

1 Article

# 2 The Salt without the Girl: Negotiating Embodied 3 Identity as an Agender Person with Cystic Fibrosis

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8 **Abstract:** In this manuscript, I build and expand on prior work by myself (Author 2016) and others  
9 exploring the dynamics of embodiment among people with chronic health conditions. Specifically, I  
10 critically investigate the intersecting social and medical elements of responses to bodies perceived as  
11 too thin and otherwise lacking in physical ability, using my own experiences of living and aging  
12 with cystic fibrosis (CF) as a case example. In these explorations, I center gendered identity and its  
13 intersection with disabling physical illness. I do so by using my own lived experiences as  
14 autoethnographic anchor points to guide critical review of key concepts from the nexus of these two  
15 content areas. I focus throughout on exploring how others' reactions to a frail-looking body often  
16 constitute a form of forced gendering via the narratives people attempt to construct for why a  
17 person's body appears that way. The title of the manuscript supports this framework by referencing  
18 three cornerstones of patient experience in the CF community: the general trend of patients having  
19 salty skin due to the pathology of the disease, a prior embodiment project called *Salty Girls*  
20 (Pettigrew 2012) that engages this idea, and the more abstract concept of "saltiness" in describing the  
21 grit marginalized people display in responding to microaggressions.

22 **Keywords:** Gender; Nonbinary; Cystic Fibrosis; Embodiment; Agender Identities; Identity  
23 Negotiation

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## 25 1. Introduction

26 As a medical sociologist, I spend a substantial amount of time studying the complexities of  
27 people's bodies, identities, and lives. Yet I can convey a plethora of important information about my  
28 own experience with two simple truths: I am agender, and I have cystic fibrosis. In this narrative, I  
29 will explore the intersection of these two defining elements of my personal biography in the context  
30 of embodiment—beginning with an explanation of what each term means.

31 Being agender basically means not having an intrinsic gender identity (Bosse & Chiodo  
32 2016). The specific ways in which people who identify as agender experience this phenomenon  
33 varies somewhat (Nicolazzo 2016). Yet being agender is generally understood as not seeing  
34 ourselves through a gendered lens, even though we may be very aware of the gendered ways in  
35 which others view us (Galupo et al. 2017). Agender identity is one of many ways of experiencing  
36 oneself outside of binary concepts of gender (Nicolazzo et al. 2016). In this regard, it is part of the  
37 general group of identities that "queer" gender (Richards et al. 2016). Some agender individuals may  
38 thus identify as genderqueer in certain social and political contexts (Nicolazzo et al. 2016).  
39 Genderqueer populations may also include, but are not limited to, people with the following  
40 identities: genderfluid, androgynous, or pangender (Galupo et al. 2014).

41           What sets agender identity apart from others in the genderqueer demographic is the lack of  
42 a gender concept within oneself (Bosse & Chiodo 2016). Because we have no intrinsic gender identity  
43 at all rather than a specific gendered identity that is viewed as non-normative, we often experience  
44 our nonbinary selves differently than other genderqueer people do (Weisberg & Tompkins 2015).  
45 Relative to other nonbinary people, agender individuals often experience both less dysphoria (a  
46 feeling of not being fully oneself physically) and less stigma (a feeling of being ostracized by others  
47 socially) (Galupo et al. 2014). We also tend to find “stealth” more easily within our reach, possibly  
48 because we often do not present our gender in any highly specific manner (Nicolazzo 2016).

49           Cystic fibrosis (CF) is a complex and progressive chronic disease that starts with a relatively  
50 simple problem. People have certain body parts that lubricate themselves; these are called mucous  
51 membranes. In people without CF, these membranes produce a thin and slippery substance that  
52 works very well as a lubricant—it helps things move around. By contrast, in people with CF the  
53 mucous membranes instead produce something akin to rubber cement (Knowles & Durie 2002). This  
54 substance is not merely a poor lubricant, but rather an outright hindrance to movement (Lyczak et  
55 al. 2002). As a result, small parts of our bodies that need to move regularly—such as the tiny hairs  
56 (cilia) that clean our mucous membranes—cannot do their jobs (Gibson et al. 2003).

57           People with CF wind up with a variety of health problems because of this basic process.  
58 These include chronic infections in our lungs and other organs, blockages of small tubes in organs  
59 like the kidneys and liver, low release of substances like digestive enzymes and insulin from our  
60 pancreases, alternating bouts of constipation and diarrhea, and a host of damages to other parts of  
61 our bodies that result from these issues in the mucous membranes (Emerson et al. 2002). People  
62 often think about CF as a lung disease, but this is a misconception. CF is a whole body disease—one  
63 that impacts most everything else in the lives of patients (Segal 2008).

64           Perhaps unsurprisingly, both people living with CF and people identifying as agender often  
65 find that we have a lot in common with one another based on just those single shared characteristics.  
66 Yet in both cases, we are also diverse in a number of important ways. Indeed, one of the most visible  
67 representations of people with CF in public consciousness speaks deeply to this diversity. After  
68 being diagnosed with CF himself, photographer Ian Ross Pettigrew initiated a portfolio of work  
69 profiling others with the disease. He soon noticed that many of his subjects looked female, and  
70 began focusing in on this group of fellow CF community members. The result was a project called  
71 *Salty Girls* that is now in its second phase.

72           The *Salty Girls* project illustrates a variety of dynamics in the gendering of female-looking  
73 bodies with CF—both by the photo subjects themselves and by other people. Describing the  
74 participants as “girls” may not be substantively appropriate for each person profiled. Indeed, the  
75 gender presentation and expression of different people in the original *Salty Girls* photostream varies  
76 substantially. This can be construed as both a strength and a weakness of the project—a strength  
77 because of the visibility and empowerment that depicting diverse bodies and genders among  
78 female-looking people with CF can foster, and a weakness because of the conflation of looking  
79 female with being a girl. The use of the term “girl” to refer to female-looking adults with CF  
80 introduces an additional sociological dynamic (Duncan & Messner 1998). It speaks to the general  
81 infantilization of female-looking bodies that intensifies in cases of chronic illness (Author 2016). It  
82 also evokes the dualistic relationships that people with CF often have with the aging process—a  
83 concept I explore later in this manuscript.

84 Predictably, a lot of the bodies depicted in *Salty Girls* are very thin. Pettigrew does not select  
85 participants based on weight; indeed, a range of body sizes, shapes, and compositions appear in the  
86 project photostream. However, the overall trend favors thinness and also intersectionally privileged  
87 characteristics such as whiteness and higher economic class—in all cases features of the  
88 demographics of the disease in adults (McCormick et al. 2010). People with CF are more likely to  
89 look white because of the higher incidence of the disease in European-descended populations  
90 (Hamosh et al. 1998). We are also more likely to be thin because of the high prevalence of exocrine  
91 pancreatic insufficiency in adults with the disease (Sawicki et al. 2009). And people with CF whose  
92 families have higher levels of income and wealth are more likely to survive into adulthood because  
93 of their comparatively better access to coordinated CF care (Mehta et al. 2010). In *Salty Girls*, thinness  
94 and the experience of having CF itself are never infantilized. Rather, participants with very thin  
95 bodies all across the gender presentation spectrum are shown as strong, agentic, and resilient. How  
96 subjects perform these qualities does vary by gender presentation—for example, the roller derby  
97 athlete who projects an air of toughness and aggression versus the professional model who projects  
98 confidence through a serene expression.

99 On the embodiment front, I am probably a fairly typical example of both having CF and being  
100 agender. Like many others with a CF diagnosis, I am very thin. I weigh about 80 pounds at just  
101 under 5 feet 4 inches tall. Like many others with an agender identity, I do not present as especially  
102 masculine or feminine. My style, interests, and behavior span a large spectrum of gendered  
103 locations. Sometimes these attributes do indeed lead me to find much common ground with other  
104 people with CF diagnoses and/or agender identities...and sometimes they do not.

105 Here I must reaffirm an important caveat about both CF and agender identity: Not everyone  
106 with either or even both of these attributes is thin. Being thin is more common in the CF population  
107 than in the general US population because of the particular ways in which the disease often—but not  
108 always—impacts the functioning of the stomach, intestines, and pancreas (Stallings et al. 2008). Even  
109 in people who do have a high degree of impact on all three of these fronts as I do from my own CF,  
110 this impact still exerts itself relative to that person's individual baseline (Sinaasappel et al. 2002).  
111 People who have met my mother rarely express surprise at me being extremely thin. My  
112 mother—who does not have CF herself or even carry any of the genetic variants commonly  
113 associated with it—comes from a long line of skinny people with relatively quick metabolisms. At a  
114 similar height to my own, she just barely meets the 110 pound minimum weight requirement for  
115 blood donation, one of her favorite volunteer activities. Likewise, I know other people with CF who  
116 come from families with generally larger frames. They may be somewhat smaller than their other  
117 family members in some cases, but still more solidly built than many of their peers who do not have  
118 CF.

119 The same diversity exists in the agender community: there are fat people, thin people, and  
120 people who do not fall neatly into either of those broad categories (Kozee & Tylka 2012). Although  
121 both agender people and CF patients are frequently stereotyped as being thin—as well as white and  
122 youthful—these populations are actually much more varied and complex in their embodiment.  
123 Likewise, this diversity highlights the importance of not making assumptions about other people's  
124 gender or sex identities. In affirmation of the fact that people's sex and gender identities may not be  
125 discernible simply from appearances or casual interactions, I use open terminology (e.g.,  
126 "female-looking") throughout this manuscript. Such juxtapositions of beliefs about the CF and

127 agender communities with the lived experiences of their members highlights the importance of  
128 amplifying diverse voices on embodiment in scholarship on illness and identity.

129         Consequently, these explorations of how my own lived experiences of CF and agender  
130 identity may both converge with and differ from others with these attributes also gives way to a note  
131 on methods for this manuscript. Although this paper engages elements of autoethnographic inquiry,  
132 it also presents perspectives on the experiences of others both within and outside the intersection of  
133 the CF community and the nonbinary one. Rather than being a methodologically intensive  
134 autoethnography itself, this article instead uses autoethnographic inquiries as anchor points for  
135 exploration of both prior academic literature and the more public oriented ways in which other  
136 people have narrated experiences related to CF and gender nonconformity. I thus refer to it as a  
137 “guided review”, and commend this approach to other scholars seeking to center multiple  
138 standpoints simultaneously in reflection on prior research.

## 139 **2. Literature Review**

140         Because of the many ways CF may manifest visibly on the body, research literature on the  
141 disease has often incorporated content on embodiment. Early publications on the intersection  
142 between CF and illness embodiment offered a mixed array of benefits and drawbacks for the  
143 community. On the one hand, these manuscripts afforded insight into the physical challenges faced  
144 by people with CF, and offered context for why patients often look different relative to our peers  
145 without the disease (Williams et al. 2007). On the other, these same publications may also have  
146 reinforced narrow stereotypes of what people with CF can look like—and even who can have the  
147 disease in the first place (Wailoo & Pemberton 2008).

148         Narratives addressing the relationship between CF and embodiment also appear outside of  
149 research publications. Memoirs and essays were among the first venues to make individual accounts  
150 of embodiment visible and accessible to people without the disease (Charon 1989). Weblogs soon  
151 followed in a similar tradition with the advent of the Internet. Social media groups that are open to  
152 the public also give people without CF opportunities to access information about patients’  
153 individual experiences of embodiment (Macdonald 2006). Indeed, these patient-initiated narratives  
154 have often helped to make research inquiry on CF and embodiment more inclusive and thorough  
155 (Petersen 2006).

156         Similar patterns have appeared with narratives of nonbinary gender experience, challenging  
157 research literature to keep pace with a rapidly diversifying pool of personal accounts outside of  
158 formal scholarship. As with the academic literature on CF, research on nonbinary identity has  
159 undergone a series of evolutions in amplifying the diverse experiences and voices of this community  
160 (Richards et al. 2016). This work began with early research on crossdressing (Mason-Schrock 1996)  
161 and other gender nonconforming behavior patterns and identities (; Serano 2007). Such work has  
162 since expanded to explore the variety of ways people across the spectrum of transgender, nonbinary,  
163 and gender nonconforming identities make sense of, present, and manage their identities, emotions,  
164 interactions with others, and embodiment projects (Sumerau et al. 2016).

165         Fully amplifying the voices of people living with chronic conditions or any other  
166 marginalizing characteristic requires a life course approach. In this regard, the research literature on  
167 CF embodiment remains very much in a developmental phase. Interest in experiences of aging with  
168 CF (Author 2018, forthcoming) and gendered embodiment in CF patients (Willis 2001) has become  
169 increasingly mainstream in both the scientific and clinical communities. Reflecting this, the 2018  
170 BreatheCon event coordinated by the CF Foundation offered sessions focused on aging for the first

171 time ever. The introduction of these sessions followed on the heels of a major milestone in survival  
172 being reached the previous year. For the first time ever, people over 18 with CF outnumbered those  
173 under 18 with the disease in the United States. Yet as many key advocates have pointed out, many  
174 people with CF still die well before age 30—even if they do not appear especially ill to others. The  
175 deaths of prominent advocates Claire Wineland and Storm Johnson within days of each other  
176 highlighted this persistent truth (Esiason 2018).

177 When I facilitated one of the aging sessions myself for BreatheCon 2018, participants'  
178 awareness of and conflicted feelings about many of the recent deaths of advocates in their early 20s  
179 featured prominently in the dialogue. Our discussions focused strongly on the dissonance between a  
180 youthful appearance and the encroaching specter of death. The lack of an intensive focus on aging  
181 topics within the general intersection of CF and embodiment thus remains both understandable and  
182 problematic. Because the research literature on experiences of CF past early adulthood remains  
183 narrow to begin with, it has thus far failed to incorporate explicit content on the experiences of  
184 gender nonbinary individuals living with the disease.

185 This poses an especially difficult challenge for scholars studying CF and patients'  
186 experiences of embodiment because many people often do not achieve a fully actualized gender  
187 identity until well into their adult years (Fausto-Sterling 2012). Even as some children gain more  
188 options for exploring transgender identities at younger ages of late, the vast majority of people come  
189 to an understanding – as well as resources for making sense – of their gender identities as part of  
190 early and later adulthood (Meadow 2018). Despite an increasingly developed awareness of how and  
191 when people come into nonbinary gender identities as they age—both generally and within the  
192 specific context of chronic illness—formal scholarship on nonbinary experience with CF and its  
193 relationship to embodiment remains largely nonexistent.

194 Yet awareness of gender diversity in the CF community is growing. Within the last few  
195 years, groups for trans and nonbinary patients have begun appearing on social media—along with  
196 more general communities focused on LGBTQIA populations. These groups arose largely in  
197 response to connections that people with CF who participated in larger social media communities  
198 forged. I vividly recall my first experience of meeting another patient who identified as both  
199 nonbinary and queer. Both of us expressed immense excitement and relief at connecting with  
200 another person we felt could understand our gender identity as well as the shared experience of  
201 having CF.

202 My inspiration for this manuscript came from observing these general trends in prior  
203 literature on CF and then later using them to contextualize two interrelated experiences. First was a  
204 sustained history of interactions involving CF, embodiment, and gender. Second was an acute  
205 incident that illustrated gaps in our collective understanding of the connections between these three  
206 constructs. In critically analyzing that one specific incident, I rapidly progressed to generating  
207 copious field notes about experiences from my own personal biography and the lives of my peers in  
208 various CF social media and advocacy communities.

### 209 3. Results

#### 210 *Scripting Thinness through a Gendered Lens*

211 The incident that tipped me into developing a manuscript of my own about CF, gender, and  
212 embodiment went approximately as follows. One morning as I was heading to work, I stopped to

213 buy a cup of tea at a convenience store that I used to visit frequently. As I was paying for my  
214 beverage, the other clerk—the one who was not ringing up my purchase—fixed me with a stern look  
215 and asked “Why are you so skinny?” Both the tone and body language of the cashier, a male-looking  
216 person of apparent South Asian descent who appeared to be around my age, conveyed derision. The  
217 other cashier, a female-looking person of apparent African descent, looked mortified and told me I  
218 did not have to answer. However, I saw an opportunity to educate. So I looked the other cashier in  
219 the eyes and said “That’s a shitty question to ask someone.” My words were met with silence, so I  
220 offered an explanation. “I have cystic fibrosis,” I said, fingering the medical ID bracelet around my  
221 left wrist. “CF is the most common fatal genetic disease among people with European ancestry. Our  
222 median life expectancy is about 47 years right now.”

223 Usually references to potentially terminal illness shut down an awkward conversation with  
224 relative speed, or at least prompt a stammering apology and a change of subject (Gramling &  
225 Gramling 2012). However, this person chose a different route—and in the process fell back on  
226 heavily gendered scripts of how female-looking people experience our bodies. “Well, you know, I  
227 didn’t know,” he scoffed at me. “You women like to work out and everything.” I just stared at him,  
228 momentarily speechless. Then he added, “But you still look good—I wasn’t saying you’re ugly or  
229 anything.” This last was said as if my appearance were my main concern—a classic tactic used to  
230 demean and minimize the voices of female-looking people both individually and collectively. Still  
231 staring at the cashier, I responded, “No, I just have to take pills every time I eat because the disease  
232 has damaged my pancreas too much for me to digest my own food. The only thing I’m working at is  
233 trying not to starve.”

234 The exchange then took a familiar turn that many female-looking readers will recognize quite  
235 viscerally: the “you bitch” waiting on the tongue of a street harasser whose catcalling does not elicit  
236 the desired response (Filipovic 2007). “If you want to take it like that,” said the cashier, glaring at me.  
237 His coworker, at this point, had her head buried in her hands and was whispering “shut up, shut  
238 up”. I took a more direct approach, spreading my arms wide and hissing “If I want to take it like  
239 that? Really?” I sucked in the biggest breath I could and then shouted “Are you fucking kidding  
240 me!” before removing my credit card from the other register and leaving without a second look.  
241 Some of the other customers in line applauded as the door swung shut, and I could hear the other  
242 cashier berating her coworker for being “such an idiot”.

243 This encounter crystallized an acute awareness of the general lack of education about CF  
244 and embodiment among those without the disease, gendered expectations of how I will prioritize  
245 managing the feelings of others, and the unfortunate intersection of these two phenomena. Even  
246 once I had explained that I had a life-threatening illness, the convenience store clerk continued to  
247 treat me as if I were violating the entitlement of the male gaze to a less sick-looking body (Author  
248 2016). When I responded adversely to his behavior, he then acted as if my aggressive response to the  
249 situation were strange and inappropriate (Richardson & Green 1999). In the process, he also reduced  
250 my own allotted emotional range to a superficial concern for whether or not he found me attractive  
251 (Marcus 2013).

252 This illustrated both the generalized dynamics of deriding the bodies of the many people  
253 with CF whose bodies show common consequences of our illness (Author 2016), and the gendered  
254 expectations people often hold about how we should respond to such comments (Richardson 2005).  
255 My male-looking peers with CF have often told stories of interactions that began similarly, but had

256 different outcomes when they responded with a similar degree of indignation. The incident at the  
257 convenience store affirmed evidence from the literature that female-looking people with chronic  
258 conditions are often expected to respond to derisive comments about our bodies by seeking  
259 affirmation that we “still look good” (Bartsky 2002), whereas male-looking people are expected to  
260 respond with anger when insulted (Hess et al. 2005).

261 As an agender person, I did not spare a thought for whether or not my own behavior in this  
262 scenario was “unladylike” or “overbearing” (Hess et al. 2009). Rather, I focused on the discomfort of  
263 the other person attempting to force me into gendered scripts for my thinking that have never  
264 matched how I actually experience my own body (Young 2005). This specific incident thus provided  
265 a flashpoint for organizing a much broader array of observations and insights about the  
266 relationships between CF, gender and embodiment. It did so by sharply highlighting the often  
267 contradictory ways in which people react to my body—both through the individual lenses of health  
268 and gender and through the intersection of the two frames. In the process, it illuminated a variety of  
269 ways in which my own agency becomes subordinate to rigid norms of how I should experience my  
270 own body and the illness that envelops it, and provided context for the liberation I find in spaces  
271 that simultaneously center my identities as a CF patient and agender person.

272

### 273 *On Food and Eating*

274 A common manifestation of contemporary American society’s pervasive assault on the  
275 agency of female-looking people is the recapturing of perceived control through rigid behaviors  
276 surrounding food and eating (Ata et al. 2007). “What do women eat” is often a question with no  
277 good answers—a minefield of sorts where the only safe steps are hidden from view (Strong et al.  
278 2000). This introduces an added level of social complexity for female-looking people with CF who do  
279 not identify as women, or indeed with any binary gender. We experience a lot of the same pressures  
280 that cisgender women do surrounding food, weight, and related topics (Bowman 2018). On top of  
281 that, we experience cognitive dissonance about the gendered ways in which these concepts are  
282 applied to our own lives by outsiders (Warwood 2016).

283 Being a thinner person even by standards adjusted for my CF diagnosis, I often experience a  
284 variety of frustrating and contradictory feedback concerning my eating behaviors and their  
285 perceived connection with my physical appearance. People constantly point out—as in the example  
286 above—that I am very thin. Sometimes the language is merely pitying: “frail” or “waiflike”.  
287 Sometimes it takes a more cutting tone: “skeletal” or “emaciated”. I have been told by many people  
288 over the years that I look “fragile”. The degree of explicit gendering present in these reactions varies,  
289 but the underlying implicit message seldom does: “I expect a woman to look a certain way, and  
290 you’re not it.” To date, no one has bothered asking if I am actually a woman in the first place.

291 The double jeopardy faced by both those who actually are women and those who are merely  
292 perceived as such by others becomes even clearer in the ensuing portions of such exchanges. If I am  
293 not in a situation where I am actively eating something, this infantilizing and gendering response to  
294 a thinner female-looking body generally segues into people telling me I need to eat more. In some  
295 cases, this involves trying to push food on me. I have written in the past about people grabbing my  
296 grocery cart at stores and trying to put additional items into it (Author 2016)—a perplexing behavior  
297 given that I actively choose foods rich in caloric energy and monounsaturated fats. And if I *am* in a  
298 situation where I am actively eating, I get mocking comments for eating more than a tiny amount at

299 a time. No matter how much or little I might put on my plate during a given meal in a public space,  
300 someone will invariably comment on it. When I diligently follow national guideline  
301 recommendations for my energy intake, people—and almost uniformly male-looking ones—mock  
302 me by suggesting I cannot possibly eat “all that”. When I take only a small amount, the same  
303 people tend to assume that I have an active eating disorder—and rush to reassure me that I “still  
304 look good” (Charmaz & Rosenfeld 2006).

305 Leaving aside the massive flaws in this broader public understanding of disordered eating,  
306 a phenomenon with which my own past experience can hardly be separated from my CF diagnosis  
307 and its gross mismanagement in my younger years, these occurrences show a clear pattern of  
308 constraining the agency of female-looking people in feeding ourselves (de Groot & Rodin 1994). As a  
309 person with an agender identity, I find some comfort in my own internal freedom from concerns  
310 about whether or not people perceive my eating habits as somehow dissonant with femininity  
311 (Strong et al. 2000). However, my female-looking body renders this comfort a neutral space at best  
312 because it still prevents me from accessing any actual social rewards for following a guideline-based  
313 diet (Leavy et al. 2009). By contrast, my male-looking peers with CF often get supportive comments  
314 and other positive reinforcement for eating large amounts of food at once (Ruby & Heine 2011).  
315 Following the recommended high-calorie, high-fat diet for CF patients (see Stallings et al. 2008)  
316 becomes one of many ways that male-looking people with CF—even ones who are very thin—can  
317 perform and affirm masculine identities.

318 My own understanding of these phenomena has historically been reinforced by observing  
319 that adverse reactions by others to my own food behaviors occur markedly less on days when I dress  
320 more androgynously and/or have my hair cut shorter. On days where I present myself physically in  
321 ways that center the dualism in my own gender identity more, I experience fewer confused reactions  
322 from others to food and eating behaviors that are specific to my CF. Yet days like these come at a  
323 price in the form of confused and even threatening reactions to my gender presentation itself.  
324 Because my body is viewed as female-looking rather than male-looking, these threats usually do not  
325 come to any sort of fruition (Burdge 2007). For agender people with CF who look male but present  
326 with more femininely coded styles, a different set of concerns may arise. These additional concerns  
327 may likewise be partially mitigated by having a thinner body, which itself invites interpretation as  
328 being more feminine (Pine 2001).

329

### 330 *Dualistic Approaches to Aging*

331 Such contradictory responses to how gender nonbinary people with CF experience and  
332 respond to our bodies extend far beyond food and eating (see Lucal 1999). Interactions related to  
333 aging may represent another common node around which dualistic experiences related to  
334 embodiment tend to cluster. I refer to this phenomenon in a more general sense as “the ‘young lady’  
335 paradox”, which may well become the focus for its own manuscript in the future. In the context of  
336 this broader synthesis of scholarship and experience on CF, gender, and embodiment this paradox  
337 involves a layered series of very particular ironies.

338 First of all, I am not that young to begin with. At 34, I am aging out of the “young adult”  
339 stage of life although not yet perceived as “middle aged” based on chronology alone (Elder et al.  
340 2003). Within the context of my CF diagnosis relative to my birth cohort, I am actually somewhat  
341 advanced in age. The average life expectancy when I was born was much lower, and remains



342 substantially different from statistics for the general US population even now (Cohen et al. 2011).  
343 This disparity is even worse for patients assigned female at birth (Davis 1999). When I was  
344 tentatively diagnosed with the disease at only a few years old, CF was still largely considered a  
345 childhood disease (Elborn et al. 1991). At the time of my conclusive diagnosis later on, my  
346 chronological age was a mere five years below the average life expectancy for US residents with CF.

347 Yet if people perceive my age as being different from the actual quantity of years I have  
348 lived, they tend to do so in a downward direction. This likely relates back to content from the prior  
349 section on food and eating related to the viewing of thinner bodies as being somehow lacking in  
350 agency or strength (Holubcikova et al. 2015). Within this context, the physical evidence of my CF  
351 ages me down in the consciousness of others. This phenomenon may be exacerbated in my specific  
352 case by general patterns of perceiving people with a more neutral or mixed gender expression as  
353 being more youthful (Fraser 2017). Rigidly gendered behavior gets encouraged quite widely in  
354 childhood, but violating these expectations does not tend to meet with the same punishment during  
355 earlier portions of the life course (Galambos et al. 1990). These dynamics then intertwine in a  
356 simultaneously causal and consequential way with the inaccurate stereotype that only younger  
357 people hold nonbinary gender identities in the first place (Fouhard-Dourlent et al. 2017).

358 As a female-looking agender person with CF, I also experience some particular nuances of  
359 these more general phenomena that speak to broader social perceptions about gender and aging.  
360 When people express surprise at my age, they generally indicate a belief that they are  
361 complimenting me (Lauzen & Dozier 2002). This almost certainly stems from a widespread belief in  
362 the US and other countries of similar culture that female-looking people and those who identify as  
363 women fear aging as both an overall process and a series of specific physical changes (Monaghan  
364 2001). Literature across a variety of disciplines describes linkages between the aging process and  
365 fears of being perceived as unattractive, powerless, nonsexual, weak, and dependent (Calasanti &  
366 Slevin 2001).

367 Indeed, suggesting that I should value being perceived as youthful represents an accurate  
368 framing of the pressures that female-looking people often face (Calasanti & Slevin 2013). My  
369 agender identity renders this framing somewhat problematic in a broader social sense. Much greater  
370 dissonance comes from the simple fact that for people with CF, getting old is a privilege historically  
371 afforded to very few (Kulich et al. 2003). Current survival data on CF suggest that those people with  
372 the disease who *do* live to very advanced ages are substantially more likely to have been assigned  
373 male at birth (Milla et al. 2005). This represents yet another gendered way in which people with CF  
374 may experience our bodies differently as we age—and how those nuances may collide for those of us  
375 with nonbinary identities (Darwin 2017).

376

### 377 *The Female and the Function*

378 Copious literature in the interdisciplinary sociomedical sciences already explores the  
379 expectations related to embodiment that female-looking and woman-identified people face (Moss &  
380 Dyck 2003). This research identifies several intersecting issues that contribute to the oppression of  
381 female-looking patients in both clinical and community settings. These include, but are not limited  
382 to: essentialist ideas about the relationship between a body's appearance and its purpose; conflation  
383 of sex with gender; binary notions of both sex and gender; disregard for reproductive autonomy;  
384 and devaluing of feminine qualities (Puopolo 2018). Female-looking people with nonbinary gender

385 identities still experience the harms of these phenomena, with additional nuances introduced by the  
386 dissonance others perceive between our physical appearances and our cognitive selves (Darwin  
387 2017).

388 It thus has never surprised me to reflect on the often divergent experiences of my  
389 male-looking peers within the CF community. Even those male patients I know with nonbinary  
390 gender identities often have very different histories with gendered expectations than I myself do (for  
391 examples of nonbinary diversity beyond CF communities, see again Darwin 2017; Schrock 1996;  
392 Serano 2007; Sumerau et al. 2016). The aforementioned example of how male-looking people with  
393 CF may experience very different social responses to following a guideline-based diet constitutes  
394 only one illustration of these differences.

395 Even staying within the realm of food and nutrition, a variety of gendered nuances in the  
396 experience of CF embodiment present themselves. One key advocate I work with, who identifies as  
397 both male and a man, spends most of his leisure time on athletic pursuits. He was raised by a  
398 professional athlete and came to value sports in his own life both for the joy they bring him and for  
399 the ways in which they facilitate keeping his body healthy. Because the ability to stay active in sports  
400 was extremely important to this person, he elected many years ago to get a feeding tube implanted.  
401 He now speaks very openly about how much he values the tube as a resource for helping him  
402 achieve his goals in sport. The language he uses to discuss his tube and its impact on his life reflect a  
403 sense of identity around athletic achievement—a theme that commonly appears among  
404 male-looking and man-identified people in the US (Coakley 2006). Indeed, people who look male are  
405 often pressured to pursue athletics even if they do not identify as men, and sanctioned if they do not  
406 comply (Wiley et al. 2000).

407 As suggested by the example above, these differences are not always uniformly positive. In  
408 the case of my one colleague who does identify as a man, gendered expectations surrounding  
409 athletic activity have likely exerted some positive influences by making him want to challenge  
410 himself in sports and reap the health benefits of doing so. However, both male-looking CF patients  
411 who identify as men and those with other gender identities may experience harm from the idea that  
412 one of their key purposes in life is to excel in sports. The idea that bodies with a certain appearance  
413 should perform certain functions can damage as easily as it can inspire (Fallon & Jome 2007). A good  
414 friend of mine in the CF community who identifies as a genderqueer male often tells me that he feels  
415 insecure about his body looking weak because it is small and thin (Leit et al. 2001). Being assigned  
416 female at birth, I probably spend less time worrying about these kinds of concerns.

417 Conversely, I have faced a slew of other challenges to my self-concept and ability to  
418 articulate it to others that my male-assigned peers often have not. Just as athletic pursuits are  
419 considered a marker of virility and thus worth in male-looking people, similar pressures apply to  
420 female-looking patients with respect to physiognomy (Tylka & Calogero 2011). Whereas US  
421 residents who are assigned male at birth are often expected to become sturdy and muscular as they  
422 grow, those assigned female face similarly strong expectations to stay slender—but not too slender  
423 (Paechter 2006). Feminized expectations about embodiment place constraints on people at both ends  
424 of the size spectrum, often leading to perceptions of very thin female-looking patients as  
425 desexualized and unfit for reproduction (Lupton 2006). The latter has never bothered me as an  
426 individual, both because I do not see myself as a woman and because I have never taken interest in  
427 having children by any means. The former, however, has impacted me both independently and in

428 intersection with negative perceptions of my more ambiguous gender presentation. I have heard all  
429 of the following comments about my body at moments that should have been very intimate and  
430 fulfilling: “you’re disgusting”; “this is like having sex with a skeleton”; “you kiss like a man”;  
431 “you’re too dominant”; “you’re too sexual for a woman”; “I don’t want to talk about your disease”;  
432 “you’re lucky I want to be with someone who looks like you”; “it’s not sexy that I can see the sinews  
433 in your stomach”; and “you never want to have sex”. I refer broadly to this history as  
434 “Schroedinger’s womanhood”—simultaneously not being a woman intrinsically and punished for  
435 not being enough of one extrinsically (Author 2016). This experience is not uncommon among CF  
436 patients as a whole (Willis 2001) but may have unique nuances for those with nonbinary identities.

437 Perhaps unsurprisingly, I have found liberation and comfort in building relationships with  
438 other CF patients who simultaneously identify as nonbinary, kinky, and polyamorous (see Willis  
439 2001). I have found tremendous understanding within these spaces—which include some of the  
440 aforementioned social media groups centering non-cis and non-hetero experiences. I have found  
441 resonance in these spaces surrounding both my generalized lack of concern about my body  
442 matching a gender identity I do not have and my specific perceptions of how I am constrained by  
443 others attempting to define gendered roles for me (Lawton 2003). I have also found community and  
444 liberation with people in queer and trans centering CF discussion groups who incorporate kink  
445 practices into their lives (Banerjee et al. 2018). These practices are often extremely diverse across  
446 patients; the “kink” moniker can describe a wide variety of activities and interests (Newmahr 2010).

447 Masochism—often one of the first things people think of when hearing the word  
448 “kink”—certainly features in the lives of many people with CF who negotiate embodiment through  
449 these channels (Williams et al. 2016). Documentarian Kirby Dick explored specific connections  
450 between CF and kink in *The Life and Death of Bob Flanagan, Supermasochist*. The performance artist  
451 profiled in the film had a male identity, but a “deviant” one that afforded him freedom from  
452 excessively gendered expectations of what he would be and do (Bannerjee et al. 2018). By practicing  
453 masochism in public forums for consumption as art, Bob Flanagan both articulated an authentic  
454 gender identity that made him feel more centered in his body and achieved a sense of being able to  
455 escape the physical challenges of living in that body (Reynolds 2007). He used kink in life course  
456 context to preserve mastery of a non-mainstream masculinity as his body changed from and  
457 eventually succumbed to the progressive damages of CF (Reynolds 2007).

458

#### 459 *Transplant and the Gendered Body*

460 The subject of organ transplantation—a common theme in the biographies of adults with  
461 CF in the US—also appeared prominently in Bob Flanagan’s work (Reynolds 2007). Indeed,  
462 transplantation constitutes a major content node in both Flanagan’s own performance art (Reynolds  
463 2007) and that of other patients following in his footsteps (Lowton 2003). His work has inspired a  
464 wide array of subsequent performances engaging kink by other artists with CF (Reynolds 2007),  
465 including a good friend of my own who recently underwent a double lung transplant. These  
466 experiences illuminate both the overall process of adjusting to a changed body (Lowton 2003) and  
467 the specific processes of renegotiating that body in relation to one’s gender identity (Riessman 2003).  
468 In Flanagan’s case, transplantation required him to revisit his sense of masculinity and consciously  
469 work to continue cultivating his identity as not merely a masochist, but a supermasochist—one who

470 could best any other (Reynolds 2007). This appears as a common trope in notions of what makes a  
471 man successful both overall and within trajectories of chronic illness (Riessman 2003).

472 In my friend's case, transplantation sparked a different journey surrounding gender and  
473 embodiment. His work as a genderqueer performance artist with CF and a double lung transplant  
474 explores themes of gendered embodiment through the lens of a masculinity that is not only kinky,  
475 but also nonbinary (Riessman 2003). He explicitly cites Bob Flanagan's work as an inspiration for his  
476 own artistic ventures (Reynolds 2007), and also points out how his work differs from these early  
477 public demonstrations of negotiating illness embodiment through kink practice. He has also  
478 described in our discussions how Flanagan's work pushed him to exercise creativity in imagining  
479 the post-transplant body in physical space and as a dynamic entity (Lowton 2003) as well as a  
480 gendered one (Willis 2001). In his own work, he focuses less on the obvious choice of highlighting  
481 the scars introduced by the transplant surgery, and more on the rest of his body and how it behaves.

482 Even the territory of scars themselves affords ample opportunity for both negotiating  
483 embodiment and highlighting the gender diversity of the CF community within that context  
484 (Lowton 2003). Indeed, *Salty Girls* centers a variety of themes related to transplant scarring, and its  
485 relationship to gender identity and presentation (see Willis 2001). Some of the narratives for the  
486 project talk about adjusting to scars and the idea of a marked-up body as unladylike (Pettigrew  
487 2012). Some patients love this because their gender presentation more closely matches their identity  
488 after transplant, whereas others hate it and feel alienated (Pettigrew 2012).

489 Both discussions with friends in the CF community and explorations of broader  
490 representation projects have helped me to reflect on my own experiences with surgery and scarring.  
491 As of yet, I have not undergone organ transplantation surgery (Author 2018). Although it appeared  
492 likely in my early 20s that I would eventually need a lung and/or kidney transplant, changes in my  
493 treatment and my positive response to those alterations appear at present to have bought me  
494 substantial time (Author 2018). I remain both open to transplantation in the future and conscious of  
495 how it would require me to renegotiate my body in both general and gendered context (Author  
496 2018). That said, complications from my own CF have already led me to undergo a variety of other  
497 surgeries that acclimated me to the process of adjusting to dramatic changes in the appearance of a  
498 particular body part (Author 2018, forthcoming) and the unique dynamics of those negotiations for  
499 me as an agender person (see Willis 2001).

500 The multiple surgeries I had to rebuild my gums, which along with my teeth had been  
501 almost completely destroyed by nearly three decades of chronic infections, proved especially  
502 instructive in this regard. I began this journey with teeth that were either mostly or entirely synthetic  
503 above what remained of my gumline, and exposed bone at the base of the remaining natural roots. A  
504 dental provider once described my mouth as "unsightly" and asked "you want to look better, don't  
505 you sweetheart?" Sitting in that office, I wondered if my dentist would have asked the same  
506 question of a male-looking patient (Moss & Dyck 2003). I shrugged and said that I cared more about  
507 the functioning of my mouth than its appearance or how that might change over time (Barrett 2005).  
508 The conversation then shifted to the substantial risk that I would lose what remained of my natural  
509 tooth material, and likely multiple sections of my jawbones, to necrosis if I did not undergo surgery  
510 to rebuild the gums and protect the underlying structures. This got my attention—and also made me  
511 wonder why the dentist had not led with this information. Lacking any concern for whether the  
512 inside of my mouth looked unfeminine or might be perceived as such by others, I found it appalling

513 that a health provider would think that I might care more about aesthetic concerns than about losing  
514 portions of my face to infection (see Moss & Dyck 2003).

515 Because I very much did not want to weather the agony of my face literally eating itself, I  
516 scheduled a surgical consult. This gave way to a series of five surgeries over an 18-month period,  
517 involving the following interventions: removing all four of my diseased wisdom teeth; harvesting  
518 connective tissue from the roof of my mouth; stitching the harvested tissue down around the  
519 exposed roots of my remaining teeth; stretching the grafted tissue to extend it; and repeating the  
520 process (Author 2018, forthcoming). Each recovery involved several days of spitting out surgical  
521 plastic and rubber sutures caked with blood and thickened mucus. The grafted tissue remained  
522 white as the bones beneath until it slowly grew blood vessels and transformed into something  
523 resembling a “normal” gum. My own sense of normalcy had long since escaped me by that point,  
524 and I watched the gore inside of my mouth as one might a particularly compelling horror film. But I  
525 never found it ugly, and took a bizarre delight in relaying all this to my students each time I would  
526 return to campus after a procedure. Their stunned reactions made me feel more authentic in my  
527 body as an agender person, rather than concerned for potential harms to my womanhood or  
528 insufficient bolstering of my manhood (Darwin 2017).

529

### 530 *Performing Toughness*

531 My experience with gum reconstruction surgeries thereby illustrates the role of toughness  
532 in the embodiment of CF (Willis 2001). I use my visible scars from the operations as a means of  
533 illustrating both the damage the disease can do and my own resiliency in coping with those harms  
534 (Lowton 2003). When I peel my lips away from my teeth to show what I refer to as my  
535 “Frankengummies”, I invite people to engage with my body in a way that involves both trust and  
536 challenge. I communicate that I feel confident that they will not mock me, and also that I am strong  
537 enough to withstand anything that they might have to say in response. In these moments I feel  
538 keenly aware of the unique dynamics of extending trust to others while occupying a female-looking  
539 body, and also of my total disregard for whether people see me as more or less feminine for having  
540 stitched-together gums that still resemble something one might see in a cadaver lab.

541 As an overall construct, toughness is centered in a broad array of narratives about CF across  
542 both gender and sex groups. For example, people who followed the activist Claire Wineland prior to  
543 her death often cited her bravery and brashness about facing mortality at an early age (Denaro 2016).  
544 Her YouTube videos featured activities like escaping a hospital to attend a political rally at the  
545 beach, with a sly but thoroughly earnest emphasis on her own desire to be “hardcore” about getting  
546 the most out of life with CF. Yet Wineland’s videos also showed her applying a distinctly and  
547 deliberately feminine touch to the spaces she occupied—soft paint colors and fuzzy throw pillows in  
548 her apartment, string lights and photo collages in hospital rooms. Her own performances of  
549 toughness communicated a desire to be seen as simultaneously strong and womanly as she came of  
550 age into adulthood (Denaro 2016). I have met other people with CF who perform toughness through  
551 competitive bodybuilding and extreme sports (see Willis 2001), and of course the aforementioned  
552 “supermasochist” practices (Reynolds 2007). Indeed, the question of the body as narrative art  
553 pervades every approach that patients use to negotiate toughness in our own lives (Lowton 2003).

554 So perhaps the most important lesson from this exploration is a broader one about the  
555 relationship between the gendering of bodies and the narration of them. As an agender person with

556 CF, I find that I experience my body in gendered ways when others attempt to control the narrative  
557 of why it appears the way it does (Gergen 2000). This happens in different but equally destabilizing  
558 ways with people who are unaware that I have CF and with people who know about my diagnosis.  
559 Much of the literature on progressive disease suggests that mentioning a diagnosis can kill a  
560 conversation, especially one of an adverse nature, thereby allowing the person dealing with health  
561 challenges to feel empowered and agentic once more (Gramling & Gramling 2012). Yet my own  
562 experiences suggest that other people's interest in gendering my body sometimes outstrips their  
563 sense of social appropriateness surrounding my life-threatening chronic disease (Willis 2001).

564 Future study of chronic diseases and gendered bodies should thus explore more nuanced  
565 dynamics in who controls the narrative of embodiment, and under what conditions this occurs. I  
566 recently resonated with an account of health embodiment nested within a broader exploration of  
567 career development in hip hop music—Jooyoung Lee's *Blowin' Up*. One of the rappers Lee follows in  
568 his ethnography, Flawliss, recounts his experiences of recovering from surgeries and returning to  
569 musical performance after getting shot. Lee relays how Flawliss initially used anecdotes about the  
570 shooting and his recovery to build himself up before battle performances, and to impress fans in  
571 conversation after leaving the stage. However, Flawliss felt his control of the narrative of his own  
572 body shift when a fan asked a very blunt question about his colostomy bag (Lee 2016). In the same  
573 way that the shopkeeper's questions about why I am so skinny shifted my own control of my body's  
574 narrative, so too did the fan's inquiry make Flawliss feel disempowered in crafting his own story. He  
575 recalled feeling weakened and emasculated by the exchange (Lee 2016).

576 I found the juxtaposition of Flawliss's message of strength, bravery, and resiliency with the  
577 fan's perception of him as weak, damaged, and compromised both powerful and relatable. I tell  
578 many similar stories in my teaching and advocacy activities (Author 2015). I might recall my many  
579 surgeries done with only partial sedation, and the experience of watching a bloody scalpel emerge  
580 from my own mouth; or I might mention casually how it feels to cough up a mucus plug during a  
581 work meeting, and have to excuse myself to the bathroom to spit the bloodied mass into a paper  
582 towel. As an agender person, I am aware of how readers might interpret the first story as a  
583 performance of masculinity and the second as one of femininity beneath their overall character as  
584 social constructions of toughness (Evans et al. 2011). I am scarcely alone among CF patients in  
585 performing this kind of grit—whether in deliberately gendered ways or otherwise (Lowton 2003).  
586 *Salty Girls* alone provides ample examples of how people living with CF turn our medical devices  
587 and the visible ravages of our condition into sign equipment that communicates our strength.  
588 Indeed, some participants wear their oxygen tubes and tanks almost like armor, posing defiantly for  
589 the camera (Pettigrew 2012). In some cases this posturing coheres with the subject's overall apparent  
590 gender presentation; whereas in other cases it diverges.

591 The performance of toughness surrounding visible evidence of CF in *Salty Girls* also begs the  
592 question of what happens outside of the artistic environment, when people on the street make  
593 invasive comments or act as if patients cannot do anything for ourselves (Kane et al. 2005).  
594 Moreover, it demands reflection on how broader gender scripts intersect with these behaviors—for  
595 example, the idea that "chivalry" dictates not allowing female-looking people to carry things for  
596 themselves (Ridge 2014). For nonbinary people with CF and other disabling conditions, a forced  
597 gendering of our bodies in completing everyday activities may bring extra layers of  
598 disempowerment (Willis 2001). When a person grabs my bags or even openly expresses incredulity

599 that “such a frail little thing” could possibly function independently, I experience my body in ways  
600 that are both inappropriately gendered and distinctly negative (Author 2016).

601 Repudiating such problematic narratives often results in further gendering, as seen in the  
602 example from the convenience store. An occasion on which I told an interloper that I could carry my  
603 own bags comes to mind. This interaction began with the person intruding into my personal space,  
604 grabbing my grocery cart, and beginning to rifle through my bags despite me telling him to back off  
605 immediately. What began with “Let a gentleman help you” quickly devolved into a demonstration  
606 that this individual was anything but. The interaction ended with the other person scornfully asking  
607 “What if I were a woman, huh?” as if to imply that I were being sexist by pointing out the  
608 inappropriateness of grabbing a female-looking person’s bags without their consent. In so doing, the  
609 other party uncannily mirrored evidence from the literature about the symbolism of bags in  
610 gendered interactions (Ridge 2014). The lack of self-reflection inherent referring to another human  
611 being as a *thing* aside (Author 2016), the other person’s responses to me used gendering as a form of  
612 dehumanizing and decentering someone who had made him feel inadequate as a man (Ridge 2014).

#### 613 4. Discussion

614 Gender and its relationship to embodiment are deeply contextual both within and outside  
615 of the CF community. How individual CF patients experience these constructs are thus unique,  
616 whether or not they identify as nonbinary. Prior literature on gender, embodiment, and chronic  
617 illness offers context for why not every nonbinary person with CF experiences their identity the  
618 same way. Even if they share the specific experience of being agender, people’s illness biographies  
619 and resulting relationships with their own bodies may differ dramatically (Charmaz 2000).

620 My experiences as an agender patient also frequently diverge from those of people with CF  
621 who are genderfluid or have a more static liminal identity such as androgynous. This may owe in  
622 part to the fact that gender identities lying in between the two poles of an established binary—rather  
623 than wholly outside of it—appear to correlate with more frequent and intense experiences of  
624 dysphoria (Darwin 2017). Because people with CF often experience conflict in our relationships with  
625 our bodies to begin with, having a more liminal nonbinary gender identity may introduce additional  
626 complexities into the negotiation of embodied illness identity (Puopolo 2018).

627 Further nuances almost certainly factor into my own experiences as an agender CF patient  
628 who looks female and identifies as such. Although my sex identity has always been transparent, it  
629 may also play a more latent role in my negotiation of embodied identity as a gender nonbinary  
630 person with CF. Specifically, there may be a hidden curriculum of sorts in gendered representations  
631 and reactions to CF because a high proportion of highly visible people with the disease are  
632 female-looking. This may be true for many reasons, but almost certainly involves more generalized  
633 survival dynamics in the chronic illness population that are sociologically conditioned (Bird &  
634 Rieker 2008).

635 Future research on CF, gender, and embodiment should thus focus both on intensive  
636 exploration of the experiences of gender-diverse groups of patients with female sex identities and  
637 assignments, and on amplification of the voices of patients with other sex identities and  
638 assignments. Centering an array of nonbinary biographies in growing the literature on CF and  
639 embodiment can offer unique perspective on how people living with the disease find empowerment  
640 and liberation while occupying bodies that often feel deeply constraining. Indeed, the notion of

641 constraint evokes important themes from prior sociomedical literature on gender and health (Bird &  
642 Rieker 2008). Understanding how nonbinary people with CF experience our bodies both within  
643 ourselves and through interactions with others affords an opportunity to support intersectionally  
644 marginalized patients in achieving effective illness management (see Charmaz 2000). Specifically,  
645 amplifying these narratives in research and practice can help nonbinary people with CF to achieve a  
646 sense of coherence in our relationships with our bodies and how they reflect our identities beyond  
647 the disease.

648

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