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The Mind-Body-Breath Link During Oral Intake in Chronic Obstructive Pulmonary Disease: A Grounded Theory Analysis

Ting-fen Lin¹, Ph.D., CCC-SLP & Samantha Shune², Ph.D., CCC-SLP

¹ Department of Communicative Sciences and Deaf Studies, California State University, Fresno, 93740, USA

² Communication Disorders and Sciences Program, University of Oregon, 97403, USA

¹ tlin@csufresno.edu¹

Telephone: +1-559-278-2423

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1 **Abstract**

2 Both chronic obstructive pulmonary disease (COPD) and dysphagia can be complicated by
3 the shared physiological-psychoemotional manifestations of the conditions, such as anxiety
4 and respiratory dysfunction. Despite their shared comorbidities, clinical research and
5 management often focus on the isolated physiological impairments of each condition
6 separately. Crucially, the oral intake experience of individuals with COPD — central for
7 improved quality of life — remains underexplored. Thus, the purpose of this study was to
8 understand the oral intake experience among individuals with COPD, including perceived
9 barriers, behaviors, and emotions. Fourteen individuals with COPD (mean age 68.9; 7
10 females; 2 with diagnosed dysphagia) participated. Using grounded theory methodology,
11 semi-structured interviews were conducted and analyzed. Four themes surfaced: (a)
12 Participants experience physiological manifestations of COPD (dyspnea, coughing) during
13 eating/drinking; (b) Emotions related to eating/drinking, such as concern, fear, anxiety, panic,
14 and frustration stem from the physiological manifestations; (c) These emotions worsen the
15 physiological manifestations; and (d) As a result of the physiological manifestations, they
16 adapt eating/drinking behaviors (e.g., choose easier-to-eat foods, reduce intake size). The
17 theory ‘the mind-body-breath feedback and feedforward loops as a contributor to the oral
18 intake experience in individuals with COPD’ is subsequently proposed. Of clinical
19 importance, many participants did not recognize their swallowing status as an issue.
20 Ultimately, to promote patient-centered care, we need to view the oral intake experience for
21 individuals with COPD through a more comprehensive lens that incorporates the
22 interrelationships between the physiological and psychoemotional manifestations of COPD
23 and better educate patients on COPD’s impact on eating and drinking.
24
25 **Keywords:** chronic obstructive pulmonary disease; dyspnea; dysphagia; lived experience;
26 person-centered care; quality of life

27 **Introduction**

28 Chronic obstructive pulmonary disease (COPD) is a life-threatening lung disease,
29 characterized by chronic obstruction in lung airflow. It is projected to be the third-leading
30 cause of death and among the top ten causes of disease burden by 2030 [1]. In 2010, an
31 estimated \$36 billion in national medical costs were attributed to COPD and its sequelae [2]
32 — a number projected to rise. Markedly, in light of the increasing prevalence and strong
33 association with dysphagia [3–5], COPD is a disease of growing concern for speech-language
34 pathologists and related healthcare professionals.

35 Most fundamentally, COPD is a physiologically-based disease, that results in
36 progressively worsening dyspnea, initially on exertion and later at rest as well [6]. Yet,
37 despite COPD being a physiological condition, its sequelae also encompass significant
38 physiology-rooted psychoemotional consequences such as anxiety and depression [7, 8]. In
39 fact, the prevalence of anxiety can be as high as 100% and depression 79.1% in this
40 population [9]. Unfortunately, these psychoemotional consequences can lead to a downward
41 spiral of the disease, including increased frequency of exacerbations and hospital admissions
42 or readmissions, resulting in increased economic burden and decreased quality of life [2, 10,
43 11]. Thus, COPD not only increases the risk of psychoemotional consequences such as
44 anxiety and depression, but the by-products, in turn, contribute to deteriorating clinical
45 outcomes.

46 Among individuals with COPD, the exact prevalence of oropharyngeal dysphagia has
47 not yet been documented [12]. However, the swallowing function of individuals with stable
48 COPD suggests consistent patterns of impaired physiology [13], and COPD is a risk factor
49 for aspiration pneumonia [14]. The essential coordination between breathing and swallowing
50 can be disrupted in the presence of even stable COPD [3, 15, 16], characterized by an
51 increased presence of inspiration before the swallow [17], in contrast with the commonly
52 seen expiration-swallow-expiration in healthy individuals [18]. Further, both stable and

53 exacerbated COPD states are associated with increased respiratory rate [15], which, along
54 with lower oxygen saturations at baseline, are associated with resultant penetration or
55 aspiration. COPD exacerbations are also linked to dysphagia in a more cyclical manner:
56 when an individual's swallow response is impaired, they are at increased risk for
57 exacerbation; and when an individual undergoes acute exacerbation, they are more likely to
58 exhibit an impaired swallow reflex [19–21]. The thoracic and abdominal respiratory
59 biomechanics as well as pulmonary hyperinflation are also key in protecting the lungs from
60 airway invasion [19]. Issues with pulmonary functions during swallow are significantly more
61 common in individuals with COPD than in healthy individuals [22]. Additionally, a plethora
62 of oropharyngeal swallow impairments have also been characterized in individuals with
63 COPD that contribute to decreased swallow efficiency and safety. These can include reduced
64 lingual control and movement, reduced laryngeal elevation and laryngeal vestibule closure,
65 reduced pharyngeal constriction, decreased laryngopharyngeal sensitivity, an abnormal
66 swallow reflex, cricopharyngeal dysfunction, esophageal motility disorders, and
67 gastroesophageal reflux disease [13, 20, 21]. Thus, the physiological disruptions associated
68 with COPD negatively influence swallowing physiology, which can also further exacerbate
69 disease status.

70 In actuality, regardless of dysphagia diagnosis status, nearly all individuals with
71 COPD experience difficulties or alterations in the oral intake process. For example, when
72 comparing healthy respondents to those with COPD without a history of dysphagia treatment,
73 nearly 75% of the individuals with COPD reported experiencing breathing discomfort when
74 eating and drinking [23]. Of those experiencing breathing discomfort during oral intake, over
75 one third described the experience as occurring “often.” For these individuals, swallowing-
76 related dyspnea was manifested across different eating and drinking activities (e.g., eating a
77 large meal, drinking a full glass of water, eating a snack). This breathing discomfort also
78 resulted in behavioral changes for more than two thirds of the sample, such as alterations in

79 their eating habits (e.g., eating less, taking smaller bites) and breathing patterns (e.g., holding
80 breath when swallowing).

81 Similar to COPD, dysphagia is not only linked to physiological impairments as it is
82 also commonly associated with psychoemotional burden. Individuals with dysphagia across
83 multiple populations have been found to present with anxiety and depressive symptoms [24].
84 Fear of choking, developing aspiration pneumonia, or dying is present in individuals with
85 dysphagia [25, 26]. Dysphagia can also lead to social isolation in work-related activities [27].
86 Overall, for individuals with dysphagia, the experience of living is often impacted broadly
87 and negatively, especially in the psychoemotional realm [28–31]. Further, psychoemotional
88 burden (i.e., anxiety, depression) can influence treatment adherence, compliance, and
89 swallowing outcomes [32] and even enhance somatic complaints [33]. In fact, despite
90 improved swallowing function, patients' perception of improved quality of life can be more
91 limited [34]. Therefore, as we target our clinical practices on the evaluation and rehabilitation
92 of swallowing impairment, it appears equally essential to consider the psychoemotional
93 factors in management.

94 Both dysphagia and COPD-related dyspnea negatively influence the broader
95 psychoemotional oral intake experience, operationally defined as eating and/or drinking.
96 Previous dysphagia research among individuals with head-and-neck cancer and neurologic
97 populations has highlighted the logistical (e.g., meal preparation) and psychoemotional (e.g.
98 social connection) impacts of swallowing difficulties on oral intake [35]. A growing body of
99 literature on individuals with COPD has described the physiological components of
100 dysphagia [13, 36], with a recent review proposing the interwoven relationship between the
101 mind, body, and breath in COPD and dysphagia [37]. However, the empirical research has
102 not yet explored the psychoemotional factors, including both contributors to and
103 consequences of COPD-related dysphagia, which would offer support for a model of these
104 proposed relationships. Further, the work to date has not examined how individuals feel about

105 challenges surrounding COPD and oral intake. As such, there is a need to better understand
106 how the psychoemotional components of the disease may manifest during oral intake.
107 Ultimately, in order to best manage COPD-related eating and swallowing challenges, a more
108 comprehensive picture of the disease impact is needed since the broader oral intake
109 experience may play a role not only in the rating of severity but the guiding of management.
110 Thus, the purpose of this study was to understand the oral intake experience for individuals
111 with COPD, including swallowing-related barriers, behaviors, and emotions.

112 **Methods**

113 *Design*

114 In order to broadly explore the oral intake experiences of individuals with COPD, and
115 more comprehensively understand the interactions between breathing, eating, and swallowing
116 in COPD, a qualitative study design guided by grounded theory was employed [38]. This
117 methodology allows for the development of substantive theory related to a target
118 phenomenon — specifically here the oral intake experience — using systematic steps,
119 including breaking down the qualitative data into codes, organizing the codes into conceptual
120 categories, and linking the categories into a theory that explains the phenomenon being
121 studied [39]. Such a systematic and iterative approach to analysis allows for the discovery of
122 the participants' points of view and experiences and for the theory to develop directly from
123 the participant data itself. Grounded theory further ensures that subsequent interventions are
124 grounded in the theoretical and empirical conceptualization of the phenomenon, based on the
125 target population's own accounts, increasing ecological validity.

126 All study procedures were approved by the institutional review board at the
127 participating institution.

128 *Participants*

129 Fourteen community-dwelling individuals with COPD participated in the study, based
130 primarily in the Pacific Northwest ($M_{\text{age}} = 68.93$ years, $SD = 10.77$ years, range 49-88 years).

131 Seven of the participants were female-identifying and the majority of the sample was White,
132 non-Hispanic. Their COPD diagnoses ranged from 3.5 to 22 years prior to study participation
133 ($M = 10.54$ years, $SD = 5.66$ years). Two required additional oxygen through the nasal
134 cannula during the day (2.5 and 4 liters). In order to most broadly explore the influence of
135 COPD on oral intake, participation in the current study was not restricted based on dysphagia
136 status, and two participants had an existing dysphagia diagnosis per self-report. Participants
137 were recruited locally (community boards, state chapters of the American Lung Association,
138 pulmonologists' offices), online (the National Foundation of Swallowing Disorders,
139 ResearchMatch), and via word of mouth. All of the participants were fluent in English.
140 Exclusion criteria included the presence of neurological disorders, head-and-neck cancer,
141 tracheostomy tubes, naso-gastric feeding tubes, active pulmonary infections, exacerbated
142 COPD, cardiac ischemia, major psychiatric disorders, and/or congestive heart failure. All
143 participants were offered \$20 compensation. Table 1 presents the participant demographic
144 information.

145 <<Insert Table 1 here>>

146 ***Data Collection***

147 Data collection for local participants occurred in person either at the participants'
148 homes or at a university research lab, per their preference. Three individuals participated
149 remotely via videoconferencing. No apparent qualitative differences were noted between the
150 modes of participation. Participants engaged in a single semi-structured, one-on-one
151 interview lasting approximately 30-75 minutes. All interviews were audio- and video-
152 recorded for later analysis. Generative questions regarding the oral intake experience, eating-
153 related barriers, behaviors, and emotions guided the process. Employment of purposeful
154 open-ended questions facilitated a more diverse range of responses (see the Appendix for the
155 initial interview guide); tailored probes were utilized as needed. Consistent with grounded
156 theory methods, data collection and analysis were concurrent. As themes developed across

157 the interviews during data analysis, the interview questions were modified accordingly for
158 subsequent participants.

159 The principal researcher (XX; blinded for peer review) completed all of the
160 interviews. At the time of data collection, the researcher was a certified speech-language
161 pathologist and a doctoral student, who had over eight years of clinical experience working in
162 the healthcare setting. None of the participants knew the researcher prior to the initial
163 research recruitment contact. During data collection, the principal researcher took field notes
164 [40], which served as one of the primary data sources for analysis. Recorded discourse was
165 transcribed verbatim for both the participant and the researcher/interviewer. The transcription
166 process involved two stages: 1) transcription of utterances, audible sounds, and unintelligible
167 utterances by a first transcriber and 2) correction and finalization of the transcript during a
168 second pass by a second transcriber. Discussion between the first and second transcriber
169 occurred if needed to discuss, add, or correct any changes. Data collection continued until the
170 same patterns of response emerged and no new topics or themes were suggested in the data
171 generated by participants (i.e., theoretical saturation or sufficiency) [38, 41].

172 *Data Analysis*

173 The researcher and two teams of research assistants comprised the data analysis team.
174 Given different time points of data collection, the first analysis team of six worked on the
175 initial eight interviews, and the second analysis team of four worked on the latter six. Data
176 analysis was guided by grounded theory methods. The field notes and verbatim transcripts
177 served as the initial primary sources of data. We first engaged in memo writing and open
178 coding through line-by-line analysis of the written data [38]. As the emerging ideas continued
179 to develop during the analysis process, we merged related concepts into categories and
180 continued to revise the categories, reanalyzing the data in an iterative manner. Each transcript
181 was read and/or coded by at least two independent research assistants. In situations where
182 there were differences in how the codes or categories were assigned or interpreted, we

183 engaged in open discussion, promoting the creation of a shared interpretation of the data.
184 Additionally, discussions among the research team took place regularly to ensure an accurate
185 representation of participants' oral intake perceptions. During the analysis process, the team
186 also identified quotations that exemplified the emerging central theory and related categories;
187 these quotations are presented in the results below. Finally, while generally not a component
188 of grounded theory, in order to offer insight into the relative prevalence of each theme and to
189 help guide clinical practice, the frequency of themes was calculated. All data analysis was
190 completed manually using Microsoft Word and Excel.

191 Data fidelity was ensured by the research team receiving the same training and by
192 completing the aforementioned steps among the research team. Employment of consistent
193 research team trainings, weekly peer debriefings, and a defined and documented step-by-step
194 process of data collection and analysis all aimed to promote dependability and
195 trustworthiness of the findings [42]. Additionally, member checking is a process to confirm
196 the accuracy of the information with participants in order to ensure credibility and increase
197 trustworthiness [38]. This helped ensure the researcher's interpretation remained truthful to
198 the participants' perceptions. Six out of the fourteen participants (43%) replied to the request
199 for feedback, by either confirming and/or updating the transcription (e.g., clarifying
200 statements). As the theory emerged during data collection and analysis, a draft of the
201 theoretical framework was also cross-checked with subsequent participants during the
202 interviews. Data accuracy was further addressed throughout the interviews through the use of
203 reflective listening and summarizing techniques.

204 **Results**

205 As extracted from the interviews, COPD's physiological manifestations during oral
206 intake are cyclically interrelated with emotional reactions, even in the absence of diagnosed
207 dysphagia. That is, COPD ultimately impacts the oral intake experience both physiologically
208 and emotionally, with the immediate physiological manifestations resulting in emotional

209 consequences, which further negatively influence the physiological manifestations. Namely,
210 the central theory that developed from the data was ‘the mind-body-breath feedback and
211 feedforward loops as a contributor to the oral intake experience in individuals with COPD’
212 (Figure 1). Participants not only acknowledged the ways that their bodies physiologically
213 responded during oral intake, but also how they then responded emotionally to those
214 physiological sensations. Consequently, the physiological-rooted emotions triggered more
215 physiological responses, thereby further interrupting the oral intake experience and
216 enjoyment — creating feedback and feedforward loops between the mind, body, and breath.

217 As two participants shared:

218 During your mealtime, you can potentially develop coughing or shortness of breath,
219 and these actions can lead to some negative emotions.... More of an anxiety but fear
220 would be there too because there again it’s disrupting my breathing. (P12)

221
222 [When I panic] it’s harder and harder [to breathe]. I start into the wheezing phase then
223 coughing. (P10)

224
225

<<Insert Figure 1 around here>>

226 Four interrelated categorical themes surfaced from the qualitative interview data that
227 illustrate the components involved in the feedback and feedforward loops and individuals’
228 responses to the oral intake experience (Figure 1): (a) physiological manifestations of COPD
229 emerge across oral intake experiences; (b) coughing and/or dyspnea trigger emotional
230 responses among individuals with COPD; (c) the emotional responses magnify the
231 physiological manifestations of COPD; and (d) individuals with COPD implement behavior
232 modifications to facilitate the oral intake process. The themes are described below, illustrated
233 by participants’ own words.

234 Firstly, most participants (85.71%) reported coughing and/or dyspnea during oral
235 intake that were linked to their COPD physiological responses. As one participant noted,
236 COPD symptoms of “more shortness of breath. And just, coughing” (P12) commonly occur
237 during oral intake. Participants reported:

238 Sometimes, you know, I'll have to cough and I'm in the process of swallowing at the
239 same time. And that creates problems because it gets stuff in my lungs. You know.
240 And I think that's most of the choking that I can recall is associated with coughing.
241 (P1)

242
243 If I'm just chugging water down I have to stop and catch my breath a little bit until I
244 can drink some more. (P5)

245
246 They shared that coughing often also occurs due to foreign materials (i.e., food/liquid)

247 irritating the airway, "Like a pea, a piece of rice, and sometimes I cough for hours trying to
248 cough it up" (P11). Participants recounted:

249 And the worst thing to strangle on is water. That is the worst type of strangulation
250 ever. (P9)

251
252 And I always drink it from the bottle. Because sometimes, by lifting a glass and
253 pouring it in, I'll accidentally pour a little too much and it'll choke me. (P11)

254
255 Not being able to swallow, sometimes feel like I'm choking. (P4)

256
257 [If I don't chew food well or am not conscious of food when swallowing] then [I]
258 swallow the wrong way. It goes down the, uh, the respiratory whatever. Uh. It goes
259 down the wrong way and I start to choke. (P6)

260
261 Often there was an inextricable link between COPD-related coughing and swallowing-related
262 coughing. For example, "I mean, just like now, that was kind of a COPD cough yet the
263 coughing starts after something is stuck in my throat" (P12). At times, participants seemed
264 surprised at the occurrence of these symptoms during eating, given their common association
265 with other daily activities. For example, Participant 9 noted that "I can strangle when I'm
266 eating and I'm not even talking sometimes." In fact, participants reported that coughing and
267 dyspnea can happen spontaneously during any form of oral intake (not just as related to full
268 mealtimes), as a result of a trigger from specific liquids or foods that they can identify, and/or
269 without any apparent cause:

270 So it doesn't only happen at meals. It will happen while I'm having a snack. I can
271 have a snack and get strangled... Some of the foods you eat can really bring about
272 shortness of breath... I had an episode of that yesterday where I coughed and
273 strangled and coughed and strangled. (P9)

274

275 The frequency, duration, and severity of coughing and dyspnea also varied: for some
276 participants these occur episodically, while for others, they occur more often and/or are
277 longer in duration. The symptoms can be so severe that they may require the individual to
278 completely stop all activity, greatly impacting and interrupting both the oral intake
279 experience as well as their nutritional intake. For example:

280 [Coughing] just stops my meal. It just stops it. I gotta stop all together and who knows
281 how long it will take before I can eat again. (P11)

282
283 If I get something caught in my throat, or in my tube, cause there's a tube, I have to
284 stop and process it through and then getting it out again. (P13)

285
286 If I'm just chugging water down I have to stop and catch my breath a little bit until I
287 can drink some more. (P5)

288
289 With shortness of breath I'd stop and try not to eat anything and catch my breath then
290 I'd eat. (P13)

291
292 Participants also described the clear toll that these COPD physiological manifestations bring,
293 particularly when coughing takes place in the context of eating:

294 That's very exhausting, to cough hard with COPD. It really wears you out fast. (P11)

295
296 Oh, for sure, immediately [when things go down wrong during mealtime and you start
297 coughing, the coughing can turn into more shortness of breath]. Within a minute.
298 Within a minute, yes. It's just full-blown deep coughing, hard coughing. (P11)

299
300 Well, [breathing gets] definitely worse because I'm coughing which is an anti-
301 breathing process and so I'm not getting- I'm not having control of my breathing. So
302 I'm not breathing well. (P12)

303
304 Secondly, many participants described a variety of negative emotions that can be
305 linked to oral intake (78.57%). These emotional manifestations serve dual roles, as
306 demonstrated in Figure 1, both as a by-product of physiological symptoms and as a
307 contributor to the increased physiological burden of the existing COPD symptoms.
308 Participants reported a wide range of emotions such as fear, anxiety, and frustration during
309 oral intake, often resulting from the coughing, choking, and/or dyspnea. Words related to the
310 concept of fear often emerged including "panic [when choking]" (P1) and a "tremendous
311 amount of fear associated with the choking" (P2). Often this fear and anxiety tied back to the

312 risk of airway compromise, or the severe consequences that the participants pictured as
313 potentially happening. As a number of participants shared:

314 If I choke, it cannot get out of my lung. I could die. And that frightens me. So I got a
315 lot of fear on that one. (P2)

316
317 More of an anxiety but fear would be there too because there again it's disrupting my
318 breathing. (P12)

319
320 Sometimes [the shortness of breath] scares me. Sometimes I'm- sometimes, not all the
321 time, I'm scared. And immediately I have to sit down and catch my- and do my
322 breathing exercises. Do you know the word claustrophobic? That is a good way of
323 explaining how I feel sometimes, like the walls are closing in and no place to go, you
324 know... Irritating. You know, I just don't like it [choking, coughing, hacking], and it
325 does take my breath away a lot and it could, I don't see how it could possibly be good
326 for me. (P13)

327
328 [When eating and I start coughing and choking] That's probably close to when you
329 may panic. When you get that feeling. Because it feels like you're not getting air and
330 then you got food or something caught in your- your esophagus I guess, that's- that's
331 probably close to a panic situation there... I tend not to go out to dinner much
332 anymore. I've never been much of a fast food person. I mean, foods that I used to
333 love, I can no longer eat. Scares me, I mean, you know. (P14)

334
335 For others, the coughing and dyspnea yielded concerns about others' perceptions of the
336 situation as well as clear disruptions to the enjoyment related to oral intake. These
337 participants described the experience as an "annoyance" (P6), as being "frustrating or
338 upsetting about eating" (P4), and that "it's embarrassing. I hate it; I absolutely hate it" (P11).
339 For some participants, these situations not only lead to emotions about the experience itself,
340 but also appeared to impact them more personally. For example:

341 [When liquids go down the wrong pipe, I feel] sometimes nauseous, sometimes kinda
342 stupid, frustrated. (P3)

343
344 Irritability and I'd say a little bit of sadness, you know, that I can't sit and enjoy a
345 meal and have that happen, you know. (P11)

346
347 Yeah but it's irritating and it can get- that Thick-It can get caught in my throat too
348 because it doesn't get mixed up sometimes. (P13)

349
350 [Coughing] interrupts [mealtime]. It can be a little tedious at times. And again,
351 embarrassment. (P4)

352
353 Other people get upset about my coughing. (P10)

354

355 In addition to these emotional responses being a result of the COPD symptoms,
356 participants also clearly articulated how these responses then fed back into their COPD
357 symptoms (theme three). Of the participants shown a schematic of Figure 1 as the interviews
358 evolved, 83.33% were in agreement regarding the relationship between mind, body, and
359 breath. Significantly, when these emotions manifested, participants reported a vicious cycle
360 of “anxiety-dyspnea-anxiety” [43]. That is, the negative emotions, like concern, panic, worry,
361 and anxiety, in turn contributed to worsening breathing function (e.g., “[when concerned] I
362 will pant” (P9)), which further impacted their oral intake experience and added an additional
363 load to their baseline COPD symptoms. As participants clearly illustrated:

364 I think that when you resist it [strangling/coughing/can’t breathe] and you panic, and
365 you worry, I think it escalates it. (P9)

366
367 [When undergoing panic attacks during oral intake], most of the time [my breathing]
368 gets worse. It’s harder for me to breath. (P14)

369
370 [After reading Figure 1] think that information is correct. (P14)

371
372 The fourth theme encompassed the behavioral modifications, or adaptations during oral
373 intake, that all participants (100%) developed in response to and to help cope with the
374 physiological manifestations of COPD. These behavioral changes can be sub-categorized into
375 food choices/avoidances, intake sizes, pacing, and other strategies (e.g., modifying process of
376 food preparations). First, participants reported being conscientious about their food choices.
377 They often picked soft foods and knew which foods they needed to personally avoid to
378 promote airway protection “‘cause I know I’ll strangle” (P9) and “I am conscious of what
379 could happen” (P11). This occurred even in participants who did not have a diagnosis of
380 dysphagia. For example:

381 I’ll even go so far as to make it into a smoothie in the blender so I’m eating softer
382 foods that I wouldn’t tend to choke on. (P12)

383
384 On the smaller particles such as rice or orzo or pasta, things like that, I will make it
385 into a more – a lot of sauce like soup so that it goes down quickly. (P12)

386

387 Maybe a snack that's too light to pass my airway, like a chip or something. Something
388 I stay away from, 'cause I know I'll strangle. (P9)

389
390 Participants also reported being particularly mindful about taking small, well-chewed bites
391 and small, regulated sips. Similarly, participants were also aware of the rate of their intake,
392 being careful, slow, and conscious about the oral intake process because "if I'm not, uh, I'm
393 gonna choke myself" (P4). Participants shared:

394 Swallowing large objects is more difficult now than it used to be. Like large
395 medication or if I go with a bigger piece of meat. If it's not chewed up, it might be
396 more difficult to swallow than it used to be. (P3)

397
398 Sometimes with drinking a glass of water or a beverage, I have to stop more
399 frequently. I can't like gulp down a glass of water because it's like, I need to take a
400 breath. (P6)

401
402 I make it a point to chew my food really, really, really fine, you know, so it's not a
403 trigger [to strangle or coughing]... I can take large bites, but I chew them thoroughly.
404 I chew, chew, chew. (P9)

405
406 I'm consciously aware of my chewing and swallowing so I'm not choking on the food
407 or aspirated. (P6)

408
409 Participants finally described additional preventative and rescue strategies used during oral
410 intake. For prevention, one participant without diagnosed dysphagia described limiting intake
411 and using a chin tuck during eating and drinking:

412 I don't want to get too full because then it feels like I can't breathe... And then
413 sometimes, you know, I'll try to go with my head down for everything, you know,
414 and do everything at the slightest. (P2)

415
416 Others times, participants indicated that they needed to stop or pause during oral intake in
417 order to recover before attempting to eat again, if able to resume at all:

418 [When coughing turns into shortness of breath] for me I just have to stop eating. I'm
419 done. I can't eat. I got to get up and get away from the table. (P11)

420
421 I stop eating and I stop drinking and I'll stand up and then I'll try to do my pursed lips
422 breathing until it passes. (P9)

423
424 [Shortness of breath] makes me pause longer in between taking bites. Instead of eating,
425 I'll play with the food and just stir stuff up. (P4)

426

427 A final overarching sentiment emerged that, while not tied to a single theme, was
428 particularly relevant for considering patient management needs. It appeared as though many
429 of the individuals with COPD were not consciously aware of what they were experiencing,
430 until discussing these issues over the course of the interviews. This is of particular
431 significance in light of the fact that only two of the participants in the current study had a
432 diagnosis of dysphagia. Participants shared that patient education on swallowing while living
433 with COPD could help them understand the disease better. For example:

434 If you use this for your research, that you can give this information to people who
435 might not think of it. You know, that it might be helpful, that these things might help
436 you. (P2)

437
438 **Discussion**

439 This qualitative study explored the perceived barriers, behaviors, and emotions related
440 to eating and drinking among individuals with COPD in order to better understand the overall
441 oral intake experience of this population. Guided by grounded theory and based on the
442 participants' own words, our data revealed an overarching theory that the oral intake
443 experience for individuals with COPD is influenced by a mind-body-breath feedback and
444 feedforward loops, contributing to both physiological and emotional responses during intake.
445 The current study offers empirical support for the previously proposed model, suggesting that
446 mind, body, and breath are all integral and interrelated parts of a person's health in the
447 presence of COPD [37].

448 Participants reported dyspnea and coughing during oral intake, not surprising as these
449 are commonly reported symptoms of COPD across many activities of daily life [6, 23]. As
450 even healthy young individuals exhibit a stronger drive to breathe after taking sequential
451 drinks [44], this may explain, at least in part, why individuals with COPD are more prone to
452 inhale after a swallow [16]. Further, consistent with the previous literature, the participants
453 here reported that at times their COPD-related coughs were overlaid on top of oral intake

454 [23], while at other times coughs were triggered by swallowing itself, such as foreign
455 materials in the airway [4].

456 Interestingly, most participants also shared behavioral strategies used to optimize their
457 oral intake experience in light of these physiological responses, even though the majority of
458 participants did not have diagnosed dysphagia. These self-employed strategies targeted both
459 prevention of and recovery from the dyspnea and coughing. Some of these behaviors
460 included modifying food texture and bite size, pacing rate of eating, chewing well, and being
461 more mindful; one participant without diagnosed dysphagia even reported use of a chin tuck.
462 These findings are in line with previous literature that in order to alleviate breathing
463 discomfort, individuals with COPD make modifications, such as taking smaller bites, eating
464 less overall, avoiding walking while eating/drinking, and taking frequent breaks [23].

465 Of clear clinical importance, the participants often did not recognize their swallowing
466 status as an issue. Even though they reported needing to modify the way they eat, most
467 denied having problems with swallowing when explicitly asked prior to the study — a
468 mismatch between participants' perception and what they report as occurring [23, 45]. This
469 raises the concern that many individuals with COPD may not be consciously aware that the
470 symptoms they are experiencing are indeed an issue, which may be due to the chronic nature
471 of the disease that they acclimate to over time. If individuals with COPD do not recognize
472 these symptoms as concerning, they may not subsequently see the need to reach out for help
473 or report a problem, particularly when asked a broad question such as, "Do you experience
474 any difficulties with eating or swallowing?" Thus, dysphagia may be underdiagnosed among
475 individuals with COPD. Clinical education about the impacts of COPD on eating and
476 swallowing may be warranted to guarantee optimal service delivery. Relatedly, continued
477 exploration of the most sensitive screening tools to determine the need for further evaluation
478 is warranted. Our data also suggest that many individuals attempt to manage their oral intake
479 on their own without seeking assistance from medical professionals. However, these self-

480 developed strategies may be ineffective at mitigating the challenges they face during oral
481 intake, or potentially harmful, such as a broadly used chin tuck. Such a finding further
482 supports the need for early and consistent clinical management of dysphagia among
483 individuals with COPD.

484 Participants also reported a range of emotional responses related to oral intake, in line
485 with the broader dysphagia literature [24, 28, 29]. The individuals in the current study noted
486 feeling concerned, fearful, anxious, panicky, frustrated, embarrassed, and sad as related to
487 eating and drinking, even in the absence of a dysphagia diagnosis. Previous literature in
488 COPD has also indicated that negative affect can result in COPD exacerbations, hospital
489 (re)admissions, reduced quality of life, and increased economic burden [2, 10, 11]. While the
490 current study did not explore affect related to other daily activities, it is likely that the
491 emotional responses reported here contribute to the broader emotional distress that has been
492 suggested in the previous literature. Future work should address the unique contribution of
493 eating and drinking challenges to overall distress in this population.

494 Our bodily systems are interconnected — the breathing status can affect the state of
495 mind, and the mind can affect breathing status [46]. More specific to the COPD population,
496 negative affective states can amplify the perception of dyspnea, which may, in fact, worsen
497 symptoms [47]. This was echoed in participants' accounts of how the negative emotions
498 during oral intake that stemmed from the physiological symptoms also further impacted
499 dyspnea and coughing. The common affective burden of anxiety and depression in dysphagia
500 can also further somatic complaints, and individuals may perceive little change in their
501 quality of life despite improved swallowing outcomes [32–34]. This downward spiral of
502 dyspnea and coughing both leading to and worsening as a result of negative affect could
503 potentially further expose the airway to foreign materials during swallowing, jeopardizing the
504 already compromised pulmonary status. Significantly, while much of the previous literature
505 has focused on the physiological (e.g., aspiration, exacerbation) and/or emotional burden

506 (e.g., depression, anxiety, fear) as a consequence of the impairment (e.g., dysphagia, COPD),
507 our results reveal a more interwoven synergistic relationship between the mind, body, and
508 breath. While managing the impairments is crucial, utilizing a broader panoramic view that
509 considers the whole person can ultimately benefit the patient with COPD by preventing or
510 minimizing these cascading effects [37].

511 Based on the qualitative data here, we proposed the theory of ‘the mind-body-breath
512 feedback and feedforward loops as a contributor to the oral intake experience in individuals
513 with COPD’ (Figure 1). Even in the absence of a dysphagia diagnosis and/or self-reported
514 swallowing difficulty, COPD symptoms clearly manifest into physiological challenges
515 (body-breath) during oral intake, which lead to emotional responses (mind). These emotional
516 responses (mind) then further deteriorate the pre-existing dyspnea and coughing (body-
517 breath). Past research has suggested an intimate relation between dysphagia and COPD
518 exacerbation [19–21, 48]. In line with the previous synergistic review of dysphagia in COPD
519 [37], our theory suggests that the negative affect together with an impaired swallowing
520 mechanism creates a snowball effect that taxes the already weakened pulmonary system.

521 Yet, when individuals believe that they have increased cognitive or behavioral control
522 (e.g., over the dyspnea), the anxiety-dyspnea-anxiety cycle can be disrupted, manipulating
523 the mind-body-breath loop. For example, cognitive behavioral therapy has been demonstrated
524 to reduce dyspnea scores in individuals with COPD at six months [49]. Consequently, a less
525 anxious state can be achieved [50], allowing individuals with COPD to better stabilize and
526 reduce the dyspnea by modifying their affect. It also allows them to tolerate a greater degree
527 of dyspnea and carry out activities of daily living given increased pulmonary reserve [43].
528 This is especially crucial as individuals with COPD can differentiate the dyspnea itself
529 (physiological response) from their affective response to dyspnea [51]. Thus, it is necessary
530 to target the root of the perceived dyspnea symptoms, including the affective components.

531 ***Clinical Implications***

532 Of concern, even though 86% of the participants in our current study did not have a
533 dysphagia diagnosis, nearly all reported swallowing difficulties to some extent and the
534 utilization of behavioral adaptations during oral intake. Regular swallowing screening by
535 healthcare providers as a part of standard care can help identify at-risk individuals, allowing
536 for earlier intervention and a de-escalation of pulmonary consequences. Such a proactive,
537 rather than reactive, approach would also provide an opportunity to better capture the true
538 prevalence of dysphagia in COPD. Relatedly, enhanced patient and healthcare provider
539 education can result in increased awareness of potential difficulties with oral intake and can
540 contribute to minimizing potential comorbidities through increased referrals.

541 Addressing the psychoemotional burden (e.g., via ethnographic interviews) may also
542 be fruitful in stopping or mitigating further health-related consequences. Clinicians need to
543 understand the experience of dyspnea, especially in regards to how frightening and
544 debilitating it is. While past dysphagia research has largely focused on the physiology of the
545 swallowing mechanism, the perspective in this study aligns with the definition of health by
546 the World Health Organization (WHO), where health is “a state of complete physical, mental,
547 and social well-being and not merely the absence of disease or infirmity” [52]. This study
548 additionally adds to the rapidly growing body of literature about the lived experience of those
549 with eating or swallowing difficulties [28, 29]. This line of work is particularly important as
550 patient responses vary across intervention approaches based on personal factors, such as
551 patient preferences and motivation. Ultimately, the status quo in healthcare is pivoting from
552 disease-centered care to person-centered care in order to improve outcomes. Person-centered
553 care requires clinicians to first and foremost listen to our patients’ experiences in order to
554 understand their needs and wants, and it leads to improved outcomes, patient satisfaction, and
555 self-management [53]. It also shifts management foci from physiological in isolation toward
556 the inclusion of social, emotional, and psychological implications/consequences — or a more
557 comprehensive management approach. Such an approach mirrors the WHO’s framework

558 [54], that illustrates the interactions between impairment, activity limitations, participation
559 restrictions, and personal and environmental factors. Our data support the value of this
560 paradigm shift as the physiological manifestations of COPD lead to emotional changes,
561 which in turn, additionally burden the physiological manifestations.

562 ***Limitations***

563 The goal of this study was to better understand the perceived oral intake experience
564 most broadly across individuals with COPD. While the data revealed the appearance of oral
565 intake difficulties in individuals with and without dysphagia, the sample of participants with
566 dysphagia was small and their experiences may vary. The severity of participants' COPD and
567 their cognitive status were not characterized. COPD severity and cognitive impairments may
568 impact the eating and swallowing experience, and variability in these characteristics may not
569 have been represented in the current study. Given the age range of our participants, it is also
570 plausible that presbyphagia contributed to changes in the oral intake experience along with
571 the COPD. However, the symptoms reported here (e.g., dyspnea, coughing) are generally not
572 characteristic of typical age-related changes in swallow function. Additionally, while data
573 saturation was reached, the sample was relatively homogenous on a number of variables that
574 could impact the oral intake experience and healthcare management, including oxygen use,
575 race, and geographical location. Thus, future work should focus on validating the theory
576 presented here across a more heterogeneous group of participants, including further
577 exploration into the impact of dysphagia status, COPD severity, cognitive ability, and
578 participant demographics. Finally, given the fluidity of lab personnel across the project
579 timeline, it was unfortunately necessary to have two teams of research assistants be involved
580 in data analysis. However, given the steps taken to ensure fidelity and trustworthiness of the
581 data as discussed above, it is not expected that this altered the study's findings.

582 ***Conclusions***

583 The physiology of swallowing is one aspect of the complex network involved in

584 eating and drinking for individuals with COPD. Our results revealed that even individuals
585 without a diagnosis of dysphagia experience both physiological and emotional issues during
586 oral intake, resulting in self-prescribed modifications. Markedly, the negative emotions that
587 occur during oral intake appear to be both a consequence of and contributor to the
588 physiological ramifications, cyclically impacting pulmonary status. Thus, we proposed the
589 novel theory: ‘The mind-body-breath feedback and feedforward loops as a contributor to the
590 oral intake experience in individuals with COPD’. The shift toward person-centered care
591 compels clinicians to adopt a more integrative model to COPD management. The integration
592 of the lived patient experience within a more comprehensive approach to care can yield
593 meaningful and functional improvements in quality of life.

594 **Figure and Table Legends**

595 Figure 1. Graphical representation of the emerging theory: ‘The mind-body-breath feedback
596 and feedforward loops as a contributor to the oral intake experience in individuals with
597 COPD’

598

599 Table 1. Participant demographic information

600

601 Appendix. Initial interview guide

602

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772 and health
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775 Table 1.

776 *Participant demographic information*

<u>Participant</u>	<u>Age (years)</u>	<u>Race</u>	<u>Ethnicity</u>	<u>Gender</u>	<u>Geographical Region</u>	<u>Oxygen Use</u>	<u>Years Since COPD Diagnosis</u>	<u>Dysphagia Diagnosis</u>
P1	68	White	Non-Hispanic	M	Pacific Northwest	No	15	No
P2	70	White	Non-Hispanic	F	Pacific Northwest	No	8	No
P3	79	White	Non-Hispanic	M	Pacific Northwest	No	5	No
P4	52	White	Non-Hispanic	M	Pacific Northwest	No	6	No
P5	49	White	Non-Hispanic	F	Pacific Northwest	No	7	No
P6	56	White	Non-Hispanic	F	Pacific Northwest	No	3.5	No
P7	88	White	Non-Hispanic	F	Pacific Northwest	No	20	No
P8	76	White	Non-Hispanic	M	Pacific Northwest	No	6	No
P9	71	African American	Non-Hispanic	F	West	No	22	No
P10	73	White	Non-Hispanic	F	Pacific Northwest	No	13	No
P11	72	White	Non-Hispanic	M	Pacific Northwest	No	10	No
P12	74	White	Non-Hispanic	M	Pacific Northwest	2.5 liters via nasal cannula during the day	15	No
P13	75	White	Non-Hispanic	F	Pacific Northwest	4 liters via nasal cannula during the day	9	Yes

P14	62	African American	Non- Hispanic	M	Southeast	No	8	Yes
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777 *Note.* COPD = chronic obstructive pulmonary disease; F = female; M = male

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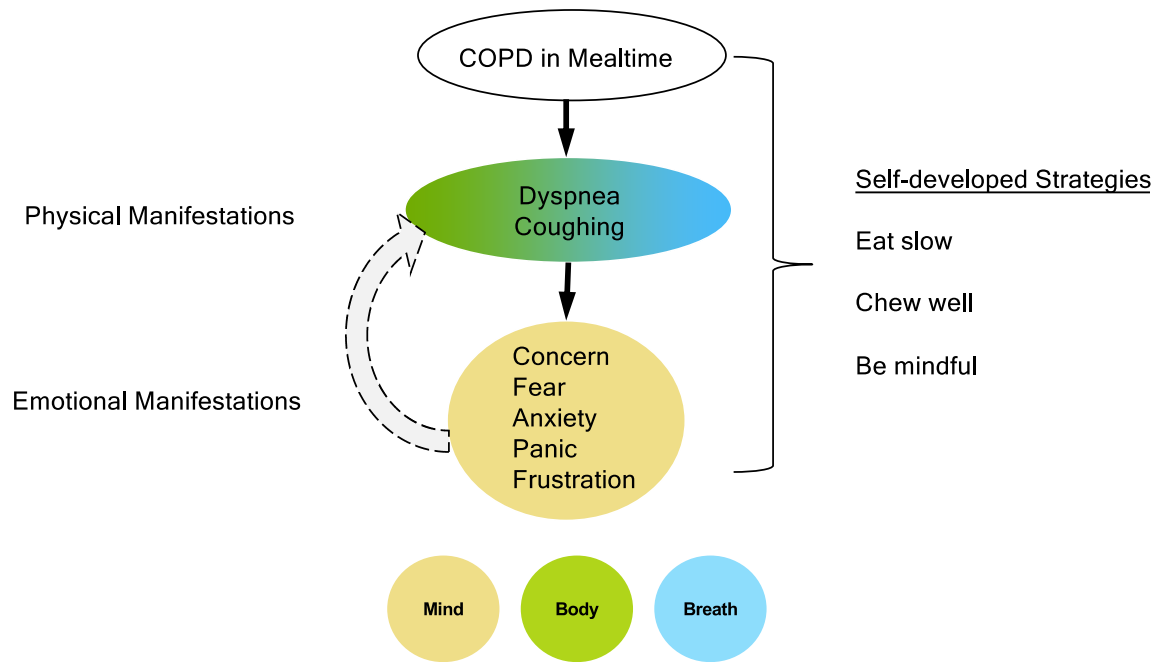
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Figure 1. The mind-body-breath feedback loop as a contributor to the oral intake experience in individuals with COPD. *Note:* The mind is represented in tan, body in green, and breath in blue.

797 Appendix

798 Interview guide of open-ended questions used during the interview.

- 799 1. When were you diagnosed with COPD?
- 800 2. Describe the onset of your COPD.
- 801 3. What were your feelings/thoughts when you first heard this diagnosis?
- 802 4. What action did you take in the first few days/weeks?
- 803 5. What do you know about your condition?
- 804 6. What symptoms are you currently dealing with?
- 805 7. How do these symptoms affect your activities of daily living?
- 806 8. How does climbing stairs or carrying heavy loads of grocery make you feel, for
- 807 example?
- 808 9. Thinking about those symptoms you just described, do you experience any of the
- 809 same during eating/drinking? How do the two activities compare?
- 810 10. What do you do when these symptoms come up during eating/drinking?
- 811 11. When these symptoms come up in the eating/drinking, how do they affect your
- 812 eating/drinking?
- 813 12. What do you do differently now during eating/drinking to avoid these symptoms
- 814 from coming up?
- 815 13. When the symptoms you mentioned earlier come up during eating/drinking, how
- 816 do you feel?
- 817 14. How does eating/drinking make you feel? What emotions do you associated with
- 818 eating/drinking?
- 819 15. Tell me about the types of food may be more difficult or easier to eat now.
- 820 16. How big or small of a bite size do you take?
- 821 17. How long does it take you to finish a meal?
- 822 18. Do you find yourself modifying the way you drink your liquids?

- 823 19. What do you do differently now before/after eating/drinking to avoid these
824 emotions or symptoms from coming up?
825 20. What does your typical meal look like?
826 21. What do you think of your overall swallowing?
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