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A B S T R A C T
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, Wilfey, & Wilson, 2015), and of the impact of various methodological features on study outcomes (Wilson, Wilfey, 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 disordered answered in the affirmative. There was not yet a
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, Petrelli, 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 was well-established that eating disorders are associated with high levels of distress and psychosocial impairment (Agh et al., 2015; Mitchison, Hay, Slewya-Younan, & Mond, 2012; Preti et al., 2009; Sareen, Cox, Abdin, Ghara, & 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, Gaeske, & Bachmann, 2013; Kessler et al., 2013; Striegel-Moore & Bulkik, 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, Pordes, Paiva, Abreu, & Auad, 2013; Kimmel, Ferguson, Zerwas, Bulkik, & Melter-Brodry, 2015; Misra, Golden, & Katzman, 2015; Mitchell et al., 2015; Norris et al., 2015; Raevuori et al., 2015; Sachs, Hanne, Mehler, & Krantz, 2015; Striegel, Bedrosian, Wang, & Schwartz, 2012; Weigel, König, Günz, 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 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, Kramer, & 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).
a testament to Professor Wilson’s generativity that the BEST study led to two successful follow-up projects. A-BEST was directed by Dr. DeBar and because the target population consisted of adolescents, the intervention was adapted to incorporate parents into the treatment. The second was a proof of concept study adapting the CBT-GSH interventions for Mexican-American women, directed by Dr. Fary Cachelin. All three projects found evidence in support of the use of CBT-GSH for recurrent binge-eating (Cachelin et al., 2014; Debar et al., 2011; Debar et al., 2013; Shea et al., 2012; Striegel-Moore et al., 2010).

Since we began the BEST study, Professor Wilson has collaborated with other colleagues on the further evaluation and dissemination of CBT-GSH for the treatment of eating disorders (Wilson & Zandberg, 2012). His innovative and central contributions to dissemination science are described by others in this special volume. Therefore, in this article we do not provide a summary of our findings, nor a literature update, concerning the efficacy or effectiveness of CBT-GSH in improving the target behavior, binge eating, or secondary outcomes such as improvements in psychosocial functioning. Rather, in this paper, we focus on the three aforementioned areas that had underpinned our interest in developing the BEST project: (1) unmet treatment needs; (2) cost-of-illness studies, and (3) cost-effectiveness studies. For each of these areas, we sought to determine the current state of the literature by conducting searches for research published after the BEST study. Before offering an update and discussion of this subsequent research, we first provide some additional background information concerning each of the three areas of concern and report relevant findings from the BEST study.

1. Eating disorders go undetected or untreated

It is widely assumed that eating disorders are “hidden” mental health conditions (Fursland & Watson, 2014) in that many individuals with an eating disorder “go undetected” or untreated. Unmet need for treatment is not unique to eating disorders and the proportion of individuals with a mental disorder who seek treatment varies based on a myriad of factors (e.g., demographic and other patient characteristics, economic and societal factors) including the particular mental disorder (Blanco et al., 2015; Ishikawa, Kawakami, & Kessler, 2015; Iza et al., 2013; Wang et al., 2007). The most commonly used approach to determining whether a disorder goes undetected has been to conduct systematic diagnostic assessments in a representative community sample and ask individuals with a given diagnosis whether they ever had been told by a health professional that they experienced the target disorder or had been treated for the disorder. Another approach to determining unmet treatment need involves screening patients presenting for primary care visits, although it is well established that this sampling approach introduces bias because certain patient characteristics (e.g., female sex; access to health insurance; mental health comorbidity) increase the likelihood of patients visiting a primary care provider (Wang et al., 2007; Westreich, 2012).

Epidemiological studies consistently have shown that many individuals do not access health care specifically for their mental disorder and even when they do come in contact with a health care provider, their mental disorder often remains undetected or untreated (Hasin & Grant, 2015). Whether an individual seeks treatment varies considerably by diagnosis, comorbidity, and demographic characteristics (Mack et al., 2014). For example, based on over 34,000 study participants, “lifetime” treatment seeking from onset of the disorder to assessment in the epidemiological study) among community cases with an anxiety disorder ranged from a low of 26% for social phobia to about 50% for generalized anxiety disorder to a relative high of 68% for panic disorder (Iza et al., 2013). In contrast, community cases identified to meet diagnostic criteria for a substance use disorder were quite likely to report seeking treatment (as many as 90% of individuals with substance use disorder, SUD, reported lifetime treatment seeking), albeit often with a considerable delay between disorder onset and seeking treatment (only 13% of cases with SUD sought treatment within a year of SUD onset) (Blanco et al., 2015). Treatment utilization for a mental disorder also varies widely across different countries, even in affluent societies (Ishikawa et al., 2015; Mack et al., 2014). Unfortunately, epidemiological research of unmet treatment need in individuals with an eating disorder typically is based on far smaller samples than is the case for studies of mental disorders such as mood, anxiety, or substance use disorders. Indeed, some of the largest epidemiological studies in the United States (US) or Europe either did not assess eating disorders (Hasin & Grant, 2015) or did so in only a subset of the participants (Hudson, Hiripi, Pope, & Kessler, 2007; Preti et al., 2009).

A systematic review of 14 studies (published between 1989 and January 2010) designed to examine the unmet treatment need among community cases of individuals with an eating disorder found that the pooled proportion of treatment seeking specifically to alleviate eating disorder symptoms was 23.2% (95% Confidence Interval, CI = 16.6, 31.4%) (Hart, Granillo, Jorm, & Paxton, 2011). The authors cautioned, however, that with the noteworthy exception of research by Mond and colleagues in Australia (Mond, Hay, Rodgers, & Owen, 2007; Mond, Hay, Rodgers, Owen, & Mitchell, 2006; Mond et al., 2009), the studies included in the review involved relatively small or select samples recruited in the United States, raising concerns about the generalizability of the findings.

1.1. BEST findings regarding unmet treatment needs among individuals with an eating disorder

In our work with Dr. Wilson, we were able to access the comprehensive electronic health records of our RCT study participants who had to meet diagnostic inclusion criteria, which were current BN, BED, or binge eating at least 1/week for the past 3 months, assessed using the Eating Disorder Examination (EDE) (Fairburn & Cooper, 1993) and found evidence for unmet treatment need (Dickerson et al., 2011). Among 100 women who later enrolled in our RCT, 99% received health-related services in the year prior to enrollment. The insurance claims codes indicated that 42% received services related to weight or eating disorders. Yet, only 4% of these patients had received an eating disorder diagnosis in that same time period. Hence, in a population of insured women almost all of whom had had at least one service contact with their health care provider and thus, at least in principle, made it possible for their eating problem to be detected, only a small minority received an eating disorder diagnosis. Unfortunately, our data did not permit a more detailed exploration of why services in the category of “weight and eating” were provided absent an eating disorder diagnosis.

2. Cost-of-illness (COI) studies

Economic studies are increasingly common in the mental health field because they can help address policy questions about resource allocation (Beecham, 2014). A key question posed in economic studies concerns the costs involved in supporting those with a given illness or disorder, or “cost of illness.” As described by Beecham (Beecham, 2014), the full costs of a psychiatric disorder in the public sector are not limited to health services utilization costs; rather, costs also may arise in the educational system or the justice system. To date, to our knowledge, research of the economic burdens in the public sectors arising from eating disorders has focused...
only on the health and mental health sector. Ideally, cost-of-illness calculations are conducted from a societal perspective which takes into account both the payer’s perspective (“direct expenses”), including payments for medical treatments and supplies, costs associated with accessing the medical care such as transportation to appointments or time spent in treatments, as well as society’s perspective (“indirect costs”) such as the monetary value of curtailed educational attainment, diminished productivity or premature death (Beecham, 2014; Crow, 2014; Stuhldreher, Konnopka, Wild, Herzog, Zipfel, Löwe, et al., 2012).

In a systematic review based on research published before 2012, Stuhldreher and colleagues (Stuhldreher, Konnopka, Wild, Herzog, Zipfel, Löwe, et al., 2012) differentiated three types of economic studies in eating disorders: cost-effectiveness analysis (CEA) studies (N = 2), COI studies (N = 5), and “other cost studies” (OCS, N = 11). The category of OCS was used for studies that fell short of being COI studies because they were limited to assessing only costs from a single sector (e.g., costs of a specific treatment or costs from only the provider’s or the patients perspective) or fell short of being CEA studies because they provided no comparison between two or more treatments. (Stuhldreher et al.’s summary of the CEA studies is described later in our section on CEA research). Stuhldreher and colleagues offered three overall conclusions: one, the COI estimates varied widely both across and within eating-disorder categories (e.g., the annual disease-specific cost varied from US$127 to US$8042 per patient), likely owing in large part to considerable variations in research methods and differences in sample characteristics. Two, the variation in results notwithstanding, the studies likely under estimated the full cost of an eating disorder because of sampling biases or incomplete assessment of costs. For example, only one study measured symptom-related costs for food, an expensive category of obvious relevance to individuals with BN or BED (Crow et al., 2009). And finally, three, comprehensive evaluations of all costs associated with eating disorders are still lacking, as are studies that utilize an appropriate non-disorder comparison group for estimating excess costs due to an eating disorder.

2.1. BEST findings concerning cost-of-illness

During our collaborative work on BEST, Dr. Wilson and Dr. Weissman also served on the American Psychiatric Association’s DSM-5 Eating Disorders Work Group. One of the questions the Work Group debated was what frequency cut-point to use for defining BN or BED. In their authoritative review of the literature, Wilson and Sysko concluded that there was no compelling empirical support for the DSM-IV frequency threshold of an average of two binge-eating episodes per week for a diagnosis of BN or BED (Wilson & Sysko, 2009). Wilson and Sysko recommended a change to a one episode per week threshold for binge eating (and for purging). Informed by these findings and recommendations, we took advantage of our access to health service use data in the BEST study to test whether, in the aforementioned sample of 100 women with current BED (N = 50, mean age = 36.4, SD = 7.3) or “recurrent binge eating” (RBE, minimum average of one binge-eating episode/week in the past three months, N = 50, mean age = 38.6, SD = 8.3, p = 0.16), frequency of binge-eating episodes would be associated significantly with health services costs incurred over a 12-month period (Dickerson et al., 2011). Cost data (in year 2006 US dollars) represented all expenses incurred by the health plan across inpatient and outpatient sectors and included costs for prescription medications. We examined the association between binge eating and health plan costs in two ways, each time adjusting for the potentially confounding effects of age, BMI and severity of self-reported depression. One, we compared the total costs of health services in the past 12 months and found no statistically significant differences between the BED group (mean total cost = US$3,319, SD = US$4050; median = 2037) and women with “recurrent binge eating” (mean total cost = US$3,588, SD = US$4665; median = US$1858) (p = 0.63). We did, however, find that age and depression scores were significantly associated with higher health services costs. In a second model, we examined whether frequency of binge eating (measured as number of days with at least one binge-eating episode) was associated with total costs and found no statistically significant association. By our inclusion criteria, all women in this sample reported a minimum average of one day/week during the past three months during which they had at least one binge-eating episode. Our findings suggest that in women who met this threshold, a greater number of “binge days” did not correlate with increased medical costs. Health services utilization is widely accepted as a behavioral indicator of impairment. We concluded that the lack of significant differences in health care costs between women who met all research criteria for BED and women who reported at least once/weekly binge eating and the lack of a significant association of binge-eating frequency with costs supported Drs. Wilson and Sysko’s recommendation to lower the frequency threshold of binge-eating for a clinical diagnosis of BN or BED from the minimum average of twice/week in DSM-IV to once/week in DSM-5. The Work Group endorsed this recommendation and the DSM-5 now specifies the lower frequency threshold.

3. Cost-effectiveness studies

Cost-effectiveness analyses (CEA) studies report on the relative costs of at least two alternate treatments and may be used to make decisions about resource allocation. The cost-effectiveness of an intervention is a function both of its effectiveness (how well does the treatment do in terms of improving the targeted problem?) and its cost (how expensive is the treatment in terms of the costs to design and deliver it to the patient and the costs to the patient in terms of engaging with the intervention?) (Drummond & Jefferson, 1996). In their comprehensive review that included economic studies published in or before 2011, Stuhldreher and colleagues identified only two CEA studies, including the CEA study we conducted as part of BEST (Stuhldreher, Konnopka, Wild, Herzog, Zipfel, Löwe, et al., 2012). As is common in CEA research, these CEA studies were conducted in conjunction with RCTs where investigators collected data about the treatment costs and treatment outcomes. Alternatively, in other fields, experts also have employed modeling using data from the literature. The latter approach is based on assumptions derived from other studies and often combines data from a multitude of studies that were not initially designed for the purpose of a CEA. At the time of their review, no “modeling study” of the cost-effectiveness of eating disorder treatments was found.

3.1. BEST findings concerning cost-effectiveness of treatment

One of the primary goals of the BEST study was to demonstrate the cost-effectiveness of CBT-based guided self-help treatment (CBT-GSH) for recurrent binge eating compared to treatment as usual (TAU) (Striegel-Moore et al., 2010). In the BEST study, 123 adult members of a large HMO were randomly assigned to TAU or TAU plus CBT-GSH, permitting us to conduct an incremental cost-effectiveness analysis. This type of analysis allowed us to estimate the cost of CBT-GSH over and above the cost of TAU for the additional benefit of CBT-GSH over and above the benefit of TAU. Both groups were informed of their diagnostic status and the HMO’s (extensive) resources available for patients interested in receiving treatment. In keeping with an augmentation trial, the CBT-GSH group was not precluded from accessing usual care services while
participating in the study. The CEA was undertaken from a societal perspective and used data from participants’ clinical assessments and self-reports as well as data obtained from their electronic medical records. The clinical outcome used in the primary CEA was days with zero binge-eating episodes (“binge-free days”). Binge eating was assessed using the Eating Disorder Examination, EDE (Fairburn & Cooper, 1993), by evaluators (blind to treatment condition) at baseline (prior to randomization) and at 12-, 26-, and 52-week follow-up. Summing across the follow-up periods, we calculated the total number of binge-free days in the 12 months following the intervention.

We also calculated a secondary CEA analysis to estimate the incremental cost effectiveness ratio (ICER) per quality adjusted life years (QALYs). The ICER is a statistic that expresses the differences in costs between two interventions (here TAU only versus CBT-GSH plus TAU) divided by the difference in their effect. Health economists calculate the ICER per QALY to gage whether an intervention is cost-effective: a threshold of ≤ $50,000 per QALY gain has been recommended for deeming an intervention to be cost-effective (Grosse, 2008). QALY is a measure that combines length of life and quality of life (where 1 is perfect health and 0 is death) into a single outcome; QALYs are used as the unit for determining health benefits received from an intervention and are widely accepted because they allow comparisons across different health conditions and populations (Griebisch, Coast, & Brown, 2005). QALYs are derived by assessing the amount of time spent in different health states, for example, days with binge-eating episodes versus days without binge-eating episodes, and multiplying this by a utility weight indicating the relative value of these different states. Days without symptoms are generally assigned a weight of 1.0 (full health) and days with symptoms are assigned a lower weight based on empirical evidence or expert opinion. Using preference weights derived from Vos & Mathers (Vos & Mathers, 2000), the only study at the time to report utility weights for eating disorders, we assigned a utility weight of 1.0 to binge-free days and a weight of 0.72 to days with binge-eating episodes. Total societal cost was estimated using both patient costs (e.g., travel time to health services, wait time for services, out-of-pocket costs for health care services and weight/weight-loss related services and products) and costs to the health plan for the intervention itself (e.g., cost of intervention materials, therapist time) and all other health service use (e.g., cost of office visits or calls to nurse line) during the 12-month follow-up period.

Specifically, intervention costs were determined from HMO accounting records of costs for study staff payroll, facilities use, and purchases of goods and services. Study staff provided reports of time with participants as well as intervention-related use of capital equipment, space, and supplies. The cost of therapist training and ongoing supervision was also included in the intervention costs. Comprehensive profiles of usual care HMO services extracted from electronic medical records and HMO administrative records were created to estimate health services costs. Additional health service and patient costs (outside those provided by the HMO) were assessed through a self-report survey. At baseline and all follow-up points, participants reported any health-care or other HMO services they had received as well as all non-medical expenses (e.g., cost of travel to an appointment) or purchases (e.g., diet books or products) related to their eating disorder or weight symptoms or concerns. Patients’ time spent traveling to, waiting for, and participating in treatment was also measured and valued using wage information. Excluded from the primary CEA were data on productivity loss; days from work due to binge eating were reported as a separate outcome.

The cost of providing the intervention to those in the CBT-GSH group was US$167 per participant. In the 12-month follow-up period, total patient costs were US$147 lower on average and non-intervention health care plan costs were US$447 lower on average in the CBT-GSH group compared to TAU. Overall, those who received CBT-GSH had lower total societal costs of US$427, primarily due to a reduction in the use of TAU services. The intervention produced an incremental cost savings of US$20.23 per binge-free day and an incremental cost effectiveness ratio per QALY of −US$26,847 (indicating a cost saving). Thus, while providing an evidence-based treatment for recurrent binge eating does come with an initial cost (US$167 per patient in this instance), the treatment provides long-term cost savings for both patients and health plans. In light of the threshold recommended for acceptable costs of new interventions (≤US$50,000/QALY) (Russell, Gold, Siegel, Daniels, & Weinstein, 1996), CBT-GSH also was found to be cost-effective in terms of the health improvement achieved (as measured by QALYs). We caution that our results need to be replicated in other health care settings. One advantage of delivering CBT-GSH within the HMO was that duplication of services could be avoided because the health care providers had electronic access to all patient information; moreover, patients may have saved time by being able to access services efficiently via a single point of entry rather than having to research on their own various treatment options or providers. Were the intervention to be delivered as a free-standing program, it is possible that costs would be higher. We note as a further limitation that, notwithstanding its wide use, the QALY indicator has been shown to be calculated in a wide variety of ways and, therefore, one cannot assume that all measurements are inherently comparable (Griebisch et al., 2005).

4. Method

Given the breadth of our focus ranging from unmet treatment needs to cost of illness and cost-effectiveness of treatments for eating disorders, a complete review of each area was beyond the scope of our paper. Rather, we endeavored to provide updates of the most recent literature, including unless noted otherwise, studies published in the past 5 years. We identified relevant literature for each of our three topics using three iterative search strategies. First, using Web of Science, we identified articles that referenced key BEST publications pertaining to unmet treatment need, cost of illness, and cost-effectiveness and then reviewed the abstracts to determine whether the reference was for a study offering new research findings on the topic. This search identified three review papers that were published in the past ten years (Agh et al., 2015; Hart et al., 2011; Stuhldreher, Konnopka, Wild, Herzog, Zipfel, Lowe, et al., 2012). In a second step, as described in further detail in each of the three topical sections below, we conducted systematic PubMed and PsycInfo searches for the literature published since the publication of the review papers. And finally, we perused the reference lists of the relevant articles we uncovered in our systematic searches for any published studies our search might have missed. In all instances, we restricted our searches to English language, peer reviewed journal articles.

To update the literature on unmet treatment need, we first replicated the title search reported by Hart et al. (2011) in which PsycInfo and PubMed databases were searched for titles reflecting a combination of terms related to eating disorders and treatment seeking. Specifically, we combined the results of a title search for “(eating AND (disorder or disorders or disordered or pathology or disturbance or disturbed) OR (anorexia or anorexic or anorexies or bulimia or bulimic or bulimics or binge)” with results from a title search for “(help or helping or helped or helps or care or treatment) AND (seek or seeks or seeking or pathways or pathways or barrier or barriers or present or presenting or presentation or presentations or presented or engage or engaging or engaged)”. This search
yielded 39 hits from PsycINFO and an additional 23 from PubMed. Upon closer inspection, however, these articles either did not focus on unmet treatment need as a primary research question or failed to meet all of the inclusion criteria employed by Hart and colleagues (Hart et al., 2011), which included recruiting a representative sample of community cases, using a standardized eating disorder screening instrument to determine eating disorder status and providing information concerning all possible ED diagnosis (AN, BN, BED, and EDNOS) outcomes, and, reporting percentages of participants who sought formal treatment specifically for an eating disorder. We also conducted Web of Science cited reference searches for both our relevant work (Dickerson et al., 2011; Striegel-Moore et al., 2008) and Hart et al. (2011), and we reviewed the reference lists of identified articles for additional papers. These searches identified five studies that were not included in the review by Hart and colleagues and that provide some information on the extent to which individuals with an eating disorder accessed treatment specifically for the eating disorder (Kessler et al., 2013; Marques et al., 2011; Preti et al., 2009; Smink, van Hoeken, Oldehinkel, & Hoek, 2014; Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011).

To update the cost-of-illness literature, we conducted searches in PubMed and PsycINFO combining each of five eating disorder terms (anorexia nervosa, bulimia nervosa, eating disorder, binge, or purging) with "cost" or "economic" or "expenditure." The searches yielded 99 (PubMed) and 133 (PsycINFO) articles, yet upon inspection, we found that only three of the articles described cost studies and all three fit the Stuhldreher category of OCS (Gatt et al., 2014; Munro et al., 2014; Toulany et al., 2015). Common reasons for inadequate fit as a COI study were use of the term "economic" in the context of sample description ("socio-economic") or use of the term "cost" in the context of research of binge drinking or in the conclusion sentence of the abstract calling for research of cost-effective treatments. By searching in Web of Science for articles that had cited the Stuhldreher article or any of our own cost studies, we identified four additional articles describing OCS (Ballard & Crane, 2015; Bellows et al., 2015; Haas et al., 2012; Raenker et al., 2013) and two articles describing COI studies (Sammaliev, Noh, Sonneville, & Austin, 2015; Stuhldreher et al., 2015).

To ensure that the searches for COI studies had not overlooked research on cost-effectiveness, we completed abstract searches in PubMed and PsycINFO by combining “cost-effectiveness” with each of the following terms: AN, BN, BED, eating disorder, binge, or purging. In addition to three research papers we had found in the COI studies searches (Agras et al., 2014; Crow et al., 2013; Wang, Nichols, & Austin, 2011), the searches on “cost-effectiveness” yielded one more citation (Wright, Austin, LeAnn Noh, Jiang, & Sonneville, 2014). (We note parenthetically, that our searches had included the ESMedD study here because it was the only study we included the ESMedD study here because it was the only study we included here because of the dearth of data on minority populations. Nonetheless, the findings suggest unmet treatment needs in a substantial number of individuals with an eating disorder diagnosis and raise particular concern about access to mental health treatment for ethnic minority populations (Marques et al., 2011).

Swanson and colleagues (Swanson et al., 2011) examined data from a nationally representative sample of adolescents in the US and found that treatment specifically for an eating disorder was even more uncommon than what had been reported for adult samples: only 27.5%, 21.5% and 11.4% had received treatment for AN, BN, or BED, respectively. However, a majority of these youth (77.6%, 88.2%, and 72.6%) had received some form of mental health treatment, suggesting that there was opportunity to make a referral for disorder specific treatment (Swanson et al., 2011).

In contrast to the low number of US youth who had received treatment specifically for AN or BN, a study of a Dutch cohort of 1584 children (age 11 at study entry) reported that by age 19, 56.3% and 37.5% of youth with AN or BN, respectively, had received eating disorder treatment. Treatment for BED, however, was also uncommon in the Dutch sample (12%) (Smink et al., 2014).

The European Study of the Epidemiology of Mental Disorders, ESMed (Preti et al., 2009), recruited a probability sample of non-institutionalized adult citizens of Belgium, France, Germany, The Netherlands, and Spain. A subsample of 4139 persons was randomly selected to undergo diagnostic assessment for an eating disorder. Lifetime health service use for “any emotional problem” was reported by 51.4%, 51.9%, and 38.8% of participants with AN, BN, or BED diagnosis, respectively. It is unclear how many individuals received treatment specifically for their eating disorder, but we included the ESMedD study here because it was the only study we could find that reported on a broad spectrum of European populations. These relatively low estimates for service use for an emotional problem are noteworthy both because (as has been shown in other epidemiological studies) psychiatric comorbidity was high (e.g., 70% of individuals with bulimia nervosa met criteria for at least one other mental disorder) and because the countries involved in the ESMedD offer universal access to health care.

In the WHO World Mental Health Survey Initiative (Kessler et al., 2013), a randomly selected subsample of over 20,000 adults was assessed for current or lifetime diagnoses of an eating disorder and findings were reported regarding the use of health services to treat BN or BED (but not AN). Less than half of those with a diagnosis of BN (47.4%) or BED (38.3%) had accessed treatment for their eating disorder. Of note, most of the participants with BN (84.8%) or BED (79%) had at least one other mental disorder. Given that individuals with multiple disorders are more likely to access health services than individuals with a single disorder (Olfsen, Liu, Grant, & Blanco, 2007), a more recent study (Marques et al., 2011) in which the NCS-R sample was combined with two additional US study samples representing ethnically distinct subgroups (African American, Asian, and Hispanic) reported that lifetime mental health treatment for any eating disorder was significantly less common among African American (62.2%), Asian (63.2%) or Hispanic (61.7%) individuals than among non-Hispanic white participants (75.8%). It was not reported how many individuals with an eating disorder had received treatment specifically for the eating disorder, but we included the study here because of the dearth of data on minority populations. Nonetheless, the findings suggest unmet treatment needs in a substantial number of individuals with an eating disorder diagnosis and raise particular concern about access to mental health treatment for ethnic minority populations (Marques et al., 2011).
2012), the number of individuals seeking eating disorder care appears low. Of further note, in analyses that adjusted for other temporally primary (to the eating disorder) comorbid mental disorders, individuals with BN or BED were found to be at elevated risk for the development of a number of physical disorders such as chronic pain, diabetes, hypertension, and among those with BED, chronic headaches. Studies have shown that individuals are more likely to access health care for physical health conditions than for mental health problems (Mack et al., 2014). Experiencing comorbid health problems may thus bring individuals with an eating disorder into contact with a health care provider and screening for eating disorders among patients presenting with physical complaints that are specifically elevated among individuals with an eating disorder may help improve access to eating-disorder treatment.

5.2. Research update: cost-of-illness studies

Stuhldreher and her colleagues (Stuhldreher et al., 2015) conducted a COI using a subsample of 225 women (mean age 27.6 years) with a diagnosis of AN or “subsyndromal” AN (defined as lacking one core symptom of AN) who were enrolled in the Anorexia Nervosa Treatment of OutPatients (ANTOP) study, a large multicenter treatment of AN study conducted in Germany. At study entry, patients completed a self-report questionnaire about direct and indirect costs patients had incurred during the past three months. Direct cost measures included frequency, duration and type of health services utilization and transportation costs to attend medical care. Indirect cost measures included productivity loss in form of absenteeism (sick leave), “presenteeism” (i.e., degree of impairment while at work), and receipt of a disability pension. Health services information was valued based on average prices within the German health care system. Average wages for women in Germany were used to calculate the economic impact of lost productivity. The average 3-month cost of illness (combining both direct cost and indirect cost) for these patients with AN was €5,866 (SD = €576) (year 2008 values) of which 57% were attributable to direct costs. The median for total costs was €1,275, suggesting, as is typical in cost studies, that the data were heavily skewed with a majority of patients reporting low costs and a minority reporting very high costs. As has been shown in previous studies, hospitalization was a major cost driver: for the 47 women who had been hospitalized for AN, average total costs were almost four times higher (€13,625) than total costs incurred by women who had not been hospitalized in the past three months (€499). The authors also examined predictors of total costs and the results varied between those who had versus those who had not been hospitalized in the past three months. Specifically, among patients who had received only outpatient care, total cost was increased significantly in those with: binge-purging subtype versus restricting AN (+€249); an illness duration of greater than 6 years (38%) versus a shorter illness duration (+€279); and with at least one mental health comorbidity (40% of sample) compared to no other mental health diagnosis (+€459). Of note, Body Mass Index (BMI), measured at three months post-randomization, did not predict total costs in patients with only outpatient care. In contrast, BMI was the only significant predictor of total cost in patients who had been hospitalized in the past three months with higher BMI being predictive of increased total costs. In this study, BMI was measured at the end of the 3-month study period and costs were based on per diem rates. Thus, the findings regarding BMI as a predictor of costs for patients with AN likely reflect increased weight gain among those patients with longer hospital stays. Studies measuring BMI at hospital admission (for example (Haas et al., 2012)) report an inverse relationship between costs and BMI such that more emaciated patients had higher hospitalization costs. The ANTOP study reported novel data about the adverse effect of AN on productivity. Extrapolating from their 3-month results, the authors estimated that women with AN reported an average of 81 more sick days/year than do women with no mental disorder. Finally, because the ANTOP sample excluded individuals with especially severe symptoms (e.g., acute suicidal ideation or substance abuse, bipolar disorder), the reported costs may be lower than what might have been found in a sample without exclusions.

Using five years of data from the Medical Expenditures Panel Survey (MEPS), Sammalie and colleagues (Sammaliev et al., 2015) estimated the difference in annual healthcare cost, employment status (among those age 18 or older) and earned income (among those age 18 or older who were employed within the prior 12 months) in a nationally representative sample of the noninstitutionalized, civilian US population (ages 0–85 years). From among the 168,951 males and females in MEPS 2007 to 2011, 86 (0.05%) were identified to have an ICD-9 code for a current eating disorder, including AN, BN, binge eating, pica, other eating disorders, rumination disorder, or psychogenic vomiting. About 40% of individuals with an eating disorder (ED) diagnosis also had at least one mental disorder comorbidity. Analyses adjusted for demographic differences (age, gender, race/ethnicity, household size, years of education) showed that annual health care costs were significantly greater in the ED group compared to the general population (US$1,869, year 2011 values). Economic indicators were worse in individuals with both an ED and a comorbid mental disorder (N = 34) than in those with only an ED diagnosis (N = 52), although these differences reached statistical significance only for annual earnings but not for annual health care costs or employment status. Specifically, among those with a mental health comorbidity and an ED, annual earnings were almost two times lower ($19,374 less) than among those with only an ED diagnosis; the former group was 59% less likely to have been employed (OR = 0.41, CI [0.14, 1.20]) and had $1993 increased health care costs. Although in this study the association of a comorbid mental disorder and health care costs did not reach statistical significance, the small sample size may have made it difficult to detect significant differences. As the authors noted, evaluations of the economic burden of an ED need to encompass consideration of comorbid disorders and, except for one of the OCS described below, we could not find another study that examined the contributions of comorbidity to direct or indirect costs in eating disorders. To our knowledge, this is the only economic study that included individuals with pica, rumination and psychogenic vomiting as part of the eating disorders under investigation.

5.2.1. Research update: other cost studies

Seven studies fell short of meeting Stuhldreher’s classification as COI studies because they examined only a subset of costs, such as costs incurred by a specific payer such as a health plan (Ballard & Crane, 2015; Bellows et al., 2015), household (Gatt et al., 2014), or caregiver (Raenker et al., 2013), or costs associated with a specific treatment modality such as hospitalization (Haas et al., 2012; Munro et al., 2014; Toulan et al., 2015) or outpatient care (Ballard & Crane, 2015). One study focused specifically on BED and EDNOS and did not include data on patients with AN or BN (Bellows et al., 2015); all others either included data from patients with AN or their caregivers (Ballard & Crane, 2015; Gatt et al., 2014; Haas et al., 2012) or were focused solely on patients with AN (Munro et al., 2014; Raenker et al., 2013; Toulan et al., 2015). Notwithstanding their more limited focus, these studies contribute to the knowledge base about the economic burdens of eating disorders as follows.

Indisputably, hospitalization is an expensive way to deliver medical treatments both because of the complexity of treatments
given and the range of providers involved and because of the considerable overhead costs hospitals incur. Because hospitalization is the treatment of choice for medically unstable patients with an eating disorder (most commonly, though not exclusively patients with AN), researchers have endeavored to understand the factors that are associated with hospitalization use or help reduce costs arising from hospitalizations. To estimate all hospital costs arising from treating an eating disorder, a German study (Haas et al., 2012) selected data from 256 patients (91% female) who had received inpatient treatment between 2006 and 2009 for AN (N = 101), BN (N = 95), or “eating-related obesity” (OB, N = 60). Cost calculations included costs specifically due to patient-related activities (e.g., time spent delivering a treatment or expense of medical supplies), non-patient-related activities (staff attendance at meetings), and overhead costs (e.g., medical equipment; building maintenance; financial administration; etc.). Costs were reported per day and per case (in year 2009 Euros) for all patients and compared across the three diagnostic groups. The daily cost of treating a patient with an eating disorder in hospital was €208 (median: €183) and differed significantly between those with AN (mean = €224, median = €178) and those with OB (mean = €194, median = €183), but not those with BN (mean = €200, median = €183). These averages obscure substantial individual variations, due in large part to considerable ranges in length of stay (9-153 days): total costs (hospital costs and caregiver costs) per hospital admission ranged from €16,488 to €201,036. In this study, admission BMI was the only significant predictor in a regression model testing the associations of demographic and or clinical variables and hospital costs (excluding caregiver costs) per admission. The authors estimated that for every unit increase in BMI a decrease of about €33,350 would be achieved. In terms of caregiver costs, patient’s age and admission BMI were found to be significant predictors. Specifically, when adjusting for BMI, for every patient year of life, caregiver costs were estimated to decrease by £125; for age, every unit increase in BMI decreased caregiver costs by about £370. It is unclear why the Canadian hospital costs were so much higher than the costs reported in the German study, despite the fact that the German study included a more extensive range of hospital overhead costs (e.g., administrative costs) and was based on 2011 costs (versus 2013 costs).

Efforts are underway in the United Kingdom (UK) to improve community-based services for individuals with AN. Munro and colleagues (Munro et al., 2014) described a study of the impact of the introduction of an intensive community treatment approach (Anorexia Nervosa Intensive Treatment Team, ANITT), on hospitalization costs for the treatment of AN in the Lothian region of the UK. ANITT is considered a third tier in a service model that matches patients to treatment modes based on severity of the patients’ symptoms. Tier 1 involves either guided self-help or internet based CBT and Tier 2 involves outpatient treatment including individual or group therapy, dietetic and psychiatric treatment. ANITT can accommodate 35 patients and offers them an 18-month course of intensive outpatient care delivered by a multidisciplinary team and as many as ten contacts per week, tailored to the patient’s clinical needs. Tier 4 is specialist inpatient treatment. The authors reported that after implementing ANITT in 2009, the annual costs savings for treating patients with AN in the region in 2011 relative to pre-ANITT costs in 2008 was £391,636. The reduction in costs was attributed to an overall decrease in the number of days patients with AN spent in hospital. Hence, findings from this uncontrolled study suggest that by shifting economic resources toward an expansion of intensive outpatient treatment, a substantial savings was achieved not only in hospital costs but in the overall costs associated with the treatment of AN. We will return to the question of the economics and cost-effectiveness of inpatient care for eating disorders when we consider cost-effectiveness studies.

Taking into consideration all direct costs of eating disorders requires measurement of patient and carer expenditures such as co-payments or other unreimbursed expenditures associated with treatment (e.g., travel to appointments) as well as time lost due to the treatment or the impact of the disorder on productivity. Two studies endeavored to illuminate such costs; one interviewed carers (Raenker et al., 2013) and the other surveyed patients (Gatt et al., 2014). The study of carers was conducted in the UK as part of a multicenter RCT offering supportive treatment to the carers of 197 patients who received inpatient (30%) or day treatment for AN. A total of 267 carers (144 mothers, 80 fathers, 28 partners) reported how much time they spent in patient-related caregiving tasks during the month prior to the patient’s index hospitalization (or day treatment episode). A semi-structured interview was used to capture the time spent in specific caregiving activities in six broad
areas: “medical,” “food,” “non-food/medical practical support,” “emotional,” and “obtaining information about ED and local services.” Findings indicated that carers spent an average of 72 h/month (SD = 31.6–155.5) providing some form of care to the patient. Although the data reflected a considerable range in the amount of time spent on daily care, nonetheless, the results suggest that for many parents or partners, supporting a patient with AN can be quite time intensive: three-quarters of partners, 48.6% of mothers, and 37.2% of fathers reported spending more than 21 h/week of face-to-face time with the patient in caregiver activities. The study did not calculate the estimated economic impact of carers’ time spent on disorder-specific activities nor did it include a comparison group of parents or partners of individuals who did not experience an eating disorder. Moreover, because it focused on the month prior to the patients’ admission to intensive treatment, the study may have captured a time of particularly extensive carer burdens. Nonetheless, the comprehensive assessment of carer time burdens developed by the authors offers a novel measure for more fully accounting for the family burdens associated with an eating disorder.

An Australian study (Gatt et al., 2014) investigated the household economic burden of eating disorders by surveying individuals (via self-administered or interview-administered questionnaire) who either had received treatment at one of two clinic settings in New South Wales or responded to a recruitment effort via postings on two national eating disorder support organization websites over a period of four years (2009–2012). Household economic burden of eating disorders was measured by asking about out-of-pocket medical and health-related expenditures (“expenditures”) in the past three months, household income, and cost-related non-adherence to treatment (e.g., not attending a medical appointment or filling a prescription due to cost). Participants were asked about eating disorder related out-of-pocket expenditures for medications (prescription and non-prescription), medical and allied health care, hospitalization, medically related transportation, home and self-care assistance, medical equipment and supplies, and special food requirements. The proportion of household income spent on disorder-related out-of-pocket expenses was also calculated. Completed surveys were returned by 89 women and one man (mean age 24.5, SD = 8.3); self-reported eating disorder diagnosis options were AN (N = 49), BN (N = 15) and “Other” (N = 26). Highest expenditures were reported by those with a diagnosis of BN (mean = AUS$3175), twice the amount reported by respondents with AN (mean = AUS$1525) (mean - AUS$850, exact amount not reported). The burden of expenses relative to household income was highest among respondents with BN (35.6%, SD = 48.1%), followed by those with AN (22.9%, SD = 33.8%), and lowest among individuals with “Other” EDs (7.4%, SD = 8.3%) (p < 0.04). These differences in out-of-pocket expenditure may reflect in part the fact that significantly more individuals with AN (56.2%) or BN (64.2%) than individuals with a diagnosis of “Other” (23.5%) had been hospitalized in the previous 12 months. About 18% of respondents indicated that they had not adhered to health treatments due to cost burdens. Generalizations from this study to other populations are limited due to the relatively low study participation (30.5% and 14% of patients recruited at the two clinics). Yet, this study represents an important first step toward documenting the substantial economic impact of an eating disorder even among individuals with health insurance.

Bellows and colleagues (Bellows et al., 2015) examined electronic medical records of adult patients (>18 years) who had received treatment at a US Department for Veterans Affairs medical center (“VA”) between 2005 and 2011. Health services use and healthcare costs of patients with a diagnosis of BED (N = 257, 75.1% male) were compared to patients with an EDNOS diagnosis (N = 823, 60.7% male) or no ED diagnosis (N = 743, 74.7% male). EDNOS diagnosis was based on the ICD-9 code (307.5); absent an ICD-9 code for BED at the time when the data were collected, a natural language processing algorithm was developed and validated (Bellows et al., 2014) to identify individuals with BED based on clinical case notes reflecting key terms used in clinical practice to describe the core BED symptoms. Inclusion in the study required that patients had received care within the year preceding and following the index visit (first visit when clinical records suggested a BED or EDNOS diagnosis) and that at the index visit, height and weight measurements had been recorded. A sample of non-eating disordered (non-ED) patients was established using the same inclusion criteria and some, but not all, of these comparison patients were matched to the BED or EDNOS cases on demographic variables and VA index visit.

The study captured healthcare utilization and costs from the provider’s (VA’s) perspective at two time points: the year prior to the index visit and the year following the index visit. Total average costs (in year 2011 US dollars) during the 12 months prior to the index visit did not differ significantly between the BED (US$18,411, SD = 22,871; median = 9454) and the non-ED (US$16,871, SD = 23,936; median = US$8422) groups, but those with an EDNOS diagnosis (US$26,466; SD 12,483; median = US$19,717) incurred significantly greater costs when compared with the BED group (p < 0.001). The mean total costs in the 12 months after the index visit rose in all three groups (within group differences for time related cost changes were not reported), with small increases observed in the non-ED comparison group (US$19,548, SD = $35,780; median = US$9733), moderate increases in the EDNOS group (US$37,052, SD = US$40,719; median = US$24,528), and largest increases in the BED group (US$33,716, SD = US$38,928; median = US$22,297) relative to the baseline costs. The group differences in total costs between those with a BED diagnosis and the non-ED cases were statistically significant; in contrast, the differences between patients with BED versus those with EDNOS were not statistically significantly different. Analyses adjusted for demographic characteristics, baseline comorbidities and pre-index visit costs showed that patients with BED had 77% higher costs than the patients in the non-ED group which corresponded to an incremental increase in total costs of US$18,152 (95% CI [US$11,986, US$24,318], p < 0.001). Findings likely are not representative of the population of individuals with BED in the US (or anywhere else) given that the VA population is predominantly male and older than the US civilian population or samples that were included in other economic studies of eating disorders. Nonetheless, the study findings are similar to our own results of significantly elevated health services use and cost in women with an ED diagnosis following an index visit where treatment for an ED was initiated, compared to a matched group of women with no ED diagnosis (Striegel-Moore et al., 2008).

Another cost study conducted from a payer’s perspective (Ballard & Grane, 2015) focused solely on outpatient mental health treatment and calculated costs as the US dollar amount the insurer (Cigna, a large US health insurance company) paid treatment providers for all services for a given patient over a six year period. Using administrative data from 2001 to 2006, a sample of 5445 patients (93% female) was identified who had been diagnosed with AN (N = 1137; mean age 22.72, SD = 10.4), BN (N = 1869; mean age = 25.9, SD = 11.9), or EDNOS (N = 2439; mean age = 30.85, SD = 14.4). These individuals represented 1.1% of all patients receiving outpatient services for individual or family treatment during the time period under investigation. Average costs were reported separately for 18 subgroups which reflected sorting patients by diagnostic group (three) and age group (six: from <15...
years to > 55 years in 10 year increments). Costs ranged from US$165 (EDNOS, age group > 55 years) to US$474 (AN, age group > 55 years). The authors reported that across the three eating disorder categories, costs were lowest among patients in the oldest age group, which differed significantly from costs in any other age group. Reporting costs for 18 subgroups and over an extended time period makes it difficult to compare the findings with those reported in the literature where results more typically have been reported by diagnosis and based on far shorter time periods (3 months–12 months). Nonetheless, this study provides information on two under-researched questions, namely the average length of a treatment episode and the type of mental health treatment received. Specifically, treatment length was defined as “a series of continuous services for the same patient”, with breaks between treatments exceeding 90 days marking the onset of a new treatment episode. Inspection of the length of treatment episodes the authors reported (by age group only, not by age group and diagnosis or by diagnosis) suggests that patients received very few sessions per course of treatment, ranging from <4 sessions in patients over 55 years of age to 6.53 (<15 years) or 6.73 (15–24 years) among the youngest patients. Because this study did not examine the number of sessions across a predetermine time period (Striegel-Moore et al., 2006), an unadjusted outcome is relative to results reported in other studies or relative to recommended standards of care. Yet, four to less than seven sessions are well below the number of sessions that comprise a course of evidence-based psychotherapy for an eating disorder, such as CBT (Turner, Marshall, Stopa, & Waller, 2015) or Family Based Therapy (Lock, 2011). As we have previously noted (Striegel-Moore, 2005), the low number of sessions comprising a treatment episode may be a function of managed health care in the US where the provider exercises tight control over the treatment dose. The other noteworthy finding concerns the use of family therapy in the treatment of young patients either as the sole modality or conjunctive with other treatment modalities. Specifically, the authors reported that although about 80% of children under 15 years received family therapy, less than 44% of those aged 15–24 years received family therapy (solely or along with individual therapy), despite growing recognition of the efficacy of family based treatment for adolescents or emerging adults with an eating disorder (Agras et al., 2014; Couturier, Kimber, & Szatmari, 2013; Lock et al., 2010; Stiles-Shields, Hoste, Doyle, & Le Grange, 2012).

5.3. Research update: cost-effectiveness studies

Our searches yielded four new publications describing CEA studies; of these, two were conducted in the context of a RCT and two represented “modeling” studies using data collected in a variety of published studies. Each of these four CEA studies focused on a distinctly different target: one study compared the cost-effectiveness of two types of family therapy for the treatment of adolescents with AN (Agras et al., 2014); another treatment study examined cost-effectiveness of a stepped care approach versus standard CBT in a sample of patients with BN (Crow et al., 2013); a third study reported on the cost-effectiveness of a program aimed at prevention of BN (Wang et al., 2011); and the fourth study investigated the cost-effectiveness of school-based eating disorder screening (Wright et al., 2014). Each study is described next.

A multisite family therapy RCT study (Agras et al., 2014) compared the efficacy and cost-effectiveness of two distinct outpatient treatments for AN in adolescents, namely family behavior therapy (FBT) and systemic family therapy (SyFT), in a sample of 164 adolescents (ages 12–18 years). Both treatments were manualized and involved 16 1-h sessions delivered over a 9-month period. A clinical safety protocol specified rules for admitting study patients into hospital if they became medically unstable. In brief, the principal focus of FBT is to engage the parents and families in restoring the patient’s eating behavior and achieving weight restoration. Families are supported in taking control over the patient’s eating and gradually shifting the control back to the patient. Adolescent developmental issues are considered in the final treatment session. In contrast, SyFT focuses on the family system and its interactions and communication patterns rather than on eating behavior or weight. Through an exploration of family beliefs and behavioral patterns, SyFT seeks to help the family to draw upon its existing strengths and identify solutions to the target problem. In regards to the primary outcome of weight restoration, the study found no statistically significant difference between the two treatments. Specifically, 92.1% of the FBT group and 91.1% of the SyFT group had reached their target weight at the end of treatment and at the 12-month follow-up patients, 94.6% and 93.3%, respectively, had achieved their target weight. Remission rates at end of treatment and 12-month follow-ups also did not differ significantly (FBT: 33.1%, 40.7%; SyFT: 25.3%, 39%). Of note, however, was the finding that patients in the FBT group gained weight significantly faster than patients randomized to SyFT. Moreover, the study identified a moderator for change in weight: Patients with elevated obsessive-compulsive features showed significantly greater improvements when treated with SyFT compared to FBT.

Cost-effectiveness comparisons were based on calculations of the costs of the family treatments plus the costs of any hospitalization during the course of treatment until the end of treatment, using each participating study center’s site specific costs. Mean treatment costs per patient and per patient in remission were reported in US dollars (the study was conducted between 2005 and 2012). Cost-effectiveness results highly favored FBT: Mean treatment costs per FBT patient were US$8963 versus US$18,005 for SyFT patient, and mean costs for individual remission were US$21,847 (FBT) and US$46,465 (SyFT). The authors explained that the differences in costs, in part, were a function of significant differences in hospitalizations required for the study participants. Specifically, the median number of hospital days was 8.3 for FBT patients versus 21.0 days for SyFT patients. The authors did not report cost-analyses where the moderator findings were considered. Therefore, it is unclear whether SyFT would be the treatment of choice for patients with obsessional-compulsive features not only from an efficacy perspective but also from a cost-effectiveness perspective. That said, this methodologically highly rigorous study is an important contribution to the cost-effectiveness literature in eating disorders.

Efficacy and cost-effectiveness of two formats of individual CBT were examined in a multisite RCT involving 293 patients with BN (Crow et al., 2013). Specifically, over the course of 4 months, patients received either an immediate course of eighteen 50-min sessions of CBT or an initial course of eight 20-min sessions of guided self-help that, if unsuccessful, would be followed by more intensive CBT (“stepped care”). In either group, if patients did not show at least a 70% reduction in the frequency of purging by the sixth session, they were prescribed fluoxetine as an adjunctive treatment to CBT. Abstinence from binge eating was the primary outcome and was achieved in 18% of the CBT group and 26% of the stepped-care group. Costs (in year 2005 US dollars) were assessed using a health care diary patients completed daily to capture health services utilization during the course of the study. Patients were asked to record emergency room visits, day-, partial- and inpatient hospitalizations, and medications. Including the cost of the intervention (CBT: US$1328; stepped care involving CBT and self-help: US$915), average total costs were US$3129 for the self-help group and US$3650 for the CBT group (p not reported). The average cost
The authors also collected data about time burdens due to the patients' eating disorder symptoms, as reported by a family member or significant other nominated by the patient. The target family member/significant other completed a questionnaire at study entry and after 18 weeks, each time focusing on the preceding four weeks. In all, the questionnaire information was available for 28% of patients. Across the two treatment groups, average reported time burden decreased from 4 h/week at study entry to less than 1 h at the end of treatment (p not reported). The authors concluded that a stepped-care approach to the treatment of BN was more effective and cost-effective than the standard delivery ceding four weeks. In all, the questionnaire information was

Taking a modeling approach and adopting a societal perspective, Austin and her colleagues (Wang et al., 2011) used RCT outcome and cost data from the US based “Planet Health” study as well as other published data to model the economic impact of Planet Health on preventing the development of BN in girls. Planet Health is an educational program for middle-school girls designed to prevent obesity and eating disorders. In brief, the authors built their analytical model based on efficacy results of the Planet Health program and baselined epidemiological findings concerning the development of BN in adolescent girls to project the number of girls prevented from developing BN by age 17 years. In light of the estimated number of prevented BN cases and based on the published literature describing the average illness duration, health services costs of adolescent patients with BN, and discounted quality of life years, the authors then estimated the medical treatment cost savings as well as the estimated quality-adjusted life years (QALYs) gained over a ten-year period, per BN case. The authors estimated that were the intervention to be implemented in 100 schools of a similar size to the five initial schools involved in the Planet Health RCT (245 girls), an estimated 26 cases of BN would be prevented, US$680,000 (in year 2010 US dollars) would be saved in medical costs, and an estimated 13.2 QALYs would be gained. The authors caution that further research is needed to verify the accuracy of key assumptions made in the model such as the progression probability from eating disorder symptoms to full syndrome expression or the long-term medical costs for medical treatment of BN. Nonetheless, the study provides a first effort to model the economic impact of a preventive (rather than treatment) intervention.

The impact of school-based screening on eating disorder diagnosis and treatment was the subject of a US study that developed a Markov-based decision-analytic microsimulation model to estimate theoretical cost savings over a ten-year period due to screening (Wright et al., 2014). As was the case for the aforementioned prevention study, numerous assumptions were made in regards to the model input parameters which were derived from the published literature on prevalence of and recovery or relapse from eating disorders, health-related quality of life, and treatment costs. The authors estimated that the net cost of the screening program was US$2260/student (95% CI = US$1,892, US$2668), and that the screening resulted in a net 0.25 fewer life-years with an eating disorder (95% CI = 0.21, 0.30) and a net 0.04 more QALYs (95% CI = 0.03, 0.05) per child over 10 years. The incremental cost-effectiveness for screening versus not screening was US$9041 per life-year of an eating disorder avoided (95% CI = 6,617, US$4,266). As the authors noted, there are no established thresholds for how much a society is willing to pay to avoid a year spent with an eating disorder. As such, whether screening is “worth the money” depends on the value placed on not experiencing an eating disorder. Another way to examine the cost-effectiveness of the screening involved calculating the incremental cost-effectiveness ratio for QALY gains. In this study, it was US$32,359 per QALY gained (95% CI = US$22,671, US$44,266). As mentioned earlier, health economists typically describe an intervention as cost-effective if its incremental cost-effectiveness ratio falls at or below US$50,000 per QALY.

6. Discussion

6.1. Unmet treatment need

Because of differences in methodology, it is difficult to draw firm conclusions about unmet treatment needs in individuals with eating disorders. Findings of the few large epidemiological studies included in our review suggest that adolescents (compared to adults) may be especially unlikely to have accessed treatment for an eating disorder, a finding that is consistent with results from studies exploring correlates of seeking or receiving mental health care. For example, Mackenzie and colleagues (Mackenzie, Reynolds, Cairney, Streiner, & Sareen, 2012) explored the association between age and mental health treatment seeking and found that adolescent/young adults (<25 years) were less likely than adults to access care. Looking more closely at the adult population, however, revealed that treatment seeking for mental disorders was less common among the older adults (65 + year of age) than in the middle-age group of adults (25–65 years-of-age).

Findings further suggest that individuals with an eating disorder do access health care and that, therefore, efforts should be deployed to take advantage of those contacts with health care providers for detecting the eating disorders and referring patients as indicated by their current symptoms. Such efforts should be focused both on patients to address potential patient barriers to seeking care including internalized stigma about eating disorders or insufficient mental health literacy and on health care providers to ensure that providers are knowledgeable about the signs and symptoms of eating disorders and how best to facilitate referral for appropriate care.

6.2. Cost of illness

Although the nine studies we reviewed varied widely in terms of the specific costs that were assessed (e.g., direct costs of treatment to a health plan vs. costs to care providers), the methodologies used to assess costs (e.g., extraction from electronic medical/insurance records or self-report), the ED diagnostic groups included in the study (e.g., AN only, BED or EDNOS), and other participant characteristics (e.g., adult only samples or only adolescents), making direct comparisons impossible, a few findings were replicated across two or more studies. Hospitalization was associated with high costs, especially for those with AN (Haas et al., 2012; Munro et al., 2014; Stuhldreher et al., 2015). Comorbidity was also associated with increased costs (Haas et al., 2012; Samnaliev et al., 2015; Stuhldreher et al., 2015). For patients with AN, lower BMI was associated with higher direct costs (Haas et al., 2012; Munro et al., 2014; Toulany et al., 2015; see Stuhldreher et al. 2015 for an exception) and caregiver costs (Toulany et al., 2015). Only two studies included a non-ED comparison group and both found that in comparison to those without an ED, those with any ED (Samnaliev et al., 2015) or with a diagnosis of BED or EDNOS (Bellows et al., 2015) incurred greater health care costs. Only two studies included a direct comparison of costs for different ED diagnoses and the findings suggest that the cost for different ED diagnoses likely varies with the type of cost assessed. For example, while Haas et al. (2012) found higher hospitalization costs among those with AN compared to those with BN, Gatt et al. (2014) reported greater patient expenditures for those with BN compared to
those with AN.

Documenting the economic burden of eating disorders is a relatively recent, but mounting, concern for both researchers and health care providers. Of the 16 cost-related studies (COI and OCS) reviewed by Stuhldreher and colleagues (2012), only 1 was published prior to 2001, 5 were published between 2001 and 2005, and 10 were published between 2006 and 2010. Our searches yielded another nine studies (2 COI and 7 OCS) published from 2011 to 2015. These studies were conducted with samples from the United States (N = 3), United Kingdom (N = 2), Germany (N = 2), Canada (N = 1), and Australia (N = 1), suggesting that interest in the societal costs of eating disorders is not bound by borders nor limited to a particular type of health care system. Despite growing interest among researchers and the potential implications for public health policy and allocation of health resources, assessing the full economic burden of eating disorders has proved challenging. Our review of the studies published since 2010 supports the general conclusions reached by Stuhldreher et al. (2012): cost of illness estimates vary considerably from one study to another, existing studies often focus on only a single type of cost and thus are likely to underestimate overall economic burden, and studies including non-ED comparison groups and comprehensive evaluations of all costs, including those beyond immediate health care, are still needed.

6.3. Cost-effectiveness of eating disorder treatments

Given the dearth of CEA studies, we are left to echo others’ calls for more such research in eating disorders (Stuhldreher, Konnopka, Wild, Herzog, Zipfel, Löwe, et al., 2012). It is encouraging to find that a number of ongoing clinical trials promise to collect economic data for CEA (Bulik et al., 2012; Hilbert, 2013; Schmidt et al., 2013; Stice, Rohde, Butryn, Menke, & Marti, 2015).

7. Conclusions

Our research update highlights major gaps in the literature in each of the three topical areas. Epidemiological research continues to generate limited data on unmet treatment needs in part because, worldwide, epidemiological studies focus first and foremost on the most common mental disorders, namely the triuvmirate of mood disorders, anxiety disorders, and substance use disorders in adults, or on a slightly larger list of disorders in children (usually expanded to include attention deficit/hyperactivity or disruptive behaviors) (Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015; Steel et al., 2014). Even when eating disorders are included among the list of mental disorders to be assessed in epidemiological studies, not all such studies inquire about treatment specifically for the eating disorder. Given the high levels of psychiatric comorbidity in eating disorders, disentangling whether treatment targeted the eating disorder or another comorbid disorder (e.g., mood or anxiety disorder) poses challenges. For example, it may be up to the study respondent to judge whether a given treatment (e.g., antidepressant medication) targeted the eating disorder versus another, comorbid mental disorder (e.g., depression). Moreover, when studies do ask about treatment for the eating disorder, in some studies the question is limited to whether the person had received mental health or specialty treatment. While we recognize that specialty care is the recommended care for individuals who have not benefitted from a stepped-care approach, findings based on a narrowly worded question about treatment may underestimate the true extent of treatment seeking or treatment receiving by individuals with an eating disorder. Recognizing the magnitude of unmet treatment needs among individuals with a mental health problem and recognizing that in some areas across the globe it is utterly unrealistic to think that such needs can ever be met by the mental health sector, experts have called for a shift away from specialty care toward primary care or even further task shifting toward para-professionals or community based providers (Kazdin & Blase, 2011). Therefore, studies of unmet treatment needs of individuals with an eating disorder should ask more inclusive questions about treatment rather than focusing only on mental health treatment and only then follow with more specific questions about the type of care received.

Beyond the methodological concerns about the gaps in knowledge concerning unmet treatment needs of individuals with an eating disorder, there is the substantive question of how to better meet the treatment needs. A review of the barriers that stand in the way of people receiving the care they need is beyond the scope of this paper. Such barriers arise at the level of the patient (e.g., failure to recognize the disorder as a problem; fear of being stigmatized; poor mental health literacy), the health care provider or system (stigma of eating disorders; failure to provide adequate resources for treatment), and at the societal level (insufficient availability of treatment providers or facilities; inadequate health care policies). We note, parenthetically, that stigma and, to a lesser extent, poor mental health literacy have been most extensively researched as barriers to seeking or receiving care for an eating disorder and have prompted calls for educational interventions to improve access to care (Bentley, Gratwicke-Sarl, & Mond, 2015; Ebneter & Latner, 2013; Griffiths, Mond, Murray, & Touyz, 2015; Puhl & Sub, 2015). Yet, efforts to close the gap of unmet treatment need also should occur at the public policy level and ensure availability and (geographical and financial) accessibility of treatment (Alman et al., 2014; Austin, 2012; Kazdin & Blase, 2011).

Cost-of-illness studies have focused primarily on medical costs from a health plan perspective and research taking a societal perspective continues to be sparse and incomplete. Findings regarding medical costs vary widely across studies yet are difficult to compare because of the differences in the organization and financing of health care in the countries represented in this literature (see also Beecham, 2014). Cost-of-illness studies have focused most extensively on AN, yet findings suggest that hospitalization is a major cost driver across all eating disorders. Efforts to contain costs should focus on the question of whether there are effective alternatives to hospitalization that do not compromise clinical safety and efficacy. Although we were able to locate an RCT testing the efficacy and safety of two forms of treatment for medically unstable adolescents with AN (N = 82), one involving shorter hospitalization until medical stabilization was achieved and the other involving longer hospitalization until weight was restored to 90% of ideal body weight (both followed by 20 sessions of manualized FBT), the study did not report an economic analysis (Madden et al., 2015). The primary outcome was number of hospital days by the 12-month follow-up. Contrary to expected results, the study found that a longer initial admission did not result in a subsequent reduced need for readmissions due to relapse. The number of hospital days after the initial hospital discharge did not differ significantly between the groups (Weight Restoration: mean days = 27.51; Medical Stabilization: mean days = 22.78, not significant) and both groups had comparable outcomes in terms of full or partial remission (Weight Restoration: 32.5% and 85%; Medical Stabilization: 30% and 90%, respectively). The longer initial hospitalization combined with subsequent readmissions resulted in a significant group difference over the course of 12 months with patients who had been randomized into the weight restoration group requiring on average 20 more hospital days than did patients who were randomized into the study group where the goal of the initial hospitalization was medical stabilization. The authors noted that both groups were permitted to utilize additional family
therapy sessions if remission had not been achieved by completion of the 20 session protocol. More families of patients in the weight restoration group required additional family therapy sessions, again a finding counter to initial prediction. The authors concluded that while hospitalization is required in medically unstable patients, their findings support shorter hospital stays when combined with FBT. We note that beyond the potential cost savings, shorter hospitalization may have the added benefit of less loss of time adolescent patients spent out of school and, therefore, less adverse impact on educational outcomes.

Given the typical onset of AN and BN in adolescence, notably lacking are studies of the economic impact of eating disorders on concurrent excess service needs in the educational sector. For example, the disruption of schooling as a result of hospital stays likely imposes added demands on parents and teachers to adjust the students’ academic schedule or help with making up for lost time and instruction. Also under researched are the economic effects of eating disorders in the workplace both for patients and their families or partners. For example, studies of depression have found that the largest share of cost of illness is attributable to effects of eating disorders in the workplace both for patients and time and instruction. Also under researched are the economic effects of eating disorders in the workplace both for patients and time and instruction. Also under researched are the economic effects of eating disorders in the workplace both for patients and time and instruction.

We note that beyond the potential cost savings, shorter hospitalization may have the added benefit of less loss of time adolescent patients spent out of school and, therefore, less adverse impact on educational outcomes. In conclusion, our research update has illustrated the considerable personal and societal burdens arising from eating disorders, has shown that further efforts are required to improve access to and dissemination of evidence based treatments for eating disorders, and has identified a continued need for economic studies in eating disorders.

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References

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