



# Disordered Society: Women in Eating Disorder Recovery Advise Policymakers on Change

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## Abstract

This qualitative study draws on a photo-elicitation method (“PhotoVoice”) and semi-structured interviews to examine the key areas stakeholders (30 young women between the ages of 18 and 35 in eating disorder recovery) identify as meaningful venues of policy-based change. Photography and the accompanying narratives capturing personally-meaningful social, cultural, and systemic influences on recovery were shared with the research team. Photographs and interviews were examined for policy implications using thematic analysis, and six areas of improvement emerged: media, healthcare practice and access, health insurance reform, education, objectification of the female body, and mental health stigma. Implications for reform are discussed.

**Keywords** Eating disorder · Policy · Health insurance reform · Media · Objectification

*And I think in order to start really working on eating disorders for individuals, treatment for individuals, we really have to focus on treating society. Because, like, society as an entity needs some residential [treatment] right now. (Steph, age 31)*

Eating disorders (EDs) are a significant public health issue in the U.S., affecting 13% of all young adult women (Stice et al. 2013). Eating disorders have the highest mortality rate among mental illnesses and nearly 30% of sufferers remain symptomatic at 10-year follow-up (Keel and Brown 2010), due in part to treatment barriers such as cost and access, and limitations in the effectiveness of many common treatment options currently available (Kazdin et al. 2017). Frontline medical providers, particularly primary care physicians, are

not well-trained in identifying EDs (Linville et al. 2010), and when individuals do seek medical and psychological support for disordered eating, the vast majority do not receive evidence-based care (Harvey and Gumport 2015), or receive care delivered without fidelity to core components (Shafran et al. 2009).

While the American Psychiatric Association (Yager et al. 2010) and the American Dietetic Association (Ozier and Henry 2011) have offered treatment guidelines and recommendations for EDs, progress in obtaining insurance coverage for the recommended course of care has been slow and the current system fails to reduce the individual and public health burden (Mond 2016). Very few internal medicine doctors are trained to identify disordered eating and provide referrals to specialists (Vetter et al. 2008), highlighting a major gap between research and practice, and an opportunity for change. These issues have been systemically examined for decades (i.e., Sigman 1996), yet barriers to insurance and adequate treatment persist (Kazdin et al. 2017).

Given the vast and multifaceted costs associated with the hardship of EDs for both patients and society (Whitford et al. 2013), it is critical to identify ways to improve ED recovery outcomes via empirically-informed policies designed to improve access and reduce barriers to care (e.g., Anna Westin Act, H.R. 2515; Helping Families in Mental Health Crisis Act, H.R. 2646). The Anna Westin Act (2015) is the first piece of ED-related legislation to be approved

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by Congress in U.S. history, and requires the U.S. Department of Health and Human Services to make ED-related educational information freely available. The act prohibits insurance companies from denying coverage to an individual based on a mental health diagnosis. However, there has been little progress towards expanding this act, which represents just a beginning for social-level change in this area. In addition, there is scant limited research on EDs that can be easily or directly translated into policy and action to reduce the burden of EDs on both the individual and society (Austin 2016). More research is needed to strengthen national ED-related health and social policies. The purpose of this paper is to provide an in-depth, participant-based set of recommendations, guided by feminist theory and social justice aims.

### **Objectified Body Consciousness and the Development of Disordered Eating**

The current body of research implicates sociocultural pressures for thinness and internalization of the thin ideal as the most salient predictors of disordered eating and the development of clinical EDs (Culbert et al. 2015). Exposure to these environmental factors, and to society's patriarchal views on women and the female body (i.e., sexual objectification) lead to the development of objectified body consciousness (OBC; Fredrickson and Roberts 1997; Moradi and Varnes 2017). Women who are hyper-focused on their own appearance, as is common with women diagnosed with EDs, are more aware of both their own and other women's physical appearance, and thus engage in frequent body comparisons. The act of comparing oneself against others likely both (1) perpetuates the objectification of other women's bodies and (2) reinforces OBC tendencies, situating the woman who is engaging in comparisons as both the source and target of objectification (Tylka and Sabik 2010). This cycle of comparison, self-objectification, and disordered eating is maintained and intensified by sociocultural factors promoting thin idealization (Lindner et al. 2012).

Per objectification theory (Fredrickson and Roberts 1997), cultural practices of sexual objectification, such as sexualized gazing and media portrayals of women's bodies, lead to OBC, in which women place greater emphasis on their appearance than on their internal attributes. This over-focus leads women to disregard their own physical cues and attempt unrealistic body-change strategies. As a result of adopting an observer perspective on oneself and internalizing messages regarding the malleability of the body to achieve cultural expectations, OBC manifests through body surveillance, body shame, and appearance control beliefs (McKinley and Hyde 1996). Each of these three components has been found to support the development and maintenance of the pursuit of thinness typically observed in women with

EDs (Calogero et al. 2005). Self-objectification, or OBC, meets the definition of a harmful cultural practice as delineated by the United Nations (1995), as it has dangerous health consequences, arises from and is justified by gender-based power differentials from which men profit, and generates stereotypes that stall the development of girls and women (Calogero et al. 2011).

Self-objectification highlights appearance control, rather than action against oppressive cultural forces, as effective currency in the societal system of sexual objectification and gender inequality (Calogero and Tylka 2014). In controlling one's own appearance instead of acting against a sexist and patriarchal system, self-objectifying tendencies serve to defend the status-quo (Calogero 2013). Alternatively, to stimulate lasting personal and social change, the lens of self-objectification needs to be re-focused toward a more holistic view of the self and of women in general, that will undermine the beliefs that keep this system in tact (Calogero and Tylka 2014). At the personal level, this re-focusing likely happens during ED recovery, during which time many social-cognitive changes occur. Women in recovery may therefore be well positioned to identify opportunities for re-focusing our view of and approach to women and EDs at the cultural and societal levels.

### **PhotoVoice: A Novel Method for Research, Advocacy, and Change**

While empirically based, most existing literature on self-objectification and disordered eating, and the few existing policy recommendations to prevent and intervene on disordered eating, have been directed and guided by the scientific, medical, and academic communities, giving limited voice to the individuals most affected, and profoundly restricting the depth of our knowledge and capacity for change (Ridge 2008). One way to address this gap is through participatory action research (Morrison and Lilford 2001), which invites participants to co-create the research protocol and policy agenda. Recent shifts in research priorities, such as the development of the Patient Centered Outcomes Research Institute, have placed increased emphasis and importance on the voices of the stakeholders and others most directly impacted by a mental health issue (Frank et al. 2014). However, there is a dearth of patient centered studies for individuals in ED recovery.

Participatory action research (PAR) frameworks function not only to increase understanding of a particular problem, but also to collect information for action and advocacy (Cornwall and Jewkes 1995) and place the power for directing change in the hands of the affected community. Participatory action research frameworks differ from conventional social science methodologies by involving participants

directly in research goals, planning, and design, and placing heavy emphasis on community action (Kemmis and McTaggart 2005). Participant-centered research has led to recent changes in cancer screening techniques, childhood asthma prevention, firearms violence, and early childhood education (Woolf et al. 2016). Over the last several decades, few researchers have begun to draw from this research framework to improve ED prevention (i.e., Piran 2001) and better understand the ED recovery process (LaMarre and Rice 2016), and much room remains for additional exploration.

PhotoVoice is one PAR framework especially well-suited to examining ED recovery. The PhotoVoice method has three complimentary goals: (1) provide a platform for participants' lived experiences and viewpoints, (2) involve both the culture and community to exchange ideas surrounding key themes that emerge via photographic art and oral exploration, and (3) ensure that the information is not confined to the academic and scientific communities (Wang and Burris 1994, 1997). The method involves the use of photography and accompanying narratives to explore social issues. To date, PhotoVoice has been used to examine a broad array of systemic problems, including homelessness, disability, illness, war, and violence (Hergenrather et al. 2009). PhotoVoice has been highlighted as an appropriate method for exploring sensitive topics, including body image, because participants are recognized as the experts surrounding a given issue, and are able to provide information and insight at their own pace and comfort level (Brunsdon and Goatcher 2007). The PhotoVoice method has been correlated with multiple mental and physical health-promoting outcomes, such as empowerment and improved self-efficacy (Foster-Fishman et al. 2005). Notably, PhotoVoice projects have led to health policy changes in a variety of areas, including obesity prevention at the local level, improved access to handicapped parking, and reduced tobacco sales (Sanon et al. 2014).

## Current Study

Given the identified gaps in the literature around participant-centered ED recovery research and research with direct policy implications, the current study used PhotoVoice to collect and synthesize the insight stakeholders bring to this issue, for the purpose of informing policy and practice. Previous research suggests PAR projects offer a unique perspective unable to be captured through the use of typical quantitative or basic qualitative methods. We were especially interested in the suggestions women in ED recovery would have for policymakers regarding the social and cultural forces that can make recovery challenging. Specifically, the current study sought to examine reform suggestions and

highlight areas of change that are most significant for individuals directly touched by these disorders.

## Method

### Participants

The current data are part of a larger PhotoVoice qualitative data set on perspectives of women in ED recovery, a portion of which has been previously analyzed for other research questions (Authors, in press). Women self-identifying as in ED recovery ( $n = 30$ ) from the northeastern U.S. ( $n = 6$ ) and the southeastern U.S. ( $n = 24$ ) participated, following informed written consent. Women in self-defined ED recovery between the ages of 18–35 were invited to participate ( $M = 23.37$ ,  $SD = 4.35$ ). All participants were U.S. citizens, and had lived in the U.S. for at least 5 years. The sample was racially and ethnically diverse, with the majority self-identifying as White Hispanic ( $n = 17$ , 56.67%). One-third of participants identified as White non-Hispanic ( $n = 10$ ), two identified as Black Hispanic (6.67%), and one as Indigenous North American (3.33%). Contributors represented both convergent and diverse views held by community members within two areas of the U.S.

### Procedure

Participants were recruited via multiple methods: the distribution of paper flyers across the campus of a large, Southeast, Hispanic-serving public university; electronic advertisements on social media platforms; and snowball sampling. After learning about the study goals and providing informed consent for participation and use of photographs, participants were presented with the study prompt (Saunders and Eaton 2018):

“Give us insight into your recovery world. What are the social and cultural pressures and expectations in your world that support you in your recovery, and what are those that are challenging for you in your recovery? What role does comparison to others play in making recovery more challenging? What types of comparisons serve to support your recovery process? Please take photos of the things you encounter in your everyday life to answer these questions and help me to better understand your recovery process”

Participants had 7 days to creatively respond to the prompt by taking as many photographs as they deemed necessary to best capture their experiences. Participants had the option of using a disposable camera offered by the research team. However, all photos were taken on smartphone cameras. The number of photographs taken by each participant

varied widely, from four to 28 ( $M = 10.13$ ,  $SD = 5.56$ ). In-person semi-structured interviews reviewing and discussing the photos were conducted between May and November 2017, one-on-one with the first author ( $n = 16$ ) or the trained graduate research assistant ( $n = 14$ ). The first and second authors jointly trained the graduate research assistant, in-person and by having the graduate research assistant review previously completed interviews. Participants chose to hold their interview in a variety of locations (private on-campus office space,  $n = 21$ ; coffee shop,  $n = 7$ ; park,  $n = 2$ ). The interviews ranged in length from 30 min to one hour and 20 min ( $M = 49$  min 20 s,  $SD = 13$  min 12 s). Thirty percent of participants shared older photographs in conjunction with new photos they took for the project.

The semi-structured interview began with rapport building between the interviewer and participant, and the sharing of brief demographic and ED background information. Participants were then asked to reveal the photos they brought, and answered a series of questions about each one. The semi-structured interview protocol featured open-ended questions, allowing the participant to determine the amount and content of the information she wished to share, and to defer questions pertaining to areas of recovery she was uncomfortable sharing with the interviewer. The semi-structured interview used the SHOWeD technique (Hergenrather et al. 2009) to probe participants about each of their photos. Corresponding to guidelines established for Photovoice work, participants (S) discussed what can be *seen* in the photo, (H) expressed what is *happening*, or the potentially unseen tale behind the photo, (O) connected the picture to *our* lived experiences, (W) highlighted *why* things are this way, and (D) discussed *ideas* for a strong solution to the underlying issue captured in the picture. At the end of the interview, participants had the opportunity to reflect on their recovery process, offer direct suggestions to policymakers and the government, and ask any questions they had about the study process. Participants were asked if their photographs and narratives could be shared with local, state, and national representatives to promote policy change. All participants granted consent, and nearly all expressed gratitude for this step of the research process. None of the participants were involved in other ED related advocacy. With participant consent, interviews were documented on a mini Sony ICD-UX71 digital voice recorder. Participants selected a pseudonym, which is used throughout the manuscript, to preserve anonymity. Participants received a \$25 e-gift card as compensation for their time. All procedures were approved by the university's Institutional Review Board.

## Data Analysis

A team of five undergraduate research assistants and one graduate research assistant transcribed the 30 interviews. A

random selection of six interviews (20%) were evaluated by an independent transcriber for accuracy. The primary goal of the overarching study was to examine social-cognitive (i.e., social comparison and self-objectification) processes during women's ED recovery journeys, particularly to identify the types, targets, and effects of social comparison for this population. After viewing the photos the participants shared and conducting the semi-structured interviews, it became clear that this work has important policy implications and recommendations; hence, common to data interpretation from PhotoVoice projects (Han and Olliffe 2016), the data were re-examined using thematic analysis to extract patterns of meaning (Braun and Clarke 2006) regarding participant health and social policy suggestions.

The research team took an iterative approach to coding the interviews. After reviewing all 30 interviews, the first author and a graduate research assistant met to discuss all of the possible policy-related content. The first author then developed an initial codebook using a series of steps customary to qualitative research to reinforce reliability and consistency between coders (Strauss and Corbin 1998). Two independent coders reviewed the transcripts, and extracted participant commentary relevant to policymakers across six domains: (1) objectification of the female body, (2) depictions of women in media, (3) mental health stigma, (4) health care practice and access, (5) education, and (6) insurance reform. These domains were chosen given prior work on ED etiology and recovery, and salient themes that persisted across the sample. The first author and a graduate research assistant then coded six random transcripts, and met to discuss the codes and assess reliability ( $\kappa = 0.78$ ). To assure continued reliability, the first author coded all thirty transcripts, and the graduate research assistant also coded seven randomly selected interviews ( $\kappa = 0.84$ ). At both junctures, discrepancies among codes were resolved by a third random coder, another graduate research assistant.

## Results

In response to the guiding prompt, participants shared a total of 304 photographs ( $M = 10.13$ ,  $SD = 5.56$ ), and offered 82 suggestions (range 1–11,  $M = 2.82$ ,  $SD = 2.07$ ) across the 30 interviews. These suggestions fell into six categories or themes: media ( $n = 18$ ), healthcare practice and access ( $n = 18$ ), insurance reform ( $n = 14$ ), education ( $n = 13$ ), objectification of the female body ( $n = 12$ ), and mental health stigma ( $n = 7$ ). Each of these themes is expanded upon below, with key participant examples, and appear with relevant sub-themes in Tables 1, 2, 3, 4, and 5, with the exception of mental health stigma, which was not comprised of additional sub-themes. Example photographs associated with each theme appear in Fig. 1, 2, 3, 4, 5, and 6.

**Table 1** Sub-themes and examples within the media theme

Media	Airbrushing/editing of images (n=9)	I think it was American Eagle that they had like their Aerie bathing suits... That they're like not retouching the models... that helps a lot, definitely...
	Increased diversity in tv/movies (n=6)	I would have them [fat women] not in token roles. I would have them as main characters doing serious stuff as well as... yeah I just think they need to increase body diversity on tv.
	Fashion designed for bodies of all sizes (n=4)	I'm not gonna be able to pull off certain fashions ever. It's okay, and I'm learning that but it's really painful when the only examples you ever see are like boxes you'll never fit in
	Decreased body shaming (n=3)	I don't think its ok to fat shame, I don't think its ok to skinny shame, I don't think its ok to shame anyone for whatever they look like

**Table 2** Sub-themes and examples within the healthcare practice and access theme

Healthcare practice and access	More thorough training for doctors (n=8)	I think that it says that our doctors are being trained wrong... they, they're not trained. They don't know how to talk about body weight.
	Improved treatment of co-morbid physical health issues (n=6)	I know that losing weight will solve a lot of the [diabetes] problems but, it might not, it might just backfire
	Less of an emphasis on weight and BMI (n=5)	You know, I'm 5'6" and then they weigh me and technically, I'm over the weight limit of my height range and my body mass index should be. But I'm not fat, I'm not unhealthy, it's just muscle. And they, sometimes they make you feel that you're overweight or you don't fit into those sort of border-line guidelines that they have.
	More treatment options and resources (n=4)	I guess it would help to have more support groups, art therapy, things like that, that are more therapeutic and easy to access.

**Table 3** Sub-themes and examples within the healthcare insurance reform theme

Health insurance reform	Affordability of treatment (n=9)	I mean that [cost] kept me the longest from ever reaching out cause how can you drop that much money as a college student?
	Insurance stopping coverage prematurely (n=5)	..insurance has no right to all of a sudden say oh you ate three meals a day for 7 days in a row you must be fine.

**Table 4** Sub-themes and examples within the education theme

Education	Education for young girls (n=11)	...maybe there should be like a class like early on before college. Maybe in middle school like of to bring awareness of like the girls and um really um incorporate body positivity
	Education for medical providers (n=8)	I wish they [doctors] were more empathetic. More, like, that they would kind of educate themselves of the mind of someone going through an eating disorder
	Education for families (n=3)	...it's just not part of the culture so like, I don't expect them [family] to understand everything overnight and like how psychology and all this stuff works together but, I mean, I wish it would be... there would be more like, education on it

## Media

Unsurprisingly, nearly all (90%) of participants noted the role media and social media and the sociocultural pressures from the general media played in their disorder and the ways in which these messages both help and hinder their recovery process. Thirteen of those participants had specific suggestions for the curation and regulation

of images and diet information from both the media and social media. Participants supported a reduction in the number of depictions of underweight women in advertisements, television, movies, and across photo-based social media platforms, such as Instagram. Social media, websites, commercials, and magazines were also mentioned as conduits of information promoting disordered eating

**Table 5** Sub-themes and examples within the objectification of the female body theme

Objectification of the female body	Decreases in the use of women's bodies to sell products (n=4)	...putting restrictions on certain like advertisements and things like that. Like there's a commercial that I hate...I wish there was a restriction where it would be like if you you know...Just stop. Like no more portrayal of sexualized females anymore in any media anything like that
	Shifts in the idea of using beauty as currency (n=3)	...if you are pretty, then the men can take advantage of you and then you'll get parts because they took advantage of you and as long as your quiet, you'll keep getting good [jobs] so I think that's probably why pretty girls succeed, pretty thin girls
	Giving women more permission to take up space in society & male-dominated fields (n=3)	I think the big cultural message that everything boils down to is that women are not supposed to take up space. And that's the thing I am fixating on. How much space am I taking up, and is it more space than I'm allowed?

**Fig. 1** Photographic example from media theme**Fig. 3** Photographic example from health insurance reform theme**Fig. 2** Photographic example from healthcare practice and access theme

behavior that was supremely unhelpful during the ED recovery process. According to Caroline (age 19):

It should be regulated more, it shouldn't be so... maybe it's not even up to the government, but they should regulate more what we're all exposed to... because, you know you go anywhere and all you see are these molds, these perfect molds that we're pushed to fit. I think that it should be regulated and there should be a certain limit...not everything should be about how to lose weight and how to, you know, how to get smaller. Also on the internet there's so much that should be taken down. All these tips and tricks and how to you know starve yourself and how to purge and how to do this and that...



Fig. 4 Photographic example from education theme



Fig. 5 Photographic example from objectification of the female body theme



Fig. 6 Photographic example from mental health stigma theme

## Healthcare Practice and Access

The area most frequently mentioned as an avenue for policy change was healthcare practice and access. Thirteen participants (43%) offered four unique areas of improvement healthcare access and practice for women in ED recovery: more thorough training for doctors, improved treatment of co-morbid physical health issues, less of an emphasis on weight and BMI, and greater access to competent care. Nearly a quarter of the sample ( $n=7$ ) noted the lack of education medical doctors receive on diagnosing and treating eating disorders, or spotting co-morbid psychological and medical conditions. The two participants in the sample who had experienced pregnancy highlighted the importance of receiving specialized pre- and post-natal care informed by ED treatment specialists. Furthermore, participants noted the lack of sensitive and empathic discourse they received from medical providers about eating and weight concerns. According to Steph (age 31):

I think that it says that our doctors are being trained wrong. I have heard numerous stories from friends across the board of insensitive doctors in a wide variety of like areas, not just like PCP not just like... and they, they, they're not trained. They don't know how to talk about body weight. I've had one friend uh, shamed by her gynecologist, yeah... And I think in a field especially like endocrinology you can't just tell people they're fat and that's why they have problems... (They need) training for the doctors... that would be more sensitive about language and I would actually get them nutrition information that is accurate instead of just what the US government says.

Relatedly, participants spoke with frustration about lack of access to mental and physical healthcare in the United States, as it can be especially cost-prohibitive and the requirements for admission into intensive treatment can be extreme. More than one participant noted that when she began seeking treatment, she was told her BMI was not low enough to warrant care, or her electrolyte values were not abnormal enough. For example, Ber (age 32) noted:

...and I wasn't 'anorexic' at the time because I would eat but I would just throw up and I wasn't underweight so I was eating nonetheless so I didn't have an actual diagnosis, I checked what my BMI was. (I was) on the brink of death and I had to fight them like do you know how devastating it is when you're finally willing to get the help and then you have to actually have to prove that, like you have doctors telling you, no you're not sick enough...like, do you know how messed up that is? So like, tell someone who's trying to get sicker that they're not sick enough, and it causes self-sabotage.

## Health Insurance Reform

Over one-third ( $n = 12$ ) of participants mentioned the need for insurance and healthcare reform at the national level, to ensure that individuals receive the mental and physical healthcare they need, as it is often out of reach for low and middle-income US families. Participants expressed frustration at both insurance corporations and politicians for regularly failing to meet the needs of this population. One participant (Jen, 23) remembered the financial drain her recovery placed on her family's resources:

A lot of insurances don't see this as medical situation, they don't cover fully the treatments, they might cover psychiatrist and medication but at this point there's not a lot of medication you can take maybe something for the anxiety. But I do remember having to stop treatments because I couldn't pay for it when I was around maybe 15... at the time, if I remember correctly, there used to be these powdered mixes that had a lot of calories, a lot of protein, I want to say they were called like the (shake name). They tasted really gross but insurance wouldn't cover that because they consider it a health shake, protein shake. And those were very expensive, it was like \$60 for a box, maybe like a week's supply. We've always had a very low income, my grandmother never worked in this country and my grandfather had minimum wage his whole life, since we've been here. So it was difficult to afford that kind of treatment.

Em (age 23) reflected on how detrimental the 2017 Republican-backed Healthcare reform bill would be for women in general, particularly those recovering from clinical EDs:

I want to feel like politicians are actually working hard to help us...Instead of you know, taking away like, I mean I can list so many things actually... but, you know, the big thing is taking away like our um... access to basic health care for example I think that's an important things because if, if I had been this age when I developed an eating disorder I wouldn't have been able to afford treatment um...so it's kind of like "help us, don't make us...don't villainize us" and we're not...this isn't something that we do out of vanity. It's more like, we can't help it, it's a disorder, you know, just like I can't help that you know I'm depressed or that I have anxiety.

## Education

Over one-third ( $n = 12$ ) participants highlighted the need for more education around EDs, both to prevent their development and also to help parents, friends, and family members support individuals through the recovery process. Participants saw the benefit of teaching intuitive eating and dietary flexibility at a young age, educating adolescents on the detrimental effects of social media use and the realities of the fashion and performing industries, and educational programs to improve self-esteem, self-efficacy, and self-worth in children and adolescents. Anastasia (age 21) reflected:

A lot of times I think that when people go into an eating disorder, they just don't...they're not educated enough. Well obviously they're not educated about food or anything... it has to be implemented in like the families have to get educated on how to see those things and how to prevent those things because for me no one knew like....I guess it has to be education...for parents. Mostly for parents. First place. So that they can see it and watch it and like have an idea of that that can happen. I don't think my parents had any idea that that could have happened. So definitely that, and I feel like that's one of the few things that can be done in this situation.

## Objectification of the Female Body

Nearly one-third ( $n = 9$ ) of participants thought it prudent to improve upon the way society views the female body, primarily as an object that needs to be pleasant to look at and fit unrealistic beauty ideals. Participants who had been pregnant ( $n = 2$ ) spoke of the unique objectifying statements they received during their pregnancies. Furthermore, participants discussed the use of beauty as currency in our current culture, and the overarching belief that this message extends beyond looks to merely having permission to exist—that women are not supposed to take up physical, emotional, or intellectual space. As put by Kate (age 20):

You have to be thin if you are perfect. And you have to be perfect if you are a woman. It's like the price you pay to exist in this world as a woman. I read that somewhere. I didn't come up with that. The rent you pay is by being pretty and perfect... I'm not sure why we are this way, but we have put this requirement on women that unless you are a certain body type, you do not belong, especially in the United States..... we have decided that for some reason that women have to look a certain way and if you look anything different then that certain way, then you are wrong and



you don't actually deserve to exist in this world and that's not very fair.

## Mental Health Stigma

Nearly one-quarter of participants ( $n = 6$ ) offered recommendations for decreasing mental health stigma and increasing empathy for those suffering from EDs at the individual and societal level. Several participants noted the helpfulness of medical marijuana in overcoming their EDs, and wished the legalization of marijuana was a less polarizing topic. Nearly every time a participant mentioned mental health stigma, it was made clear that the stigmatized societal attitude extended beyond eating disorders to general mental health. Ali (age 35) said,

It needs to be a less taboo subject. And it needs to be taken more seriously. Because I feel like so many people just think it's this vain disease, that it's, you know, nobody understands how much deeper it goes, unless they've been there. Um, and there's so much... it's not just the eating disorder, it's mental health in general, there's such a negative stigma that like, nobody talks about it. And it just makes those dealing with it that much less likely to seek help, feel that much more alone, and that needs to change.

## Discussion

Using the PhotoVoice method, the current study identified areas for potential policy and healthcare reform, informed by recommendations of a diverse group of women in ED recovery. Six themes related to ED policies and practices emerged: changes to mass and social media, healthcare practice and access, health insurance reform, education, objectification of the female body, and mental health stigma. Contributors' frustrations and suggestions for improvement echoed those from professional organizations specializing in the treatment of eating disorders (Puhl et al. 2014). For example, both highlight inadequate access to quality care (Kazdin et al. 2017), and the research-practice gap (Schoenwald et al. 2012), as women continue to be affected by robust sociocultural factors identified in the scientific literature, such as objectification (Grabe et al. 2008), and these sociocultural factors result in the perpetuation of unachievable cultural norms, such as the thin ideal. Thus, findings from the present study underscore opportunities for change action at the policy and societal level to support larger-scale impact (Austin 2016).

## Opportunities for Reform

### Mass and Social Media

The most frequently mentioned avenues for reform were mass and social media outlets. Both have been frequently implicated as causal and correlational factors for increases in body dissatisfaction and disordered eating (Mabe et al. 2014; Saunders and Eaton 2018). Many participants were familiar with the recent law in France banning models with low body mass indices ( $< 18$ ) and warning labels indicating an image had been altered (Wissinger 2015). While providing a warning label has not proved efficacious in experimental settings (Bury et al. 2016), body diversity in advertising and images holds the potential to decrease body dissatisfaction, for instance, for individuals with a greater tendency to engage in appearance-related social comparisons, or for whom the body does not conform to the thin ideal (Convertino et al. 2016). Also successful in improving body image, and thus reducing the risk of disordered eating, is a focus on body function over appearance (Paraskeva et al. 2017).

Given these prior findings, one suggestion emerging from the PhotoVoice project concerning social and mass media would be to place a similar restriction on the size of models portrayed in the fashion industry and advertisers, and instead, feature women representing a wide diversity of shapes, colors, and sizes. More women in positions of power within the media structure would aid in promoting this change. The current and prior findings also highlight the need for more thoughtful and educated consumers. Programs to promote mass and social media literacy for consumers at a very young age (such as that designed by Bird et al. 2013) would assist young girls in accurately processing the images they are inundated with from a young age (Dohnt and Tiggemann 2006). Lastly, the media could be leveraged to inspire healthy communication about sociocultural risk factors, health disparities in access to care, and disordered eating. For instance, communication about health disparities delivered through mass media channels has resulted in increased support for policies to bolster social determinants of well-being within disenfranchised groups (Niederdeppe et al. 2013). The same may be true regarding communication of the role mass and social media have on disordered eating outcomes.

### Objectification of Women

As illustrated by both the photographs and accompanying narratives, this systemic change at the societal and cultural level may have cascading influences on not only the way women's bodies are portrayed and talked about, but also by challenging the patriarchal system that promotes sexual objectification and third-person perspective of women's

bodies (Calogero and Tylka 2014). Many participants spoke of beauty and body as a currency for success in the modern world, highlighting a larger societal issue that extends beyond disordered eating. Objectification theory (Fredrickson and Roberts 1997) presumes that gender roles and sexual objectification practices promulgated by society lead women to subsume an external self-perspective, disregarding internal attributes and sensations and instead placing excessive focus on appearance and misguided attempts to achieve society's beauty standards.

Self-objectification has cascading consequences on women's mental health outcomes including but not limited to EDs. While popular media propagates the misconception that EDs are rooted in vanity and narcissism, objectification theory offers an alternative interpretation: women assimilate to an observer-oriented self-perception not out of self-absorption, but as an anticipatory strategy that allows for a modicum of agency in how one will be regarded by others (Calogero et al. 2011). The current findings support this interpretation and provide insight into how a subset of women, whether consciously or subconsciously, successfully challenge the system that promotes self-objectification and ongoing gender inequality. Participants explicitly mentioned the role of the patriarchy in maintaining an unrealistic and de-humanizing view of the female body, and how this view is made evident to girls from a very young age and pervades multiple societal domains.

### Healthcare Practice and Access

When asked directly if they had advice to offer policymakers and the government, the vast majority of participants offered areas of improvement in health care practice and access, followed closely by the need for health insurance reform. This is especially relevant as impending healthcare reform policies in the United States (i.e., repeal of the Affordable Care Act) have the potential to curtail access to necessary treatment (American Psychological Association 2016) for individuals suffering from physical and mental illness, including clinical eating disorders. Prior experimental research has indicated that both the general public and ED treatment professionals agree there is need for more training for educators and doctors, to enable the early identification of disordered eating behavior and subsequent appropriate referrals to specialists (Puhl et al. 2014). Several participants expressed anger and frustration over the seemingly negligent and weight-stigmatized care they received from non-specialists, sharing that such interactions hindered, rather than promoted, their recovery trajectory. Few individuals with clinical EDs seek medical or psychiatric care explicitly for their eating and/or weight disorder (Williams et al. 2008); hence, the current finding reiterates the need for better medical and

psychosocial training for providers most likely to interact with patients who may be suffering from an ED.

### Healthcare Reform

Furthermore, while more recent legislative changes have achieved parity for mental illness to be recognized and treated similar to a physical illness, the criteria for coverage remain quite conservative (Hewitt 2013), preventing individuals with clinical EDs from receiving the intensity and duration of care that is clinically recommended. Many participants shared details of their exasperating personal experience with this loophole in insurance coverage. These experiences are not unique to the current sample; the National Eating Disorders Association (NEDA) has issued a statement highlighting the most common reasons for denial of coverage (NEDA 2018), which include paradoxical rationales: weight not low enough, condition is either considered chronic or improved slightly without care, or lack of severe medical complications. Legislation aiming to improve access to care for individuals in ED recovery has been introduced and signed, and will hopefully serve as an important step in increased access to care for individuals in need.

### Education and Stigma Reduction

Along with educating medical providers, participants spoke of the importance of educating children at a young age to be attuned to their bodies and cultivate body appreciation. Many women noted that yoga had supported their recovery process, which is further supported by prior research incorporating mindfulness and self-care into ED treatment (Cook-Cottone 2015). The frequency with which education was highlighted as an avenue for reform suggests that existing education programs in secondary and university settings may be insufficient to mitigate risk for EDs. Education programs tailored to parents of adolescents have been met with success (Lock and le Grange 2005), and based on feedback from our participants, we suggest expanding such programs to peers and other close-knit social ties.

However, prior research indicates such education needs to be delivered in a sensitive and intentional manner, as ED public service announcements have had the unintended consequences of increasing negative attitudes toward individuals with EDs (Iles et al. 2017). This stigmatization was also acknowledged by participants, and challenging mental health stigma emerged as another salient theme with implications for policymaking and intervention. Stigma towards individuals with EDs is frequent and well documented (Puhl et al. 2014; Roehrig and McLean 2010), and associated with multiple adverse outcomes (Griffiths et al. 2015). Simultaneously targeting education and stigmatization will be important in maximizing the effects of any attempts at systematic

change. Ideally, efforts to improve education and reduce stigma could be efficient and synergistic, i.e., as the public (providers, families, etc.) become better informed, stigma may also decrease. Thus, interventions with an eye toward both could maximize efficiency and efficacy.

## Conclusion

Women in ED recovery highlighted six key areas of reform that they viewed as supportive of the ED recovery process. Existing agencies and opportunities, such as the Eating Disorder Coalition National Lobby Days on Capitol Hill, and annual awareness campaigns by NEDA are two mechanisms for these findings to hold influence. The current findings emphasize the importance of pushing existing legislation and reform forward, as the progress made at the national level needs to be maintained and expanded to ensure the availability and affordability of competent care for more individuals suffering from this debilitating disorder. The National Institute of Mental Health has an ED research program within the Division of Translational Research, aiming to use research to improve treatment outcomes, and the points raised by women in ED recovery underscore that this funding is sorely needed. In the words of one participant, we need to take more steps to fix this “disordered society.”

**Funding** This study was funded by the APA Division 35 Janet Hyde Graduate Student Research Grant.

## Compliance with Ethical Standards

**Conflict of interest** Jessica F. Saunders, Asia A. Eaton, and Stacy L. Frazier declare that they have no conflict of interest.

**Ethical Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Written informed consent was obtained from all individual participants included in the study.

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