It is only recently that epidemiologists have ventured into communities to understand the distribution and determinants of eating disorders in adolescents. A decade ago, nearly all evidence of eating disorder risk factors came from clinical samples. Now, a number of population-based studies have provided insights on who is at highest risk and what might
be effective prevention strategies. Even more recently, eating disorder risk has been studied using cohorts derived from registry or administrative data. For example, in the study by Bould and colleagues that appears in this issue of the International Journal of Epidemiology, the authors capitalize on Swedish registries to assess the risk associated with school-context factors in female students.1 Linking data registries with information on the adolescents, parents and schools, the resource is unparalleled in many ways.

As the use of registry data has grown, epidemiologists have recognized key differences in outcome assessments when using administrative data versus questionnaires or interviews. For some outcomes, the distinction may be relatively minor: a cancer diagnosis in a medical record versus self-reported cancer history, although each can suffer from measurement issues, are ascertaining the same general construct. This is less true for psychiatric disorders and diseases for which stigma, denial and other treatment-seeking barriers are realities. An eating disorder diagnosis in a medical record is a compound outcome: engagement in eating disorder behaviours and cognitions, recognition of symptoms, recognition that the symptoms are problematic, desire for treatment, pursuit of treatment and obtainment of a recorded diagnosis. Treatment-seeking in particular complicates the definition, as relatively few adolescents who meet diagnostic criteria seek treatment.2 Meanwhile, eating disorder assessments by questionnaire or interview compound the presence and recognition of symptoms with a willingness to report one’s (or, if reported by a parent, one’s child’s) symptoms.

Whereas registry data hold substantial promise for answering important epidemiological questions, their use in eating disorder research represents a revolution in both senses of the word: a new way forward, and a full-circle return to the past. The insights gained and lessons learned when transitioning from clinical treatment-seeking samples to community samples are relevant to a potential transition from epidemiological studies with direct assessment to studies that compound the outcome with treatment-seeking. Here we consider three such ‘lessons’.

First, evidence based exclusively on treatment-seeking samples led to some misunderstanding of key risk factors. For example, eating disorders are often perceived as primarily affecting females: based on evidence from treatment-seeking samples, the DSM-IV stated the female-to-male ratio was 9:1. Community-based studies using self- or parentally-reported measures suggest a much lower ratio (2–3:1), with males exhibiting some behaviours at an equally high frequency.2–4 Thus, ‘risk factors’ identified from clinical samples may be associated with disordered eating, barriers to treatment or both. Analogously, appropriate interpretation of associations found in registry-based studies is challenging. Bould et al. observed that girls who went to schools with a greater proportion of highly-educated parents were at higher risk of an eating disorder diagnosis.1 One key question is: can this finding be used to inform targeted prevention strategies? Is the association measuring that school environments are associated with risk of an eating disorder? If so, ‘high-risk’ schools (with a high prevalence of highly-educated parents) could be ideal targets for prevention programmes. Or is the association measuring how school environments are associated with greater awareness and utility of treatment options, but not eating disorder risk itself? If so, then we would perhaps target the exact opposite schools; that is, we may consider, as Bould et al. also describe,1 developing awareness programmes at schools with the lowest prevalence of highly-educated parents. Bould et al. present some evidence favouring the former interpretation, but studies based solely on clinical diagnoses by definition cannot definitively disentangle treatment-seeking and risk.

Second, evidence based exclusively on treatment-seeking samples limited and skewed data collection on subclinical or atypical disorders. This is especially problematic because the majority of eating disorder cases fall into the heterogeneous ‘not-otherwise-specified’ diagnosis in the DSM-IV and, even with the broadened and added diagnoses in the DSM-5, some common presentations in adolescents are still not specified disorders.5,6 Because eating disorder definitions are evolving, this actually represents another challenge to registry-based research and other research using diagnostic criteria cut-offs. Without careful attention to temporal changes in definitions and coding usage, we may miss or misclassify some types of eating disorders. It also means that the only viable analytical option may be lumping all subtypes into a single outcome (‘any eating disorder’, as done by Bould et al.), which hinders our ability to find or interpret associations if risk factors vary by eating disorder subtype.

Third, evidence based exclusively on treatment-seeking samples meant, by definition, that no prospective data were gathered on the onset and early progression of symptoms and full disorders. Likewise, registry-based studies cannot provide information on early progression or even onset. Many patients have been ill for years before seeking treatment, and some of the consequences of eating disorders, such as suboptimal bone health,7 are not completely reversible. Thus, a lack of studies on prodromal or pre-treatment-seeking phases means discounting a time of critical public health relevance.

Of course, there are disadvantages to using questionnaires or interviews to assess eating disorders, including underreporting (due to stigma and denial) and the difficulty of capturing ‘clinical relevance’ (which is sometimes conceptualized as over-reporting). Further, researchers must weigh participant burden and logistical and financial constraints in choosing the type of assessment (e.g. interview versus questionnaire), length...
and number of questions (and whether skip rules are invoked) and number of informants. On the other hand, whereas there is still much room for improvement, the advantages of and novel insights due to direct assessments in population-based samples are often overlooked.

Triangulation of evidence and careful consideration of study design and analysis are hallmarks of epidemiology. This includes recognizing both the strengths and the limitations of our data sources. If we can use all available evidence appropriately and effectively to inform predicting, preventing and identifying eating disorders, then we may greatly reduce the public health burden of these chronic, often treatment-resistant and consequential conditions.

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References