



Review

Reducing the burden of suffering from eating disorders: Unmet treatment needs, cost of illness, and the quest for cost-effectiveness



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ABSTRACT

Eating disorders are serious mental disorders as reflected in significant impairments in health and psychosocial functioning and excess mortality. Despite the clear evidence of clinical significance and despite availability of evidence-based, effective treatments, research has shown a paradox of elevated health services use and, yet, infrequent treatment specifically targeting the eating disorder (i.e., high unmet treatment need). This review paper summarizes key studies conducted in collaboration with G. Terence Wilson and offers an update of the research literature published since 2011 in three research areas that undergirded our collaborative research project: unmet treatment needs, cost of illness, and cost-effectiveness of treatments. In regards to unmet treatment needs, epidemiological studies find that the number of individuals with an eating disorder who do not receive disorder-specific treatment continues to remain high. Cost-of-illness show that eating disorders are associated with substantial financial burdens for individuals, their family, and society, yet comprehensive examination of costs across public sectors is lacking. Cost measures vary widely, making it difficult to draw firm conclusions. Hospitalization is a major driver of medical costs incurred by individuals with an eating disorder. Only a handful of cost-effectiveness studies have been conducted, leaving policy makers with little information on which to base decisions about allocation of resources to help reduce the burden of suffering attributable to eating disorders.

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Our collaboration with Professor Wilson started at the beginning of the new millennium and lasted for a decade during which we spent many hours in stimulating conversations about how our complementary expertise in epidemiology and health services on the one hand, and Professor Wilson's towering expertise in the development of psychological treatments could be brought to bear to the problem that few individuals with an eating disorder ever received evidence-based care. One of the major areas of Dr. Wilson's multi-faceted research program has been to develop and refine Cognitive-Behavioral Therapy (CBT) (Wilson, 1999), and his work on developing CBT for bulimia nervosa and related eating disorders has answered successfully the question of whether eating disorders were amenable to psychological interventions (Latner & Wilson, 2000; Wilson, Fairburn, Agras, Walsh, & Kraemer, 2002). With feasibility and efficacy of CBT for the treatment of BN or binge eating no longer in question, numerous new questions were ripe

for further study. Wilson and colleagues led the field in research of moderators (for whom is CBT especially helpful?) or mediators (what mechanisms might explain why CBT works?) (Grilo, White, Gueorguieva, Wilson, & Masheb, 2013; Kraemer, Wilson, Fairburn, & Agras, 2002), efficacy of CBT versus other psychological treatments (e.g., Interpersonal Psychotherapy) (Agras, Walsh, Fairburn, Wilson, & Kraemer, 2000), efficacy of CBT by itself or in combination with other treatments (Grilo, Masheb, Wilson, Gueorguieva, & White, 2011), mode of delivery (expert therapist versus guided self-help) (Loeb, Wilson, Gilbert, & Labouvie, 2000), prediction of outcome based on early response to treatment (Grilo, White, Wilson, Gueorguieva, & Masheb, 2012; Hilbert, Hildebrandt, Agras, Wilfley, & Wilson, 2015), and of the impact of various methodological features on study outcomes (Wilson, Wilfley, Agras, & Bryson, 2011).

At the time, epidemiological studies of eating disorders were far less developed than were treatment studies, and the limited research suggested a troubling finding: when asked whether they had sought or received treatment, few respondents with an eating disorder answered in the affirmative. There was not yet a

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literature on the reasons for the relatively low prevalence of treatment among individuals with an eating disorder. Of note, however, early (and then quite crude) studies (Striegel-Moore, Garvin, Dohm, & Rosenheck, 1999; Striegel-Moore, Leslie, Petril, Garvin, & Rosenheck, 2000) using electronic medical records showed that patients with an eating disorder diagnosis accessed health services at a higher rate than individuals without an eating disorder diagnosis, suggesting that the failure to access or receive treatment specifically for the eating disorder was not a simple function of not accessing medical care in general. These early health services studies suggested a paradox of high unmet treatment need yet elevated use and costs of health services among individuals with an eating disorder: despite elevated use and cost of health services among those with an eating disorder compared to individuals without an eating disorder diagnosis, few individuals received treatment specifically to help them overcome their eating disorder.

That individuals with an eating disorder would report high levels of health and mental health services use was understandable for at least three reasons. One, it is well-established that eating disorders are associated with high levels of distress and psychosocial impairment (Agh et al., 2015; Mitchison, Hay, Slewa-Younan, & Mond, 2012; Preti et al., 2009; Sareen, Cox, Affi, Clara, & Yu, 2005); across various disorders it has been shown that psychological distress or impairment is associated with treatment seeking (Bruffaerts et al., 2015; Demyttenaere et al., 2004). Two, eating disorders often precede, occur in the context of, or follow other psychiatric disorders (most commonly anxiety disorders, mood disorders, or substance use disorders) (Bodell, Joiner, & Keel, 2013; Jaite, Hoffmann, Glaeske, & Bachmann, 2013; Kessler et al., 2013; Striegel-Moore & Bulik, 2007); research has shown that psychiatric comorbidity is correlated with elevated health services use (Mack et al., 2014). And three, while psychiatric comorbidity has long been known to be common among individuals with an eating disorder, recent research has also documented elevated risk for developing a range of health problems or physical illnesses such as obesity, diabetes, cardiovascular disease, gastrointestinal problems, compromised bone health, infertility or obstetric complications, and tooth decay (Bedrosian, Striegel, Wang, & Schwartz, 2012; Forney, Buchman-Schmitt, Keel, & Frank, 2016; Hermont, Pordus, Paiva, Abreu, & Auad, 2013; Kimmel, Ferguson, Zerwas, Bulik, & Meltzer-Brody, 2015; Misra, Golden, & Katzman, 2015; Mitchell et al., 2015; Norris et al., 2015; Raevuori et al., 2015; Sachs, Harnke, Mehler, & Krantz, 2015; Striegel, Bedrosian, Wang, & Schwartz, 2012; Weigel, König, Gumz, Löwe, & Brettschneider, 2016); seeking treatment for physical problems tends to carry less stigma than requesting help for a mental disorder. Therefore, even if an individual may be reluctant to access care for an eating disorder due to fear of being stigmatized, s/he may be willing to seek treatment for a physical comorbidity of the eating disorder.

Early empirical evidence of high health services utilization and cost came from studies of health insurance data. An examination of 12-month medical claims of almost 4 million individuals found that among those who received treatment for an eating disorder, the treatment costs were substantial: for example, the costs associated with the treatment of anorexia nervosa (AN) or bulimia nervosa (BN) were comparable with the costs associated with the treatment of schizophrenia. However, the number of individuals who had been treated for anorexia nervosa (AN), bulimia nervosa (BN), or an eating disorder not otherwise specified (EDNOS) was far smaller (by at least a factor of 10) than would have been expected based on the estimated prevalence of these disorders in community samples (Striegel-Moore et al., 2000). Medical claims data may not fully reflect the true prevalence of treatment for an eating disorder because treatment providers may use another diagnostic code by

choice (for example, if an insurance company does not support treatment of an eating disorder, which was fairly common at the time of the study). Therefore, another approach involves examining health services use in community samples where study participants are screened for an eating disorder and then queried about their treatment history. A community-based study of 2046 young adult women found that only about one in four individuals with an eating disorder (confirmed by rigorous diagnostic assessment) ever had sought or received treatment specifically directed at improving their eating disorder symptoms (Striegel-Moore et al., 2003). A subset of this sample was included in a study of health services utilization in the past 12 months. Findings indicated that women with a diagnosis of BN or BED reported elevated health services use compared to women with no history of an eating disorder (Striegel-Moore et al., 2005).

This paradox of unmet need for treatment in the context of elevated health services use and costs among individuals with an eating disorder was all the more compelling to us in light of the accumulating research (attributable in large measure to Professor Wilson) that showed that Cognitive-Behavioral Therapy (CBT) was effective in the treatment of BN and BED, and that CBT could be adapted for delivery within a stepped care framework.

Together with our colleagues at the Kaiser Permanente Center for Health Research (ably led by Dr. Lynn DeBar) and funding from the National Institute for Diabetes, Digestive and Kidney Diseases, we embarked on what for us became (literally and figuratively) the BEST study (“Binge-Eating Self-Help Treatment”) of our career because of Professor Wilson’s guidance, mentorship, and friendship. That the project required regular trips to Portland, Oregon, a city with seemingly inexhaustible opportunities for enriching our research meetings with fine food and drink was an added bonus.

Our principal aspiration for the BEST study was to demonstrate that it would be feasible to provide a relatively inexpensive form of evidence-based treatment for binge eating and that patients who received such care would not only improve but that the target treatment would be more cost-effective than treatment as usual. We targeted recurrent binge eating for the pragmatic reason that epidemiological studies had shown that eating disorders involving recurrent binge-eating episodes were more common than eating disorders without such episodes (Striegel-Moore et al., 2003) and yet, there was still a dearth of studies on the treatment of binge eating. Using a randomized clinical trial (RCT) design, we tested the effectiveness of Cognitive-Behavioral Therapy (CBT)-based guided self-help (GSH) because, at the time, CBT was the most extensively evaluated treatment modality for individuals with an eating disorder and prior research supported GSH as a viable first step in the treatment of binge eating. And, finally, we opted to conduct the study in the context of a large health maintenance organization (HMO) because we wanted to conduct our cost-effectiveness analyses based on objective data about health services utilization and costs.

The BEST study to this day is unique in that it permitted us to examine health services use and cost-effectiveness data in a community based sample of women and men whose eating disorder diagnosis was established by state-of-the-art assessment and whose health services use data were extracted from comprehensive and accurate medical records. Specifically, we were able to use medical records for the 12 months preceding enrollment in the RCT to describe health services utilization and cost in individuals with a diagnosis of BN or BED (Dickerson, DeBar, Perrin, Lynch, Wilson, Rosselli, Kraemer, & Striegel-Moore, 2011), use medical records for the 12 months following the RCT to assess the impact of CBT-GSH for recurrent binge eating on health services utilization and cost (Lynch et al., 2010), and demonstrate the relative cost effectiveness of CBT-GSH compared to usual care (Lynch et al., 2010). It is

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