style-type: none"> <li>– She did not attend a pulmonary service, and was on prescribed GP medications, prior to admission to rehabilitation unit where she was interviewed: "I've had this problem for a few years now, and I have a inhaler. The GP told me to take it twice in the morning and once in the evening, this opened my breath and allowed me to sleep".</li> <li>– She continues to smoke even though she knows it's bad for her lungs and has tried several times to quit: "I'm not angry with the disease, but with myself, because I am here [in a rehabilitation unit]. I had surgery 9 times, and 9 times I quit smoking and then I started again, I couldn't make it!".</li> <li>– She felt frustrated by the changes that the disease caused in her life: "It [COPD] makes me feel fragile, the disease makes me feel that I'm not what I used to be, that I need help, so much that where I live now, the house is big,</li> </ul>	<ul style="list-style-type: none"> <li>– She was affected by chronic kidney failure and was in dialysis for many years before having a kidney transplant. She had the COPD diagnosis a few years before, but she knew very little about it: "I didn't do anything for COPD, but I had the transplant on December 1st. After Christmas I went to the ER because I couldn't breathe, I was there all day".</li> <li>– She followed the medical instructions, but they didn't help her much: "I don't have phlegm, but I have a dry cough, and it was extremely difficult for me to cough; when I got sick, I used some aerosols, but I didn't find much help".</li> </ul>	<ul style="list-style-type: none"> <li>– He attends a pulmonary service, but he is non-adherent to the prescribed treatment: "Last summer I was prescribed the treatment I'm taking now, the drugs X and Y. Instead of taking them twice a day, one month I stopped them completely, another couple of months I only took them once a day because I felt better. Well, when I came to the checkup the pulmonologist asked me how come I was worse than the last time?".</li> <li>– He does not attribute the treatment's positive effects on his health: "I feel a hundred thousand times better today than when I started taking the treatment and stopped smoking... and this is a positive fact that I feel better without taking practically anything".</li> <li>– He believes that the strategy to cope with the disease is to ignore it: "The best thing is not even to think about it".</li> </ul>

(continued on next page)

Table 3 (continued)

Cases	High self-care - Proactive style		High self-care - Reactive style		Low self-care - Hypoactive style		Low self-care - Inactive style
Participant	P29	P03	P33	P35	P10	P13	P4
	<p>keep control of her life: "Life is mine, and I must love myself much more! I stopped always putting others ahead. I will overcome [the disease] great!".</p> <p>– She decides to combat the disease limitation: "I try to fight to the end; my freedom is everything to me!".</p>	<p>– He has accepted his disease without anger: "I don't feel any anger, it's something that has come, and I have to keep it and I have to live with it, there is nothing else to do. No one takes it away from me and well, let's just hope that something is found to be able to live longer".</p> <p>– He believes that maintaining a normal sexual life is important for his well being.</p> <p>– He knows his diseases and recognizes the limitations imposed by the disease: "I would like to play with my grandchildren, but I can't. Of course, I'm sorry I can't hold them..".</p>		<p>without oxygen there at the beach".</p>	<p>It came to me instinctively to tell my son, look for a nursing home for me, so I can stay calm there, 1 year, 2 years, 10 years, I don't know".</p>		
<b>Self-care monitoring category</b>	<p>– She monitors the increase of dyspnea.</p>	<p>– He monitors the oxygen saturation weekly at the pharmacy and at the GP office.</p> <p>– He monitors during the day the fluctuation of the symptoms: "I have noticed one thing, that walking is worse in the morning, in the evening, walking is easier".</p>		<p>– He knows the clinical manifestations of exacerbations, such as loss of appetite, fatigue, increased phlegm, shortness of breath, which he monitors.</p>			<p>– He is not very aware of the COPD symptoms and the disease long-term consequences: "From time to time in the morning I feel a little breathless, I don't get to the point that I have to stop, I feel a little breathless, but I keep walking and then it all settles down by itself without doing anything".</p>
<b>Self-care management category</b>	<p>– She takes extra medications when the symptoms worsen.</p>	<p>– He manages his dyspnea by reducing physical efforts and using breathing techniques: "If I do something and I feel out of breath, I stop and after a minute I start again. Before I did it continuously, but now I had to take my breaks and go on".</p>	<p>– She contacts her pulmonologist when she has symptoms due to the elevated carbon dioxide level.</p>		<p>– She follows the instructions given by her GP to manage the disease, although not always with effective results: "GP occasionally gave me antibiotics to free up my lungs. In fact, when I went to the hospital, I had started taking antibiotics and probiotics. But that morning there, my son saw how I was and called the ambulance".</p>	<p>– Nephrologists underestimated her lung disease: "I went to the transplant center, "yes, I'll give you a box of antibiotics" [quoting the nephrologist's words]. They told me I had nothing. But they did the x-rays, they looked at me. I was fine with the antibiotics for 2 days, but I was terrified, believe me... because I wasn't breathing (...) And look, I went on for more than 20 days, and they got me by the hair (...) There were seven of them [physicians], but they never acknowledged that it was for that".</p>	

P: patient; COPD: Chronic Obstructive Pulmonary Disease; SCES: Self-care Self-efficacy scale, score 0–100; PHQ-9: 9-item Patient Health Questionnaire, score 0–27; GAD-7: 7-item Generalized Anxiety Disorder, score 0–21; GP: general practitioner.

tool (Class B) and low psychological distress, measured by the GAD-7 and PHQ-9 (P03, P29), and two participants presented very severe symptoms (class E) and moderate-severe psychological distress (P33, P35). Furthermore, the three participants with low self-care differed in terms of the severity of the disease and psychological distress, with two participants (P10, P13) having very severe symptoms (class E) and psychological distress and one (P04) having moderate symptoms (class B) and no psychological distress.

Based on these differences, we divided our patients into the following groups: 1) high self-care and self-efficacy and moderate COPD and psychological distress; 2) high self-care and self-efficacy on all scales and severe COPD and emotional distress; 3) low self-care and self-efficacy and severe COPD; and 4) low self-care and self-efficacy and moderate COPD. Next, we compared the qualitative accounts of the participants within cases and between cases to determine differences in their experiences and possible explanations for their different self-care styles (Table 3).

Analysis of the qualitative accounts of the two participants (P03, P29), who scored high on all self-care scales and on the self-efficacy scale and who had moderate symptoms and low psychological distress, revealed that they regularly attended a pneumology clinic and followed prescribed treatments. They regularly performed self-care maintenance behaviors, including maintaining a social life, doing physical exercise, regulating their physical activities to prevent dyspnea and choosing to move to places where the environment was optimal to prevent lung problems: "Since I no longer spend winters in Italy, I have never had bronchitis" (P29). They highly valued their health and wanted to live an active life despite limitations of the disease, as one participant stated: "Life is mine, and I must love myself much more! I stopped always putting others ahead. I will successfully overcome the disease!" (P29). They reported monitoring their symptoms and managing the symptoms when needed: "If I do something and I feel out of breath, I stop, and after a minute, I start over. Before I did it continuously, but now I have to take my breaks and go on" (P03). Based on their active behaviors toward the disease and acting before complications arise, we defined these participants as proactive in their self-care.

The two participants (P33, P35), who presented high self-care and self-efficacy, severe disease, and psychological distress, reported in the interviews that they trusted their HCPs and pulmonologists and followed their prescriptions: "After various exacerbations, I met a very good pulmonologist who is with me on my journey" (P33). They knew the clinical manifestations of the disease, which they learned after experiencing several exacerbations; they monitored them and referred to the HCP when needed. Since participants performed self-care activities to respond to the clinical manifestations of their disease, we defined these participants as reactive in their self-care.

In their accounts, the two participants (P10, P13) with low self-care and self-efficacy and severe clinical conditions and psychological distress reported that they did not know much about COPD and were not referred to a pneumology clinic but were treated by physicians who underestimated the severity of the disease or focused on other health problems, with ineffective management of COPD exacerbations. They reported frustration and anger toward their disease and not being able to modify their unhealthy behaviors. "I'm not angry with the disease, but with myself, because I'm here [in a rehabilitation unit]; I was operated on 9 times, and 9 times I quit smoking and then I started again, I could not help it!" (P10). Due to the limited and ineffective self-care behaviors performed and to the underestimation of their lung problems, we defined these participants as hypoactive.

The participant (P4) with low self-care and self-efficacy, moderate disease severity and no psychological distress reported in the interview that he modified the treatments according to his beliefs and thought that the disease could be under control even though he did not take any action: "Last summer I was prescribed the treatment I'm taking now, the drugs X and Y. Instead of taking them twice a day, one month I stopped completely, another couple of months I only took them once a day because I

felt better. Well, when I came to the checkup, the pulmonologist asked me 'how come you are worse than last time?' (P4). In the absence of clinical manifestations, he reported that his strategy to cope with the disease was to ignore it. As this participant performed very little self-care and had no or mild symptoms, he was considered to be inactive.

Four different styles of self-care were identified according to the disease severity and the presence of symptoms, the level of psychological distress and the level of self-efficacy, suggesting that the identified factors may play a role in the level of self-care performance (Fig. 2).

## Discussion

We observed four distinct self-care styles when examining patients with high and low self-care levels in all self-care dimensions. Our findings underscore the variability in self-care styles among COPD patients, suggesting that differences in behaviors may be linked to specific patients' psychological and clinical characteristics. These insights could assist HCPs in recognizing diverse self-care practices among patients with COPD and consequently adapting educational interventions to meet their needs.

Exploring factors related to different levels of self-care of patients with COPD, we found that, among the three self-care dimensions, only self-care maintenance was negatively influenced by age, education level, and perceived economic status. We can hypothesize that people with low incomes and low educational levels could have access to fewer resources and less knowledge of the importance of lifestyle changes and prevention measures, such as quitting smoking.<sup>35</sup> Conversely, the factors considered in the present study did not explain low levels of self-monitoring and self-management. We can hypothesize that other personal, clinical, psychological, and social characteristics we did not consider could be associated with self-monitoring and self-management. Self-monitoring involves the general evaluation of multiple respiratory and extra respiratory signs and symptoms (such as dyspnea, oxygen levels, sputum, cough), requiring more specific skills than in other chronic diseases. For example, diabetic patients are trained to monitor their glucose levels by comparing daily observations with specific clinically defined cutoffs and varying insulin injections accordingly. In contrast, symptoms in COPD are not always easily identifiable, and treatments have a less obvious effect.<sup>36</sup> Moreover, when managing multiple conditions, patients with COPD can have difficulty recognizing which symptoms are related to COPD and are more concerned about interactions between medications, causing a breakdown in self-care for COPD patients.<sup>37</sup> Similarly, self-management entails the implementation of a group of behaviors that lead to effective decision-making and problem solving. The development of such behaviors over time can be facilitated through dedicated support, such as structured educational interventions and action plans.<sup>38</sup>

In our study, all self-care dimensions were correlated with each other and with self-efficacy. Self-efficacy has proven to be a strong predictor of self-care. Providing confidence in activating, performing and maintaining self-care behaviors despite difficulties is paramount to fostering adequate self-care.<sup>39</sup> This suggests the importance of evaluating and empowering patients' sense of control of the disease. Improving patient self-efficacy could decrease the economic burden of COPD and reduce health care costs.<sup>40</sup>

When considering participants with COPD with high and low self-care levels on all self-care dimensions, we hypothesized four styles of self-care that patients may adopt when dealing with COPD: proactive, reactive, hypoactive, and inactive.

In proactive self-care, patients assume a responsible role in managing their life and disease, taking all prescribed medications, and attending regular medical appointments. They are aware of the severity of their condition, and because of that, they recognize the importance of performing self-care behaviors to slow the progression of COPD and prevent exacerbations, such as quitting smoking, eating a healthy diet, and performing physical activity according to their functional status.



In reactive self-care, patients present worse clinical conditions and suffer from more symptoms, and these symptoms trigger self-care behaviors; they counteract changes in their health conditions and take the necessary actions to recover. They are confident in their ability to perform the necessary actions to treat their disease and adhere to treatments, and they are in moderate psychological distress.

In hypoactive self-care, patients struggle to perform self-care behaviors due to low self-efficacy and psychological distress. They seem to surrender to the disease and lack confidence in their ability to manage the disease. They do not believe that treatments and medications are effective and that their interactions with HCPs are not proficient.

In inactive self-care, patients are in good clinical condition, and they do not recognize the importance of following medical advice and prescribed therapy, as the disease is stable. They ignore symptoms when they occur, considering them temporary and not clues of a worsening condition.

These self-care styles were identified based on the characteristics and narratives from seven paradigmatic cases. Other 30 participants did not fit into these styles but showed varying combinations of self-care levels across the three self-care dimensions (e.g., low self-care maintenance, high self-care monitoring, medium [scores 31–69] self-care management; high self-care monitoring and medium maintenance and management). This highlights the broad variability in self-care behaviors among patients with COPD, which may be attributed to differences in

their ability to consistently perform determined self-care behaviors. Therefore, self-care behaviors can be seen as a continuum ranging from low to high, characterized by inconsistency in performance, as identified in other chronic diseases.<sup>41</sup> Several factors could influence their different levels of self-care performance, including personal factors, such as COPD-related knowledge,<sup>42</sup> level of education, and social resources such as access to healthcare services and healthcare professionals.<sup>43,44</sup> Further studies should investigate different self-care styles that patients may adopt when their performance varies across the three self-care dimensions and explore the underlying reasons.

*Implications for practice and research*

The results of our study may have significant implications for both clinical practice and research. Since psychological distress, disease severity, education level, age, economic status, and self-efficacy can all influence self-care behaviors, these factors should be considered when planning educational interventions. Our findings suggest that patients with COPD exhibit different self-care styles based on their specific personal and clinical characteristics. Tailored interventions that accommodate these self-care styles could facilitate the integration of self-care behaviors into daily life, enabling COPD patients to manage their condition more effectively.

The self-care styles identified in our mixed-methods case study

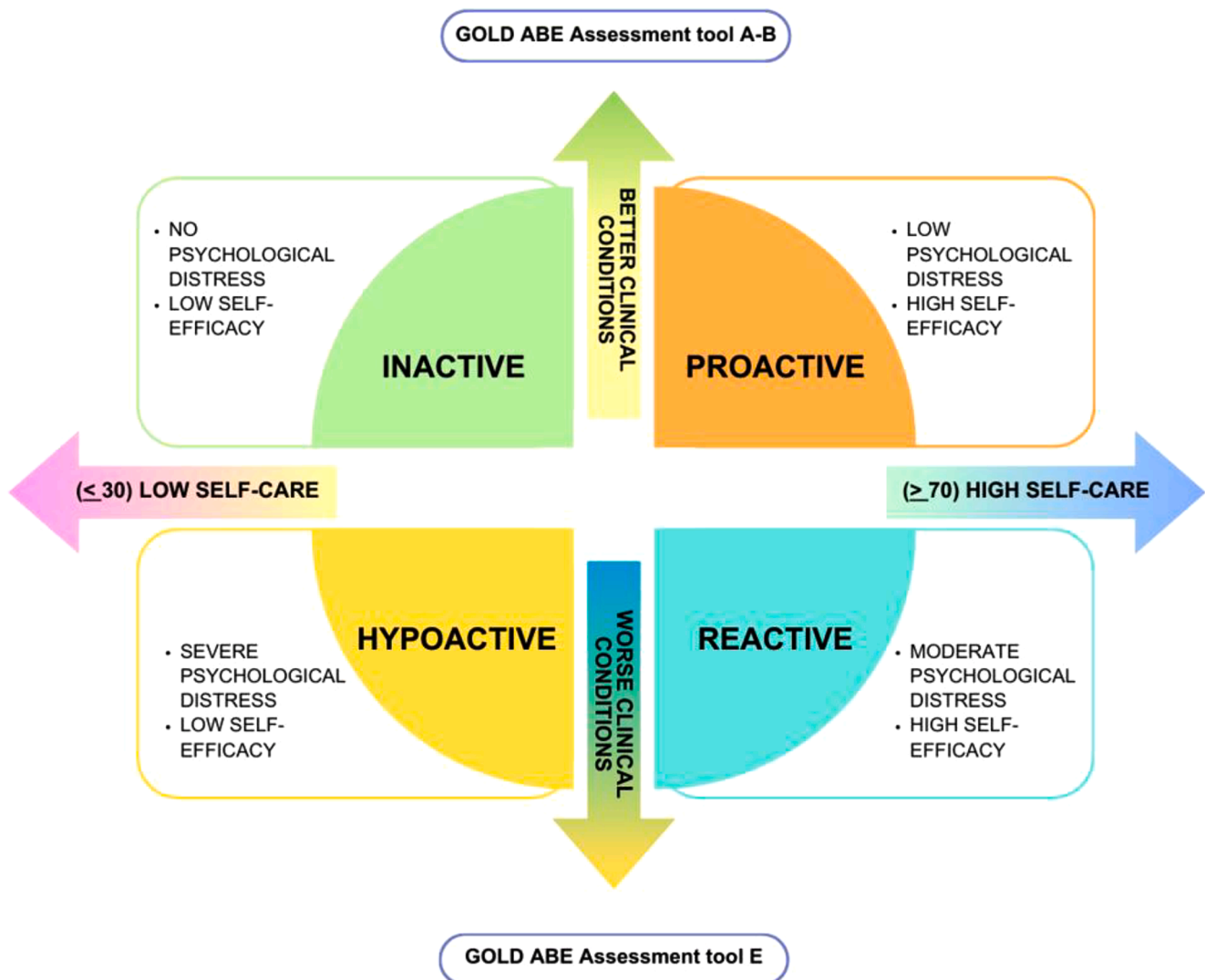


Fig. 2. Model representing the four self-care styles in COPD.

should be prospectively validated and refined in future quantitative research. Additional self-care styles may be discovered when analyzing larger datasets and considering patients who perform differently across the three self-care dimensions (e.g., high scores in self-care maintenance but low scores in self-care monitoring and management). Future research should also investigate whether factors beyond those considered in our study contribute to determining self-care styles and assess how these styles might change over time and under varying circumstances.

### Strengths and limitations

The main strength of this study lies in the mixed methods-case study design, which contributed to a deeper and nuanced understanding of the different self-care performance in COPD patients and possible influencing factors, providing a starting point for future research. One limitation of our study is the small sample included in the quantitative and qualitative analysis, which may have hindered the relation of further factors on performing high and low self-care. Moreover, we considered only a few personal, clinical, and psychosocial factors that could influence self-care. Other factors that we did not assess could have a relevant impact on self-care. Although we recruited a sample with different characteristics, we identified only a few cases for each style, reducing the possibility to have a full comprehension of the self-care styles in COPD. Therefore, the transferability of our results to other populations may be limited. Lastly, clinical data were obtained from medical records of COPD patients admitted to a healthcare institution, while data from patients recruited via social media groups were self-reported. It is important to acknowledge potential inaccuracies in the data reporting by these patients.

### Conclusions

Our mixed method-case study revealed that patients with COPD can adopt four different self-care styles when considering high and low levels of self-care maintenance, monitoring, and management: proactive, reactive, hypoactive, and inactive. These findings highlight that patients with COPD may engage in self-care behaviors in varied ways, which appear to be associated with specific factors. However, it is important to note that these findings are preliminary and exploratory in nature. Further studies are needed to validate and expand upon our results, exploring how these self-care styles manifest in larger and more diverse COPD populations and identifying further self-care styles adopted by patients with COPD. Our study highlights the variability of self-care practices among COPD patients and emphasizes the importance of personalized care strategies. Recognizing and addressing the different self-care styles could significantly enhance the effectiveness of educational interventions, ultimately improving patient health outcomes.

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### CRediT authorship contribution statement

**Marco Clari:** Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – Original draft. **Federica Riva-Rovedda:** Investigation, Writing – Original draft. **Valerio Dimonte:** Validation, Writing – Review & Editing, Supervision. **Maria Matarese:** Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – Original draft, Supervision, Funding acquisition.

### Declaration of competing interest

The authors declare that they have no known competing financial

interests or personal relationships that could have appeared to influence the work reported in this paper.

### Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.hrtlung.2024.07.011.

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