

Managing Stigma: Young People, Asthma, and the Politics of Chronic Illness

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Abstract

In this article, we explore the relationship between asthma and stigma, drawing on 31 interviews with young people (aged 5–17) in Ireland. Participants with mild to moderate asthma were recruited from Traveller and middle-class settled communities. Themes derived from an abductive approach to data analysis and a critical appreciation of Goffmanesque sociology include asthma as a discreditable stigma, negative social reactions (real, imagined, and anticipated), and stigma management. Going beyond a personal tragedy model, we reflect upon macro-social structures (e.g., ethnicity, class, gender) which underlie stigma and the management of a potentially spoiled identity. This raises issues about the politics of chronic illness, embodying health identities and efforts to tackle stigma in neoliberal times.

Keywords

asthma; stigma; Goffman; medical sociology; young people; inequality; qualitative interviews; Ireland

Introduction

Contributors to this journal have explored how children with asthma seek to “normalize” their illness and “integrate with their peers” (Protudjer, Kozyrskyj, Becker, & Marchessault, 2009, p. 103). Efforts to normalize asthma throw into relief stigma and its management, that is, individuals’ efforts to attenuate or avoid a sense of “undesired differentness” (Goffman, 1963/1968, p. 15). Goffman’s seminal text on stigma captures the vicissitudes of dealing with negative social reactions during everyday interaction for individuals marked as outsiders, or the potential shame and embarrassment for those whose stigma is not immediately apparent but who risk being discredited. This individualized “personal tragedy” model of stigma has dominated medical sociology, especially studies of chronic conditions, though there are growing calls to take a more critical and ambitious approach that is attuned to the politics of illness and macro-social structures (e.g., Parker & Aggleton, 2003; Scambler, 2009, 2018).

Heeding such calls, this article explores asthma-related stigma and its management as reported during interviews with young people in Ireland from a middle-class locale and Irish Travellers, a minority ethnic group generally living in conditions of material disadvantage and suffering high rates of morbidity (All Ireland Traveller Health Study Team [AITHST], 2010). We report and analyze their talk on asthma as a “discreditable” stigma (Goffman, 1963/1968), negative social reactions (real, imagined, and anticipated)

to their condition or attempts to ameliorate it (via use of an inhaler), and how they managed stigma. Our article raises issues about the politics of chronic illness and how potential shame, embarrassment, and blame require negotiation when “embodying health identities” (James & Hockey, 2007). Accordingly, we build upon existing empirical studies of asthma (management) among young people, alongside literature that analyzes stigma beyond the micro-social realm of symbolic interaction. This does not mean abandoning Goffmanesque sociology though it does entail thinking about the roots of stigma in the context of power relations and inequity.

Stigma, Chronic Illness, and Asthma

Research on stigma typically focuses on micro-interactions, influenced in particular by Goffman’s (1963/1968) writing on the presentation of self by people who are marked as inferior. Such “blemished” persons might be discredited because of physical stigma, “individual character” (e.g., as inferred from a history of mental illness), or reactions to “tribal stigma of race, nation, and religion”

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(p. 14). Irish Travellers, for example, encounter tribal stigma. Differentiated from the general population by their distinctive “value system, language, customs and traditions” with a “culture based on a nomadic tradition” (AITHST, 2010, p. 9), Travellers constitute a much maligned minority in Irish society (O’Connell, 2013).

According to Goffman (1963/1968), stigmatized individuals experience an unwelcome discrepancy between virtual and actual social identity. Virtual social identity refers to the expectation of what a person ought to be, while actual social identity refers to attributes the person possesses. Goffman also distinguishes between the discredited, whose stigma is visible and known about, and the discreditable, whose stigma is not immediately apparent. Discredited and discreditable stigmata, respectively, give rise to concerns about impression and information management. Scambler and Hopkins (1986), in a similar vein, distinguish between enacted and felt stigma (see also Lekas, Siegel, & Leider, 2011). The former refers to discrimination against people because of their perceived flaws, whereas the latter refers to a sense of shame associated with the fear of an imputed cultural inferiority. Goffman (1963/1968) also refers to “courtesy stigma” where shame and embarrassment spread from the stigmatized individual to those closely connected to them. Goffman calls those who know about the social situation of the stigmatized and are supportive of them “the wise.”

Goffman’s work on stigma has long influenced the study of chronic illness. For example, Jobling’s (1988) study of psoriasis illustrates Goffman’s (1963/1968) argument that stigmatization is increased if the signs and symptoms of a condition are visible to others. In the case of psoriasis, the constant shedding of waste skin makes self-presentation and everyday life difficult. Another example is MacRae’s (1999) research on courtesy stigma experienced by family members of people with Alzheimer’s disease and their strategies to minimize potential shame and embarrassment. This stigma was not reported by all family members, however, and they did not appear to be concerned to try and avoid it. According to MacRae, the ability to reject courtesy stigma depends on “techniques of neutralization” (Sykes & Matza, 1957) such as the assertion that Alzheimer’s is a legitimate medical condition undeserving of social censure. Courtesy stigma may also be avoided if symptoms of the disease can be concealed from others (MacRae, 1999). Researching children with disabilities who require mechanical ventilation at home, and their families’ experiences, Carnevale (2007) also utilizes Goffman when exploring unwelcome societal reactions (including those from health professionals), feelings of rejection and exclusion, efforts to pass as normal, and the family’s role in constructing a “protective capsule” for children. Although some limitations with Goffman’s approach to

stigma are noted, particularly regarding macro-structures and power, the study remains firmly grounded at the micro-level of “social suffering” (Carnevale, 2007, p. 8).

More recently, Scambler (2009) has urged sociologists to rethink the individualized personal tragedy approach to stigma that has been dominant since the 1970s (see also Scambler, 2004, 2006). This advice meshes with calls by clinical educators who advocate “structural competency,” that is, health care professionals’ ability to recognize how inequalities and stigma are related to larger social forces that transcend individuals’ interactions (Metzl & Hansen, 2014). Scambler (2009) asserts that a more critical approach is warranted as much has changed since Goffman (1963/1968) was writing, notably the rise of healthism and the tendency for chronic illness to be increasingly framed as a moral deficit caused by behaviors for which individuals are held responsible. For Scambler (2018), deviance attribution and blame, and not just stigma and shame, appear to be ascendant in neoliberal capitalism wherein the burden of ill health is disproportionately suffered by poorer socioeconomic groups. Moreover, such processes are centered on the body, in what Turner (1996) terms a “somatic society.” Note, for example, how lifestyle discourses for illness and implied culpability emerge in relation to obesity, with bodily appearance taken as an index of moral failure (Grønning, Scambler, & Tjora, 2013; Monaghan, 2017). Accordingly, Scambler (2018) argues stigma is “weaponized” in a manner felicitous to “neoliberal policy formation and implementation.” Referring to disability activists, he underscores oppression and reframes stigma as a political process underpinned by macro-social structures involving axes of power. Flagging power is important insofar as stigma is entwined with perceived social value, entitlement to community membership, and investment (Reidpath, Chan, Gifford, & Allotey, 2005).

Parker and Aggleton (2003) also maintain that stigmatization is a social process bound up with power, domination, and discrimination, what Bourdieu (2001) terms “symbolic” or “communicated violence.” Attuned to the political economy and macro-social transformations (e.g., inequitable wealth distribution), they write “stigma is linked to the workings of *social inequality*” thus necessitating broad thinking about the reproduction and reinforcement of exclusion (Parker & Aggleton, 2003, p. 16, emphasis in original). Such insights are echoed in a study of HIV/HCV-co-infected adults (Lekas et al., 2011). These authors argue that amid prevailing power structures, a “layering” effect or “co-occurrence of multiple stigmas” might occur when people with HIV are discriminated against for (possibly) being homosexual, poor, from an ethnic minority, a sex worker, and/or injecting drug user. Such insights have potential relevance beyond

HIV and HCV. In the context of asthma in Ireland, the focus of our study, we might expect people already discriminated against because of “tribal stigma” (Goffman, 1963/1968), such as Travellers, to be further excluded by health-related stigma. Indeed, strategies for negotiating stigma *may* be especially salient for Travellers who risk being seen as “socially abject” (Tyler, 2013) within a broader figuration of racist subjugation. Yet, given the pervasive moralization of health (Metzl & Kirkland, 2010), it might also be anticipated that young people with asthma from more privileged backgrounds will tend to resist any sense of undesired differentness—what Grønning et al. (2013) term “project stigma.” These propositions, of course, need to be explored empirically and with reference to what is “known” about asthma, including authoritative framings.

The Global Asthma Network’s (GAN; 2014) most recent report acknowledges difficulties in arriving at a definitive estimate of asthma prevalence due to gaps in the data. For example, the last global survey by the International Study of Asthma and Allergies in Childhood (ISAAC) was completed in 2003. However, the GAN (2014) claim the disease may affect as many as 334 million people worldwide with an associated burden on economies and societies (see also Kabir, Manning, Holohan, Goodman, & Clancy, 2011). High asthma prevalence, notably in Anglophone nations, has generated much concern (GAN, 2014), with the Global Initiative for Asthma (2018) recently reproducing a “problem frame” by defining asthma as a condition that “imposes an unacceptable burden on health care systems, and on society through loss of productivity in the workplace and, especially for pediatric asthma, disruption to the family” (p. 7). Concerns about childhood asthma have been amplified with reference to its putative status as an “epidemic” (Rudestam, Brown, Zarcadoolas, & Mansell, 2004, p. 424). In Ireland, where rates are deemed particularly high, the ISAAC survey showed a substantial increase in asthma from the 1980s to the mid-1990s (Manning, Goodman, O’Sullivan, & Clancy, 2007). Based on subsequent surveys using ISAAC protocol, these researchers state that the prevalence value for children aged 13 to 14 who reported “ever having asthma” in 2003 was 21.6%, representing “a 42% relative increase in Irish childhood asthma diagnosis from the period 1995 to 2002–3” (Manning et al., pp. 614–615). Kabir et al. (2011), discussing the prevalence of symptoms of severe asthma in schoolchildren in Ireland up to 2007, also state this has been a recurrent and growing problem. Such a depiction, however, appears to ignore inequalities. Measures of asthma vary, but the AITHST (2010) state doctor-diagnosed asthma in the previous 12 months is over twice as high among Travellers in the Republic than in the general population (12.5% vs. 6%, respectively).

Clinical researchers offer some insights on asthma in childhood and adolescence from “the patient perspective” (Jonsson, Egmar, Hallner, & Kull, 2014, p. 186). For example, Couriel (2003); Newbould, Francis, and Smith (2007); Meah, Callery, Milnes, and Rogers (2009); and Protudjer et al. (2009) have explored issues such as medication use in schools, non-compliance, normalization, responsibility for disease management, and interactions between parents and children to mitigate the risk of potentially fatal asthma attacks. Similar to Jonsson et al. (2014), Protudjer et al. (2009) not only flag the limitations in what is known in this field but also suggest that “early adolescence”—with an attendant exploration of self-identity—may be “especially challenging” for youths seeking to normalize their condition (p. 94).

Within medical sociology, qualitative researchers have provided insights about, for instance, the “ordinariness” of inhaler use (Prout, Hayes, & Gelder, 1999), while Gabe, Bury, and Ramsay (2002) have explored the everyday restrictions faced by young people with moderate to severe asthma. This work illustrates how young people are agentic and try to manage their condition and limit its impact. Monaghan and Gabe (2016) have also shown that a diagnosis of mild to moderate asthma and its treatment as a chronic illness do not necessarily preclude a sense of “being healthy” for young people. In another article, Monaghan and Gabe (2015) argued that asthma is biographically contingent, experienced by young people as an “only sometimes problem” that varied in terms of symptoms, meanings, and consequences. While often dismissed as “boring” and something that did not scare them, such normalization was contingent on other people’s actual or anticipated (negative, unwanted) reactions to out-of-the-ordinary breathlessness and inhaler use. Hence, asthma-related stigma retained salience as a real or anticipated problem that had to be negotiated when embodying health identities. However, that article did not systematically explore this possibility using qualitative data.

In the present article, we seek to build on this literature by exploring asthma empirically as a discreditable stigma. We consider young people’s talk about negative social reactions (real, imagined, and anticipated), and their efforts to manage felt and enacted stigma. The implications of these data amid sociological calls to move beyond a personal tragedy model of stigma are also discussed with reference to the moralization of health, young people’s desire to eschew potentially deviant identities and calls for a renewed critical and ambitious approach to such phenomena. To be clear, this means that while we draw from micro-sociology to interpret everyday stigma management, we also aim to offer an informed critique of what underlies these processes (Scambler, 2004). This approach, as Williams (2003) explains, entails going beyond individuals’ meanings and discourse. Society has

ontological depth and, consequently, research couched solely as interpretivist risks offering a picture that is:

at best partial and at worst misleading: partial to the extent that there is a [social] world beyond what people think and/or say about it; misleading to the extent that they may well be looking or pointing in the “wrong” places. (Williams, 2003, p. 47)

In illustrating this point, Williams cites research on lay health beliefs where people in the poorest circumstances were unaware of the level of health inequality in society and the relative importance of “social determinants of health” vis-à-vis lifestyle factors.

The Research

Data were generated in Ireland in 2010 as part of an exploratory qualitative study on young people with asthma. Following university Research Ethics Committee (REC) clearance, 31 in-depth interviews were conducted with participants aged between 5 and 17 years. The mean age was 12.7 years, the mode was 16 years (seven participants), and the median age was 12 (six participants). Only one participant was less than 8 years (aged 5). Unless otherwise indicated, participants quoted in our article were 12 years or older. The sample comprised 15 boys and 16 girls, purposively selected on the basis that they had mild to moderate asthma. Asthma severity was determined by asking parents to complete a questionnaire, based on the Global Initiative for Asthma classification (Liard, Leynaert, Zureik, Beguin, & Neukirch, 2000). None were newly diagnosed; the mean age of diagnosis was 5.9 years and the shortest time span between age of diagnosis and current age was 2 years (three interviewees).

Seven participants were recruited through a General Practitioner (all from a middle-class suburb) and the rest were contacted either through the health authority's Traveller Health Unit or snowballing through pre-existing contacts. The final sample consisted of 17 participants from a “settled” middle-class suburb and 14 from the Irish Traveller community. The inclusion of Travellers as a distinct minority ethnic group was justified given the high rates of asthma in this community (AITHST, 2010) and our interest in how relative positioning within the social structure may or may not shape the illness experience.

All contact with the young people was organized through their parents. When explaining the purpose of the study, contacts were told that we wanted to talk to young people about health, including but not limited to their experiences of asthma. They were also informed that we aimed to get a sense of how young people managed their asthma in everyday life. The researcher did not raise

stigma as an explicit theme for ethical reasons: There was no intention to impose negative meanings and spoil identities, though participants aged 12 years and older did subsequently volunteer talk about felt and enacted stigma. Before agreeing to an interview, young people were instructed verbally and in writing that they could withdraw whenever they wished, without negative repercussions, and they were not obliged to answer any questions. Before initiating interviews, assent forms were signed by participants' parents.

Interviews were conducted at participants' homes. It was a prerequisite of the REC that a parent should be present. In practice, many parents remained in the vicinity rather than in the room where the interview was conducted. The researcher, who established excellent rapport with young people, did not feel that they withheld information because their parents might be nearby. Indeed, as reported below, young people tended to be frank and forthcoming (e.g., when describing potentially sensitive topics such as sexuality). The average length of interviews was 41 minutes. All interviews were audio-recorded and transcribed verbatim. Participants were informed that their real names would not be used to preserve anonymity.

All data were indexed and analyzed using coding software, Atlas.ti. This allowed a systematic approach to data analysis, including comparing segments of talk about stigma within and between cases. In line with critical realist writing on health inequalities, such an approach is compatible with “a process of inference from lay (first-order) accounts of the social world to sociological (or second-order) accounts of the social world” and thus “the identification of mechanisms” which may, at least in part, explain observed events (Scambler, 2001, p. 35). Scambler refers to this process of inference as “abductive” reasoning. Abduction requires an awareness of existing theoretical frameworks or models and “careful methodological steps” when generating data (Timmermans & Tavory, 2012, p. 181). Hence, unlike a purely inductive approach, there is an explicitly recognized need to know about, draw from, and perhaps revise “multiple existing sociological theories” (p. 169). We will now present an analysis of our empirical data before discussing their broader relevance with reference to theory, research, and practice.

Young People's Talk About Asthma-Related Stigma

Participants' stage in the lifecourse influenced their talk about asthma and potential sensitivity to stigma. For our youngest participant, asthma was initially defined as a “secret” not because it was personally shameful but “because [giggling] the start of asthma word is ass, like

your bum, and that's a bit rude to say." Indeed, if the situation warranted it, she had no problem telling people that she used a "puffer [inhaler] because my breathing is stuck. That it is a nicer thing to say than that other word." More generally, she did not talk about asthma as stigmatizing and she even proudly called herself "an asthma girl." Another young participant (under 12 years) barely mentioned asthma-related stigma, instead referring to how the condition was simply part of her, like her name or hair color. However, consider a teenage boy's account after being asked why using an asthma inhaler bothered him:

Participant: It's just a bit of a stupid-looking thing. And then it makes a sound like "sshhhhhh" so it sounds like one of those rotten air fresheners going off. So if you are on the bus or something and you have to take a puff, everyone looks around because they probably figure you're some skanky old junkie that likes to hop on the bus and shove deodorant cans or whatever up your nose. You know?

Interviewer: Which do you think bothers you more: the fact that you have to use an inhaler or the fact that you have to use it in front of other people sometimes?

Participant: I suppose that other people see it. Not my family or friends or that, because they know what it is and what it's for but strangers might look at you weirdly. One might think "oh, check out the junkie" and someone else might be like "oh that poor guy" like I'm sick, or weedy or something.

Older participants indicated that publicly known about asthma (or efforts to manage it with an inhaler) could potentially "mark" them as different (possibly deviant), even if they did not feel different. Those from the age of 12 onward were vocal about these processes, suggesting they had learnt to become attuned to and had actively embodied social hierarchies of value and moral worth. Drawing primarily from interviews with these older participants, the following explores data on: (a) asthma as a discreditable stigma, (b) unwanted social reactions, and (c) avoiding and managing stigma. Themes include: the general unobtrusiveness of asthma in contrast to discredited conditions; evidence of being asthmatic in everyday life; recounted instances of enacted and felt stigma; and seeking to manage, avoid, or neutralize stigma. As will be seen, such concerns are relational processes, implicating structured practices and institutional contexts such as school, sport, ethnicity, gender, sexualities, family life, and the public world of strangers. This means our analysis incorporates matters not only relevant at the individual or interpersonal (micro-social) level, but broader structures within which everyday experiences of asthma are embedded, embodied, shaped, and negotiated. Accordingly, reference is also

made, for example, to the general self-responsibilization of health and an attendant moral obligation to self-present as fit (enough), especially among those most likely to experience inequalities and stigma.

Asthma as a Discreditable Stigma: "You Can't See When Someone Has the Asthma"

Consider some words from a participant who rejected the idea that asthma is a visible marker of undesirable difference or "outsider" status (Scambler, 2009, p. 443). His words, similar to a girl who contrasted asthma to a Cleft Palate, fit with the idea that mild to moderate asthma is a contingent or "now-you-see-it-now-you-don't" problem that is not necessarily biographically disruptive (Monaghan & Gabe, 2015):

I'd feel different if I had a big scar across my face, like a burn. But it's not like that. You can't see when someone has the asthma, like, so it's no big deal. It's just a thing that they have in the inside, in here [points to chest] and its no-one else's business.

When conceptualizing stigma and its management, Goffman (1963/1968), as outlined above, distinguishes between the discredited and the discreditable. Asthma falls into the latter category, as explained by participants who were unequivocal when asked whether people they had just met could tell they had this condition. They stressed the general invisibility of asthma, largely defined as a private matter rather than something to be openly discussed with strangers or nonsignificant others. This view fits with Goffman's observation that discreditable individuals' concerns largely revolve around information management. Accordingly, the discreditable have greater scope for passing as "normal" and, as with the above participant and people with epilepsy who fear "enacted stigma" (actual discrimination), may favor "a policy of non-disclosure" (Scambler, 2004, p. 33). The latent and episodic nature of asthma symptoms—coughing, wheezing, and breathlessness—and the general manageability of symptoms, especially through the avoidance of triggers (e.g., dust, cold air) and inhaler use, meant that participants seldom regarded themselves as inferior to their "healthy" peers. Indeed, aside from often stressing their own healthy lifestyles and bodies (including their normative appearance in a culture wherein obesity is the archetypal discredited stigma: see Monaghan & Gabe, 2016), young people emphasized that their asthma was generally unobtrusive and hardly (or only sometimes and mildly) disruptive. If there was a problem, then this primarily related to other people's (possible) reactions, which were medically unwarranted and to which we will return below.

Participants explained that awareness of somebody being asthmatic, at least in the public world of strangers, was only possible through direct disclosure, observed breathing difficulties during a flare up of symptoms (in its most extreme form, an asthma attack), or being seen to be in possession of an inhaler. As one participant remarked, asthmatics cannot be identified simply by looking at them but “if you see them using an inhaler then you would [know].” Inhalers occupied a paradoxical position (similarly, see Protudjer et al., 2009). On the one hand, inhalers could neutralize enacted stigma by preventing or managing symptoms; on the other hand, they could compound felt stigma and transmit the young person’s discreditable identity as asthmatic to onlookers. Awareness of this could result in refusal to use an inhaler thereby increasing the risk of symptoms, unwanted attention, and implied culpability because of “non-compliance” (Couriel, 2003) with treatment.

Understandably, young people had mixed feelings about inhalers. Negative feelings were especially pronounced among male adolescents whose gendered identities appeared precarious, in contrast to young girls (those under 12 years of age) who sometimes decorated their inhalers and treated them as a “cool” fashion accessory. Young men in the Traveller community used quite colorful language to express their disdain. For instance, one referred to the inhaler as a “pissy looking thing” and, laughing, said “that fucking thing wouldn’t let a fucking fairy breathe.” Furthermore, he maligned male peers who publicly used inhalers, under a general ideology of personal responsibility and culpability for chronic illness. After being asked “if you saw another lad, around the same age as yourself, using an inhaler, would you see him as being weak?” he retorted, “Bit of a pussy alright [laughs]. Like [pause] he can do stuff so that he doesn’t need it. So he should do that.” In Scambler’s (2006) sense, chronic illness is understood here as a moral rather than ontological deficit, a question of doing rather than being; contra Goffman (1963/1968), this pertains to the individual’s *will* rather than condition. Again, age, gender, and ethnicity appeared to be salient in shaping this understanding.

In summary, asthma-related stigma for our sample is discreditable rather than discredited (Goffman, 1963/1968). It represents a potential (concealable) deviation from “healthy ideals” in a neoliberal economy and “somatic society” (Turner, 1996). This is a social world wherein the chronically ill, who risk being “fingered” (Scambler, 2018) as burdensome and culpable, are disproportionately from marginalized or subordinated groups (Scambler, 2012). The interiority of asthma, under such conditions, should not be underestimated given the weight ascribed to bodily appearance as an index of selfhood, or one’s “true nature” (Grønning et al., 2013; Monaghan & Gabe, 2016). Socially

constructing asthma as a concealable and ultimately controllable condition often enabled participants to self-present as ordinary and even healthy. However, because asthma symptoms are potentially disruptive—and using or simply possessing an inhaler could identify somebody as asthmatic in “front stage” (Goffman, 1959) public regions—health-related stigma remained a real or anticipated problem.

Unwanted Social Reactions: “It Was Kind of Embarrassing!”

When volunteering talk on asthma-related stigma, participants discussed unwanted social reactions with reference to: (a) symptoms, notably “out-of-the-ordinary” breathlessness and wheezing; (b) impeded role performance; (c) their possession/use of an inhaler; and (d) verbal public disclosure of their condition. Regardless of whether social reactions were real or anticipated, or motivated out of malice or good intent, they were real in their consequences.

The first point—*unwanted social reactions to asthma symptoms*—could spoil identities through enacted or felt stigma. Some boys highlighted this with reference to disapproving girls, indicating the relational significance of gender as a social structure (Connell, 2000):

They [girls] would see it and they’d be like “oh, weirdo boy. Weirdo boy can’t breathe.” . . . the way they make big deals out of everything all the time. And the way they would never want to go out with you if you’re sick.

Reference was also made to concerned onlookers. A participant described how she felt embarrassed while experiencing breathing difficulties in public. For her, the “fuss” from strangers and others who were “watching me” was more bothersome than controllable asthma symptoms. One might surmise here that onlookers’ suggestions and offers to “call your parents” not only grated against her growing autonomy as a young woman but also neoliberal tenets of independence and self-reliance:

Sometimes it’s [pause] embarrassing because it [wheezing] could just happen somewhere [pause] like when I’m in town or something. Or one time we went over to watch a rugby match in [stadium] and there was a LOT of people there so it was a bit hard to breathe. I could just use my inhaler but then these people who I don’t even know were all like “oh no, do you want to go outside for some air?” And “we’ll call your parents.” And then everyone started looking over and [pause]. I was thinking they should just watch the match and stop watching me.

The second point above—*unwanted reactions to impeded role performance*—was also discussed. Another participant

became embarrassed after she and her asthmatic friend were mocked by other girls while “underperforming” at a team sport:

We were playing a basketball match. Me and my friend were only going for about 10 minutes, you know. And then there were these girls, they found out that we couldn’t, we couldn’t do the full time and then they started calling us “slow” and things. And they called us “gaspsers” and things like that [laughs] and it was kind of embarrassing!

Sport, physical activity, and play are important practices when embodying health identities (Monaghan & Gabe, 2016), which might explain why the above account was fairly unusual. Boys and young men were particularly keen to present themselves as physically fit and active, equaling, if not surpassing, their peers’ athletic capabilities. This is in accordance with the social construction of masculine hegemony, comprising configurations of body-reflexive practices that valorize strength, stamina, competitive action, and heterosexual prowess (Connell, 2000). Perhaps unsurprisingly, then, particular sporting subcultures could serve as a testing ground for hegemonic masculinity in the face of chronic illness, which brings us to the third point listed above: *unwanted social reactions to their possession/use of an inhaler*. Consider how inhaler usage was framed among rugby teammates. What is striking here is how this field of gendered power reconfigured innocuous inhalation into something completely different and potentially embarrassing. After being asked why he called his inhaler “stupid,” this participant said “guys think inhalers are a bit gay” adding

Participant: OK, so you know the way chicks give guys [coughs, moves uncomfortably on seat; he is reassured that he can discuss anything he wishes]. Well you know the way chicks give guys blow jobs and stuff? So, that’s what girls do to guys. They blow them and stuff. So when a girl uses an inhaler the guys are all like “oh check that out. She blows really well” and they’re all laughing, thinking about blow jobs and stuff . . .

Interviewer: So, what do they think about guys using inhalers then?

Participant: SEE. That’s the gay bit. A guy blowing on something is totally gay!

Interviewer: Would that stop you from using your inhaler in front of other guys?

Participant: NO. They know that I’m not gay but still, they could be slagging me later. Like they’d wait ’til some of the sixth year girls would be walking past the lockers and shout “you should see this guy’s blowing skills girls!”

Interviewer: Has anybody ever said stuff like that to you before?

Participant: Yeah, just the rugby lads really. They think using inhalers is just gay.

Of course, following some of the female participants quoted above, concerns about unwanted social reactions went beyond the fragile construction of heteronormative masculinities. Other females reflected specifically on how peers at school might react to their possession of an inhaler, stating they felt they would be judged as less capable and flawed:

If they see a puffer [inhaler] they think that you need to go slower or you need to sit down to breathe or something and then [pause] I don’t know [shrugs]. It’s like there’s something wrong with you. Something doesn’t work properly or something like that.

The fourth point—*verbal public disclosure of their condition*—could also be experienced as stigmatizing. This is tied to a recurrent concern among young people for privacy and their shared conviction that their asthma was a personal matter. For the following participant, her friend’s public concern about her well-being was embarrassing insofar as it entailed telling a stranger that she risked an asthma attack. While being interviewed, she objected to and refuted this public disclosure. She said she could anticipate and avoid asthma attacks by using an inhaler. Yet her friend’s disclosure amplified the perceived seriousness of her “mild” illness in the eyes of somebody who was unknown and who did not need to know about her asthma. Arguably, such defensive talk is reflective of a concern to avoid being viewed in a similar light as, for example, epileptics who suffer seizures. According to Scambler’s (2006) research, epileptics risk being labeled as “unpredictable” or “perpetrators of ‘psychosocial dramas’ in public spaces” who are “embarrassingly needy of comfort and care” (pp. 278–279):

Participant: Everyone else knows about it [my asthma] and they are my friends or my family but I wouldn’t go around telling strangers. Like me and my friend were in [a shoe shop] one day and I was waiting to see if they had my size for these runners [running shoes] that I wanted. And my friend just started rubbing her finger along the glass shelf and saying to the lady that worked there that the shelves were really dusty and that I could have an asthma attack. I was so embarrassed that I wanted to just run out of the shop but I didn’t have any shoes on so I couldn’t [laughs].

Interviewer: What did you find more embarrassing: the fact that your friend was being a little cheeky or that your asthma was being discussed with a stranger?

Participant: Erm [pause] I'd say it was that the lady was looking at me and knowing something about me that I think she doesn't need to know. Anyway, it wasn't fully true because I don't have asthma attacks. I have mild asthma you see and that means [pause] that I know when I need to use my inhaler so that I won't ever have an asthma attack.

In summary, when discussing asthma-related stigma, participants cited real or anticipated public reactions that were medically unwarranted and which could spoil their identities. Whether referring to actual social reactions to their symptoms, imagined and felt responses to their use of an inhaler (especially when among strangers), or receiving unwanted public attention because of verbal disclosure, what is clear from these data is that asthma-related stigma was real in its consequences. A fundamental theme is that participants felt vulnerable to being positioned as strange (weird), undesirable, dependent, effete, needy, and flawed—everything a healthy neoliberal citizen should not be and is obliged to redress as far as possible. Accordingly, these young people sought to avoid or manage stigma qua communicated or “symbolic violence” (Bourdieu, 1997, cited by Scambler, 2006, p. 279).

Avoiding and Managing Asthma-Related Stigma

Young people employed various strategies in an attempt to avoid or manage asthma-related stigma and implied subordination in a field of “*culture, power and difference*” (Scambler, 2006, p. 279, emphasis in original). Strategies included: (a) rejecting and expressing animosity toward the inhaler; (b) concealing their possession and use of an inhaler from public view; (c) avoiding physical activities that could trigger breathing difficulties and unwanted attention; (d) associating with supportive others, or those Goffman (1963/1968) terms “the wise”; and (e) employing “techniques of neutralization,” notably “condemning condemners” (Sykes & Matza, 1957). We will explore these below with reference to data.

Consider the first point above: *rejecting and expressing animosity toward the inhaler*. Reference has already been made to one participant who referred to the inhaler as a “stupid-looking thing” due to an imagined association with junkies, and another who called the inhaler “stupid” and “gay” with reference to heteronormative definitions of sexual deviance. Other males expressed similar disdain. After one described how he had not used an inhaler since he was 8 years old, despite regularly visiting his doctor for asthma and receiving a prescription, he expressed incredulity that “you’re supposed to get air from this tiny, fag-goty little blue plastic thing.” He added, “You’d be better off sucking in some air and letting that wash your lungs.”

Such talk should be interpreted in light of his other pointed remarks about how his peers in the Traveller community denigrated anybody who used an inhaler, a case of enacted stigma and deviance that could result in feelings of shame and blame (Grønning et al., 2013; Scambler, 2006). Elsewhere in the interview, he colorfully referred to the other boys as “small bastards” who would “call you a weakling or a weedy little cunt” for using an inhaler. Hence, his talk is double-edged: it captured his wish to avoid enacted stigma while also discrediting the inhaler and, by implication, asthmatics who rely upon it.

Second, young people who relied upon the inhaler but feared enacted stigma avoided unwanted attention and possible ridicule by *concealing their possession and use of an inhaler from public view*. In this way, they sought to avoid the discrepancy between virtual and actual social identity that results in stigma (Goffman, 1963/1968), or as implied below, the difference between the masculine ideal of invulnerability and actually observed vulnerability. After being asked whether he would use an inhaler in front of “the other lads that you’re out with?” a participant said: “NO, I do turn around like I’m scratching my balls or something and just take a drag.” Using redeeming laughter, he joked that Traveller boys “don’t want to be going around all big and tough and then look stupid” by having to take “a drag” in the middle of a potential fight. Yet, it would be misleading to suggest that only teenage male Travellers concealed their reliance on an inhaler. A female participant from the middle-class community reportedly concealed her inhaler in school because “if it’s where you can see it people would just be asking me if I have asthma and all that,” adding

Anyway, sometimes things are just private and you don’t go around blabbing about them to everyone. It would be like if someone had their period in school and then went around showing tampons to everyone, or letting them fall out of their lockers onto the floor just so everyone would know.

The third point we listed above—*avoiding physical activities that could trigger breathing difficulties and unwanted attention*—was specific to females, possibly because sport and physical activity were less valued as a means of doing gender and health. Consider another’s reference to the local swimming pool. What is also evidenced below is that the injuries associated with tribal stigma (the social construction of Travellers as “dirty”) co-existed with the potential drama of an asthma attack. Hence, the situation was avoided:

Participant: So then we started going swimming.

Interviewer: Did you enjoy that?

Participant: NO, Jesus Christ, God forgive me, no. I hated that.

Interviewer: Why?

Participant: Half of them [in the pool] would think that Travellers only goes swimming for a wash so they'd all be looking at ye when you came out from the dressing room place. And anyhow, I don't think it's very good for asthma because I can't swim and if I get a fright in the water then I won't be able to breathe.

Interviewer: Has that happened to you before?

Participant: No, not really but I bet you a million euros that's what would happen so I never goes swimming. Ever.

The fourth point is *associating with supportive others*, or "the wise" (Goffman, 1963/1968). Asthmatic friends possibly constitute one category of wise person. They might be especially important because of shared experiences and understandings, a shared social situation, differentiating them from unsympathetic people who possibly regard asthmatics as malingerers who make facile excuses for perceived failures. (This negative response has been reported in another study of pediatric asthma with reference to teachers who were deemed "unsympathetic" and "disbelieving"; Newbould et al., 2007, p. 1079). After one girl remarked that she worried about possibly "ruining" a sport team's performance, the following was said:

Interviewer: Do you discuss that with your friends or team mates?

Participant: I only discuss it with my friends who have asthma 'cos they feel the same way but not with my other friends 'cos I don't think they'd understand.

Interviewer: What makes you think they wouldn't understand?

Participant: Well because they're not in the same situation so they would probably go "Oh no you're just making up excuses" and stuff.

Family can be instrumental in avoiding or managing stigma, as similarly reported in studies of Alzheimer's disease (MacRae, 1999) and children requiring mechanical ventilation whose family provided a "protective capsule" (Carnevale, 2007, p. 10). Mothers were repeatedly mentioned in our study. For instance, one boy (with an air of indifference) described how his mother told him that famous high status men (e.g., former U.S. presidents, musicians) had asthma, while girls talked about how mothers would take their side when taunted by siblings. Support from mothers in the family setting seemed to be

most valued by girls. One mentioned how she, with mum's support, responded to her brother's taunts; they called him a "dumb blonde" after he claimed boys would not want to kiss her through fear of catching asthma.

The above observation takes us to our final point about managing stigma: *techniques of neutralization, notably condemning condemners*. Another participant, after remarking that his sister called him "scuba diver" but "she is a cow and I don't care what she says," explained how he responded to taunts in school. He said that when one boy called him "Wheezy [after] some toy in the Toy Story movie that has asthma," he fired back: "I used to tell him that he was a big whoosie for watching a small kid's cartoon." Elsewhere, a girl referred to inappropriately inquisitive people as "nosey." While such words were from participants in the settled community, young men from the Traveller community were especially vocal when employing techniques of neutralization, comprising what could be called "tough talk."

If stigma is "weaponized" (Scambler, 2018) and especially pointed in regard to "abject" Travellers (Tyler, 2013), it might be surmised that there will be heightened sensitivity to the weakness implied by asthma for such participants even when among kin. As remarked by one young man, "If the mother tells me to mind my chest the brothers might give me a slagging about being a weakling and that. But I just give them a kick in the bollocks and that sorts that out." Such "offensive" talk also extended to individuals outside of the family, or at least it figured in the narrator's account of how they would deal with an imagined scenario where they were mocked. Another, for instance, said that his peers "wouldn't fuck'n dare" to "slag" (ridicule) him, but if they did, he joked, "I'll take that gas yoke [inhaler] and I'd shove it so far up their holes that if you struck a match beside their mouth, they'd fuck'n explode!"

In sum, young people employed various strategies to avoid or manage asthma-related stigma. Ranging from avoiding use of the inhaler to techniques of neutralization, they sought to present themselves as normal, ordinary, and even healthy. While some responses were quite colorful, especially from male adolescents in the Traveller community, the shared sentiment was that a person with asthma was not an outcast and they were as good as, if not better than, anybody else. Indeed, if deviance was to be apportioned anywhere, then this was most appropriately directed at those said to be engaging in age inappropriate behavior (e.g., watching "a small kids cartoon") or displaying undesirable character traits (e.g., being "nosey"). Evidence that such identity work might be challenging for some clearly emerged with reference to talk about layered stigma at the swimming pool, indicating the extra burden Travellers might experience in a context of structural racism.

Discussion: From Empirical Research to Broader Debates and Action

Asthma is authoritatively framed as prevalent and problematic, posing an unacceptable burden on society and the economy (Global Initiative for Asthma, 2018). Such logics prevail in neoliberal times where the specter of avoidable costs and “behavioural conditionality” for health care is becoming more “explicit” (Grønning et al., 2013, p. 279). Although various studies demonstrate that young people seek to normalize their asthma and its management (e.g., Protudjer et al., 2009; Prout et al., 1999), even mild asthma may sometimes be experienced as problematic by those diagnosed with the illness (Monaghan & Gabe, 2015). Anticipated or actual *negative social reactions* represent a key aspect of this (potentially) disruptive experience. Accordingly, we explored how young people with mild to moderate asthma in Ireland from the Traveller community and a middle-class locale talked about stigma.

An immediate observation from our interviews with 5- to 17-year-olds was that volunteered talk about asthma-related stigma was largely confined to those aged 12 years and older. This observation complements Protudjer et al.’s (2009) research on asthma normalization and the challenges of identity formation in early adolescence. It also suggests acculturation into “existing structures of social inequality” (Parker & Aggleton, 2003, p. 18), where relative positioning on embodied hierarchies of moral worth matters during transitions to adulthood. As far as asthma-related stigma goes, younger participants appeared to be shielded by the “protective capsule” (Carnevale, 2007) of the family wherein parents (primarily mothers) helped to deflect potential shame and blame, though we would add that such protection did not always extend to “tribal stigma” (see also Monaghan & Gabe, 2015).

When referring to asthma-related stigma, three main themes emerged from our study. First, participants described asthma as a discreditable, rather than discredited, stigma (Goffman, 1963/1968). They downplayed their condition as being generally invisible in contrast, for example, to facial disfigurement. Such talk made sense given the “*aestheticization*—one aspect of the (hyper) commodification—of the body” in neoliberal capitalism (Scambler, 2004, p. 42, emphasis in original). However, because participants’ symptoms were potentially disruptive and/or the possession of an inhaler identified them as asthmatic, stigma remained a real or anticipated problem. Second, participants talked about the possibility of unwanted social reactions, a potential source of embarrassment. Whether discussing actual reactions to their symptoms, imagined and felt responses to their use of an inhaler (especially when among strangers), or receiving unwanted public attention because of verbal disclosure,

asthma-related stigma was consequential. Third, participants sought to avoid or manage asthma-related stigma using various strategies. For instance, if the inhaler was regarded as a marker of undesirable difference then it would be concealed. Other strategies included associating with supportive others, “the wise” (Goffman, 1963/1968), and condemning condemners (Sykes & Matza, 1957). It is through such talk that young people sought to be understood according to the moral dimensions that encircled and informed their lives.

The above is suggestive of a self-responsibilizing culture wherein bodies are subjected to a Panopticon like gaze (Foucault, 1979), a world wherein youths complained about others “watching them,” “looking,” “making a fuss,” “slagging,” and judging. Under such conditions, young people often sought to present themselves as “fit” (enough) on the social stage, challenging any sense of cultural inferiority or implied deviance. In so far as such processes are embodied (James & Hockey, 2007), they could be related to sociological arguments about “somatic society” and how “major political and personal problems are both problematized in the body and expressed through it” (Turner, 1996, p. 1). Here, we see connections between impaired bodies, culture, power, difference, and social structures that generate conditions for action. As observed, the embodied meanings of stigma management were entwined with identities, relations, and practices pertaining to age, gender, ethnicity, and sexualities (e.g., the adolescent male rugby player as a target for homophobic jokes, or Travellers who refuted the idea that they were “weak boys” who relied on a “faggoty” or “queer-looking gas yoke”).

The embodied obligation to self-present as healthy and fit, as deserving of respect and ultimately social investment (Reidpath et al., 2005), is certainly not reducible to individuals occupying *specific* locations within the social structure of bounded nation states. “Project stigma”—or active efforts to resist social degradation—is pervasive even if it is underexplored by medical sociologists (Grønning et al., 2013). Yet, when researching the Irish Traveller community, it is important to recognize that the experience of asthma-related stigma has to be contextualized in terms of social divisions and broader inequalities that have material effects. Although addressing HIV and AIDS-related stigma, Parker and Aggleton (2003) could have been discussing asthma when writing, “stigma feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality” (p. 13). This brings us to the value of thinking beyond, without ignoring, micro-social interactions in the empirical world and thus the importance of abductive reasoning that engages existing, extant theorizing and models. As noted by Scambler (2009) when calling for a post-individualistic account of stigma, interactionist work in this field has been dominated by a personal tragedy or apolitical

approach. Such work ignores or downplays macro-social structures that underlie stigma and shame and increasingly relations of deviance and blame, not to mention actual disease etiology/distribution (Scambler, 2012; Williams, 2003). “Re-framing stigma” (Scambler, 2004) within studies of health is thus crucial insofar as social scientific literature increasingly draws attention to how power, domination, and discrimination exert their effects; in short, there is greater sensitivity to the fact that what becomes stigmatized (who becomes marked as undesirable) relates to hegemonic norms and values.

We noted that Irish Travellers, a vilified ethnic minority who have long been treated as “national abjects” (Tyler, 2013), are significantly more likely to be diagnosed with asthma given its relationship with material disadvantage. This contradicts their common claim that they are as healthy as, if not healthier than, “Buffers” or “settled” people (Monaghan & Gabe, 2016). To return to Williams (2003), the world has ontological depth and it should not be conflated with members’ accounts (an “epistemic fallacy”), though this does not detract from the observation that (potentially) fallible talk may have important identity effects. Under such conditions, health-related stigma among our sample of Travellers represented a “layered” stigma that required negotiation amid multiple forms of discrimination (Lekas et al., 2011). One might surmise that feelings of vulnerability are highly likely under oppressive social, cultural, economic, and political conditions. Scambler (2004) posits that vulnerability among the chronically ill more generally is symptomatic of being deemed “surplus to labour requirements [and] for whom statutory support is potentially costly” (p. 42). If this depiction is accepted, alongside evidence regarding the “feminization of poverty” (Parker & Aggleton, 2003, p. 19), then one might easily appreciate why young Travellers with asthma avidly sought to avoid or manage stigmatization by employing various strategies, including those that could, paradoxically, increase the risk of an asthma attack (e.g., rejecting inhalers and talk about, if not actual enactment of, violence). Such strategies even had salience with reference to in-group interactions, despite a high prevalence of asthma which might conceivably lead to de-stigmatization. Yet, at least in regard to the social situation of the interview, Travellers were not radically different from other participants when negotiating potentially deviant identities. One possible explanation for this shared orientation is that in the context of chronic illness and attendant judgments/prejudices/anxieties, young people are generally loath to see themselves as anything but normal (Protudjer et al., 2009).

Accordingly, despite (or perhaps because of) the tendency for neoliberal logics to compound the moral burdens of imperfect bodies (Scambler, 2006), young people in our study overwhelmingly refuted the real or imagined

definition of their illness as an index of personal weakness (of will) (though that evaluation did not necessarily extend to other asthmatics qua maligned others who purportedly failed to manage their condition). If one interprets this with reference to sociological efforts to re-frame stigma as a “symbolically violent” (Bourdieu, 2001) process that is entwined with the larger body politic then the following proposition follows. Namely, the ostensibly private trouble of managing spoiled identity is quintessentially a public issue in an inequitable society comprising multiple points of (dis)connection with other people and oneself. Under these conditions, certain social groups are disproportionately disadvantaged, especially in the context of stigma layering (e.g., maligned ethnic minority status, young, and chronically ill), but it does not follow that they are essentially different, inherently weaker, or incapable. Much more could be written in that respect on the politics of disposability, especially in relation to young people (Giroux, 2012) labeled ill, though we lack space to do so in this article. Nonetheless, this does appear to be a relevant meta-theme, denoting processes young people may be highly sensitive to in neoliberal times.

One crucial implication from this politicized reading, derived from modes of inference employed within critical realist approaches to health inequalities (Scambler, 2001; Williams, 2003), is that relational strategies for tackling stigma and the associated “burdens of shame” (Scambler, 2006, p. 275) and “appended blame” (Scambler, 2018) must go beyond the micro-social realm. Rather, they necessitate the ascription/allocation of greater value to young people in ways that transcend the everyday contingency of asthma symptoms, individuals’ embodied desires to keep up appearances, and their felt need to act defensively or offensively through fear of being seen as anything but “normal” or “ordinary” (Prout et al., 1999). Hence, the task of redressing health inequalities for the specific benefit of young Irish Travellers diagnosed with asthma and other chronic conditions, important as that may be, is not our final word; rather, the admittedly more ambitious task is to foster a more equal and supportive society so that all young people’s sense of self-worth, value, and life-chances are not reduced to their (and our own) flawed, vulnerable, and mortal (disposable) bodies. That task includes but also goes beyond “wise” (Goffman, 1963/1968), or “structurally competent” (Metzl & Hansen, 2014), clinicians’ efforts to develop greater humility and listen to young people (Couriel, 2003). More fundamentally, it is necessary to question and possibly help transform the structures of a neoliberal society that is organized around individualism, competitiveness, self-responsibilization, healthism, forms of violence (symbolic, structural, physical), and the (hyper)commodification of “the perfect(ible)” body. Lessons from a modest study of young people with asthma may in that respect provide materials

not only for conceptual debates but also for multi-pronged efforts to tackle stigma in the larger and sometimes cruel body politic.

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