Journal of Eating Disorders

CASE REPORT

Open Access

Building RECOVERY: development of the registry of eating disorders and their co-morbidities OVER time in youth

Tracy K. Richmond[1,2*], Emily Farbman Kadish[3], Monique Santoso[1], Carly E. Milliren[1], Meredith Kells[4], Genevieve Alice Woolverton[5], Elizabeth R. Woods[1,2] and Sara F. Forman[1,2]

Abstract

Background Eating disorder (ED) research is limited by the lack of longitudinal cohort studies, particularly those in adolescents, and the lack of inclusion of multiple perspectives and diagnoses. The objective of this study was to describe the development of a longitudinal cohort of adolescents/young adults representing varied ED diagnoses and including perspectives of parents and multi-disciplinary clinicians in addition to those of patients.

Methods Patients of an outpatient ED program who were age 10–27 years, along with their parents and clinicians, were recruited to participate in a longitudinal web-based study. Using univariate, bivariate, and multivariate analyses, we assessed rates of participation among different groups (i.e., parents, patients, different clinical disciplines) as well as factors related to attrition.

Results 71% of patients, 75% of parents, 56% of adolescent medicine providers, 20% of primary care physicians, 83% of dietitians, and 80% of mental health clinicians invited agreed to participate. At 12 months, 32% of patient participants had not completed their on-line surveys. Attrition rates were higher for parents (55%) and clinicians (45% of nutritionists, 55% of primary care physicians, 51% of Adolescent/Young Adult providers, and 64% of mental health providers) at 12 months.

Conclusions A longitudinal registry of patients with EDs is feasible and efficient when using web-based surveys. However, clinician participation is particularly hard to secure and maintain.

Keywords Eating disorders, Mental health, Corona virus, Primary care, Disordered eating, Anorexia nervosa, Bulimia nervosa, Adolescents, Body image

This work was supported in part by the Appleby Family Charitable Fund [95259]; Children's Hospital – Boston PPSQ [96204]; The McCarthy Family Fund; and by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of a MCHB T71MC00009 LEAH training grant. The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement by, HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.

*Correspondence:
Tracy K. Richmond
tracy.richmond@childrens.harvard.edu
Full list of author information is available at the end of the article

Plain English Summary

We report on the development of a longitudinal cohort of just over 160 youth with eating disorders. In order to have additional perspectives on illness course, we recruited parents and clinicians of patient participants. We demonstrate willingness to participate in patient participants with acceptable rates of attrition. Community providers were more difficult to recruit and retain.

Background

Eating disorders (ED) are common and under-recognized illnesses associated with co-morbidities as well as an increased risk of mortality [1]. Recent studies have estimated that by the age of 40, 1 in 5 females and 1 in 7 males will develop an ED [2, 3]. EDs typically develop during adolescence but often fail to be recognized, resulting in, on average, 30 months of untreated illness [4]. Even once recognized, the course of illness for EDs is often long (on average lasting 6 years) [4], punctuated by recovery, relapse, and numerous complications (e.g., cardiac arrhythmias, electrolyte abnormalities, bony fractures) and/or co-morbidities (e.g., depression, anxiety) [5]. Patients with EDs have the second highest mortality of any group of patients with psychiatric illnesses and of those who survive, at least one-third do not achieve full recovery in their lifetimes. [6] Patients incur significant costs to themselves, their families, and the healthcare system [2, 3]; annual healthcare costs related to EDs are estimated at $4.6 billion and total annual costs to society estimated at $65 billion [7]. Risks associated with EDs increase the longer the illness goes on (i.e., risk of comorbidities are higher in adults than teens); thus early attention is key. Given the prolonged and onerous trajectory that patients with EDs have and the impact of EDs on individuals and society, understanding their etiology, potential points of prevention, as well as the most effective treatment strategies is critical.

In an effort to gain insights related to etiologies of and effective care strategies for EDs, the National ED Quality Improvement Collaborative (NEDQIC) was created. The NEDQIC is a collaboration between more than 20 academic Adolescent/Young Adult Medicine programs across the country. The NEDQIC has worked collaboratively to complete several studies, relying primarily on retrospective chart review [8–11]. In a study comparing clinically relevant outcomes related to EDs, the NEDQIC found that, on average, all sites demonstrated a high degree of weight restoration in patients and there was no discernible difference in outcomes by site [11]. A noted limitation of the study was the high one-year attrition rate as many patients had returned to their primary care clinicians for ED-related care, and thus, had stopped both seeking care in specialized ED programs and contributing clinical and research data. This was aligned with other studies of individuals with EDs that have noted difficulty capturing long-term outcomes due to the lack of comprehensive longitudinal data [12]. In addition to concern about loss to follow-up, there was recognition that other perspectives on recovery outside of the patients' would be beneficial. For example, the perspective of parents, who are critical to any treatment of younger patients and particularly in those pursuing family based therapy, are rarely included in studies [13]. Similarly, perspectives of clinicians such as mental health providers or dietitians are rarely included in ED studies, though they could provide care-related insights (e.g., how subjectively recovered a patient is) based on their experience caring for populations of patients [14]. Finally, there are few cohorts that include patients with a broad range of ED diagnoses as studies commonly focus on a single diagnosis, most commonly anorexia nervosa (AN), thus allowing for little accrual of evidence for diagnoses outside of AN [15].

We set out to address critical gaps in the adolescent ED literature by building a registry of patients with the full spectrum of ED diagnoses to be followed longitudinally for a minimum of three years. In addition, we set out to address limitations in existing ED studies due to attrition and the lack of input from multidisciplinary clinicians. Building on our prior NEDQIC work, we aimed to build a prospective web-based registry of patients with EDs that negated the reliance on individuals being in care at a particular site in order to contribute data. We incorporated findings from earlier qualitative work that identified potential barriers (e.g., too much time required) and incentives (e.g., feeling like they were contributing to good) to participation in a longitudinal registry [16]. The objective of the current study is to describe the development, recruitment strategies, and patterns of attrition at one year in the Registry of Eating Disorders and their Co-morbidities OVER time in Youth (RECOVERY), a longitudinal cohort of patients with EDs, including reports from caregivers and multi-disciplinary clinicians. RECOVERY was conducted at a single site in an effort to address feasibility with the goal to expand to NEDQIC sites in the future. Feasibility was measured by ability to recruit participants and rates of attrition.

Methods

From June 2017 through June 2020, the RECOVERY study enrolled participants from the multi-disciplinary outpatient ED Program, housed within the Division of Adolescent/Young Adult Medicine at Boston Children's Hospital. The primary inclusion criteria included having an assessment in the ED program and being found to have an active ED diagnosis, age between 10 and 27 years old, English-speaking, English-speaking guardian if under 18, and ability to complete web-based surveys. Patients could be recruited at their initial assessment visit or at any point in their treatment; thus, the cohort enrolled individuals new to eating disorder therapy as well as those who had been in treatment in the Eating Disorder program for more than a year. Patients were first informed of the study and their potential eligibility by their Adolescent/Young Adult Medicine clinician; a study brochure that highlighted the main details of the research and participation requirements was provided. Interested individuals were then approached by a research assistant who explained the study in more detail and completed the consent process. This approach was informed by findings from our qualitative study in which participants reported higher comfort levels and more willingness to participate if first oriented to the study by a clinician with whom they have an established relationship. Once enrolled in the study, patient participants were invited to complete 9 web-based REDCAP surveys over the course of 3 years. REDCAP is a secure online platform for building databases and allows for secure collection of survey data. Participants were sent surveys once every three months during the first year, and once every 6 months during the subsequent two years.

Patient web-based surveys included validated and non-validated measures. Validated measures included the following: the ED Examination Questionnaire (EDE-Q) [17], the ED Quality of Life (EDQoL) measure [18], the ED in Youth Questionnaire (EDY-Q) [19], the Center for Epidemiological Studies Depression Scale (CES-D) [20], and the Generalized Anxiety Disorder-7 (GAD-7) [21] questionnaire. We incorporated cutoffs for the CES-D and GAD-7, based on evidence in the literature, for clinically significant anxiety and depression [22, 23]. In addition to demographic questions (age, sex, gender identity, sexual orientation, race, ethnicity), non-validated measures were used to query patient participants regarding the following domains: length of time ill with ED, history of ED treatment (e.g., participation in eating disorder inpatient, or residential program), therapeutic alliance with various clinicians (i.e., how would you rate your alliance with your mental health clinician?) family history of EDs, self-reported degree of and motivation for recovery measured on a 10-point scale. Patients were compensated with $20 gift cards for every survey they completed. The BCH Internal Review Board approved this study.

In order to include multiple perspectives, enrollment also included parents/caregivers and clinicians from primary care, Adolescent/Young Adult Medicine, nutrition, and mental health. Patients provided contact information for these additional reporters to the research team both at the time of consent and through their baseline web-based survey response. The consent for minor aged participants (age 10–17 years) included contacting their multi-disciplinary clinicians. In acknowledgement of their autonomy, adult participants (age 18–27 years) were asked during the consent process for separate permission to recruit their clinicians and parents/guardians to participate. Only one parent/guardian was invited to participate; as many clinicians as were on the care team and were able to be contacted were invited to participate. Once these additional reporters were contacted, provided consent, and enrolled in the study, they were also emailed 9 web-based surveys over the course of three years with the same scheduled intervals as the patient surveys. However, the surveys did not always coincide with those of the patient if, for example, the patient or parent delayed responding, as subsequent surveys were sent at intervals set by the last response. Surveys of parents/caregivers included non-validated measures of length of illness, treatment history, economic consequences of the illness on the family, and their rating of their child's current recovery and motivation to recover. Multi-disciplinary clinicians were asked to describe the type of treatment they were providing including a check-list of different components of evidence-based treatments (e.g., family meals if reported participating in family-based treatment). They also rated their therapeutic alliance with the patient participant, and their patient's current recovery as well as their motivation to recover. Parent and clinician surveys were linked to the participants to which they were related/treating. A single clinician could report on multiple patients. Parents were compensated with $10 gift cards for each survey they completed, and clinicians were compensated with $5 gift cards per survey.

For all participants, if surveys were not completed within 4 days, up to 3 email reminders were sent. If any participant did not complete a survey, with the exception of the baseline survey, they were still sent the next scheduled survey. Participants were unenrolled in the study if they specifically requested removal or if they turned 18 and failed to provide additional consent as an adult to remain in the study. Additionally, at the start of the COVID-19 pandemic, there was some disruption in sending out surveys which resulted in a small number (less than 5) being delayed or missed. To encourage continued participation, a newsletter was sent out during

the COVID-19 pandemic to highlight research findings, introduce the research team, and to thank participants for ongoing participation.

Participants provided consent for their electronic medical records to be reviewed for clinical data such as growth data and dates of eating disorder assessments and follow-ups. Data presented here are based only on self-reported survey data.

Statistical analysis

We report descriptive statistics for sociodemographic and clinical factors using mean (standard deviation) for continuous variables and frequency (percent) for categorical variables. We report response rates as percentage of surveys sent by time point that were completed (e.g., if a patient asked to be removed from the study, they were no longer included in our denominator of potential respondents). We tested for potential bias in rates of attrition at 12 months by age, sex at birth, gender identity, race/ethnicity, ED diagnosis, baseline EDE-Q global score, and EDE-Q global score at the last completed survey using chi-square tests for categorical variables and t-tests for continuous variables.

Results

Since June 2017, 293 patients were approached and of those, 208 patients (71% of those approached) expressed interest. Of the 208 who expressed interest, 179 patients (86%) provided consent and enrolled, and 162 (90% of those enrolled) completed the baseline survey within the prescribed time-period. Of the 176 parents approached, 132 (75%) consented and enrolled and 110 (83% of those enrolled) completed the baseline survey. Of the 179 instances of an Adolescent/Young Adult Medicine provider being approached, (i.e., an Adolescent Medicine provider was asked to answer surveys for each of their patients enrolling in the study and most providers were asked to answer surveys for more than one patient), 99 instances (56%) resulted in consent and enrollment and 98 (99% of enrolled) baseline surveys were completed. Of the 100 primary care clinicians approached, 20 (20% of approached) provided consent and enrolled, and 20 (100% of those enrolled) completed the baseline survey. Of the 44 mental health providers contacted regarding the study, 35 (80% of those approached) provided consent and enrolled and 33 (94% of those enrolled) completed the baseline survey. Of the 42 nutritionists contacted, 35 (83% of those approached) provided consent and enrolled and 31 (89% of those enrolled) completed the baseline survey.

We present demographic characteristics of patient participants in Table 1 and clinical characteristics in Table 2. Enrolled patients ranged in age from 10 to 24 years with

Table 1 Demographic characteristics of RECOVERY patient participants (n = 162)

	n (%)
Age at enrollment, mean (SD)	17.0 (3.0)
Age 18 or over	61 (38%)
Sex assigned at birth	
Female	139 (86%)
Male	23 (14%)
Gender identity	
Boy/Male/Man	23 (14%)
Girl/Female/Woman	134 (83%)
Transgender Boy/Male/Man	1 (1%)
Transgender Girl/Female/Woman	1 (1%)
Genderqueer/Gender nonconforming	2 (1%)
Another gender identity	0 (0%)
Sexual orientation	
Completely heterosexual/straight	102 (63%)
Mostly heterosexual	24 (15%)
Bisexual	12 (7%)
Mostly gay or lesbian	4 (2%)
Completely gay or lesbian	6 (4%)
Don't know/unsure	9 (6%)
Another sexual orientation identity	5 (3%)
Race	
White	131 (81%)
Black/African-American	2 (1%)
Asian	11 (7%)
Native Hawaiian/Pacific Islander	1 (1%)
Another	7 (4%)
Multiracial	10 (6%)
Ethnicity	
Hispanic	10 (6%)
Non-hispanic	145 (90%)
Don't know	7 (4%)

Table 2 Clinical characteristics of patient participants in RECOVERY (n = 162)

BMI at Intake, mean (SD)	18.7 (3.8)
Eating disorder diagnosis at baseline	
Anorexia nervosa (AN)	80 (49%)
Atypical anorexia nervosa (AAN)	5 (3%)
Avoidant restrictive food intake disorder (ARFID)	13 (8%)
Bulimia nervosa (BN)	4 (3%)
Binge eating disorder (BED)	2 (1%)
Mixed	37 (23%)
Unknown	21 (13%)
EDE-Q, mean (SD)	2.58 (1.61)
Depressive symptoms (CESD), mean (SD)	24.4 (14.0)
Anxiety symptoms (GAD7), mean (SD)	9.55 (6.1)

a mean age of 17.0 years (SD = 3.0). Patient participants were 86% female and 81% white. There was variability in self-reported ED diagnosis: 49% reported anorexia nervosa (AN), 36% reported having mixed or unknown ED, 8% avoidant restrictive food intake disorder (ARFID), 3% atypical AN, 3% bulimia nervosa (BN), 1% binge eating disorder (BED). Participants' average score on the GAD-7 and CES-D indicated clinically significant anxiety and depression. Participants who were older than 18 years provided permission to enroll their medical providers more commonly than their parents or clinicians from other disciplines (Table 3).

Table 3 Percent of patients > 18 years of age who agreed to have parents and providers included

Participant	Percent (± SD)
Parent	59
Provider	
Adolescent Medicine clinician	81
PCP	78
Nutritionist	54
Mental Health clinician	69

In their first year of participation, 75–80% of patient participants completed surveys at the 3-, 6-, and 9-month time points (Fig. 1). Of the 162 patient participants who were sent a 12-month survey, 102 (67.1%, of those who were sent a 12 month survey or 57.0% of those enrolled) completed them. Younger participants were less likely to respond at 12 months (61% of those < 18 years responded vs. 77% of those ≥ 18 years; $p = 0.04$). At 12 months, respondents were significantly older (17.5 years, SD = 3.0) than non-respondents (16.3 years, SD = 2.8). Male sex at birth was associated with lower response rates; at 12 months, those assigned male at birth had lower response (47%) than those assigned female sex at birth (70% $p = 0.05$), but there was no difference by gender identity ($p = 0.35$). There was no difference in response rates at 12 months by race ($p = 0.95$), ethnicity ($p = 0.20$), or ED diagnosis ($p = 0.59$). There was no difference in baseline EDE-Q global score between 12-month responders (mean = 2.82) and non-responders (mean = 2.30; $p = 0.06$) or in the last EDE-Q global score collected prior to the 12-month survey in responders (mean = 2.23) v. non-responders (mean = 1.88; $p = 0.21$). Of the 102 participants who responded to the 12 month survey, 78 (76%) were still receiving ED care at BCH. Of the 50 who were sent the 12 month survey but did not respond, 32

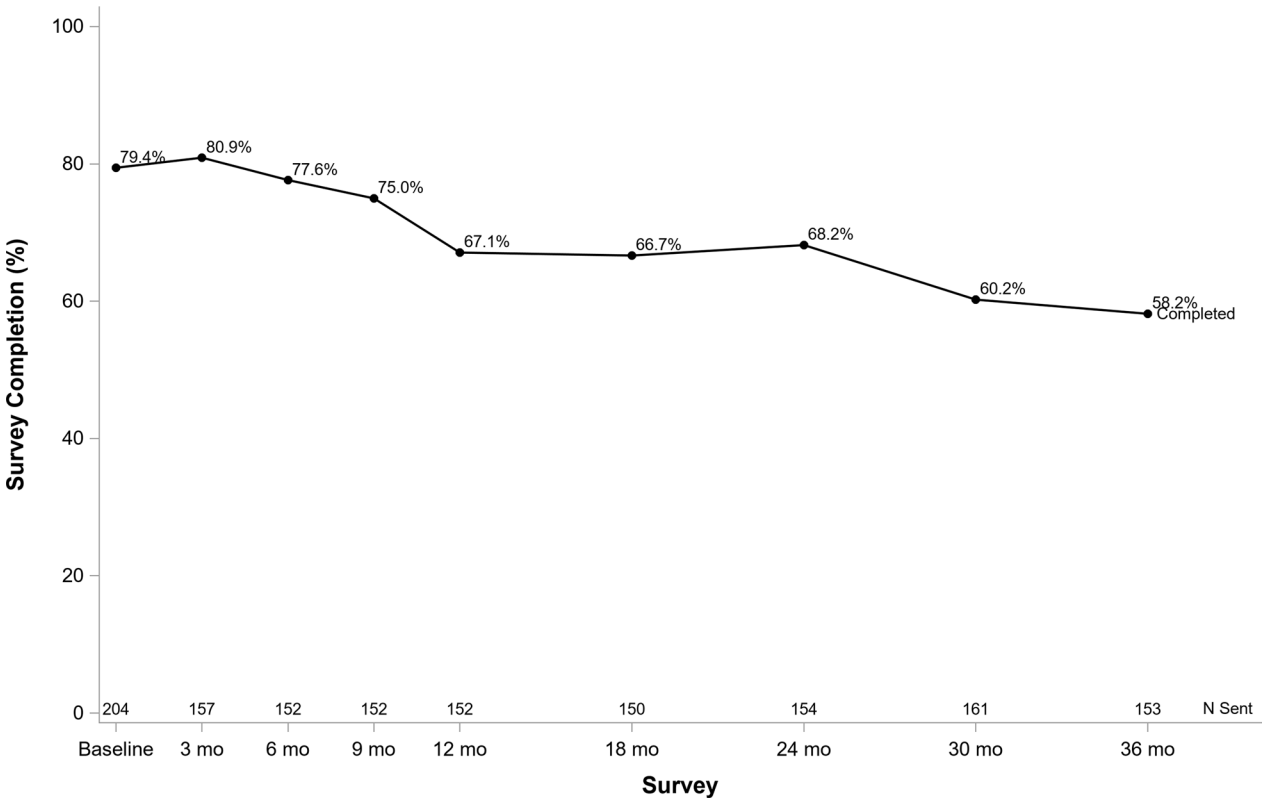

Fig. 1 Attrition Rates of Patients through 36-month survey

(64%) were still receiving ED care at BCH. There was no statistically significant difference between responders and non-responders with respect to still being in care at BCH ($p=0.11$).

Of those who enrolled and completed baseline surveys, response rates were lower in both parents/caregivers and clinicians relative to patient participants. At 12 months, 60 of 110 parents (55%), 21 of 33 mental health providers (64%), 11 of 20 primary care physicians (55%), 14 of 31 nutritionists (45%), and 50 of 98 Adolescent/Young Adult Medicine (51%) providers completed surveys.

Discussion

Informed by findings from a qualitative study of potential participants [16], we created a longitudinal web-based registry of adolescent/young adult patients with a variety of ED diagnoses along with their parents/caregivers and multi-disciplinary clinicians. In building our registry, we had high recruitment among patient participants and attrition rates similar to other studies of youth among our patient participants [24, 25]. We maintained study involvement despite data collection coinciding with the COVID-19 pandemic. We found minimal bias in attrition due to demographic or illness-related factors of patients participants. To the authors' knowledge, this is the first prospective web-based registry of youth diagnosed with any form of ED, and demonstrates feasibility while identifying challenges.

In contrast to patient participants, recruiting parents and particularly clinicians was more challenging. A significant obstacle encountered was making initial contact with providers who were working in the community (e.g., primary care physicians and community-based therapists). This was a particular challenge when the patient did not have a contact email for the provider or if the clinician was not affiliated with the parent institution, allowing researchers to easily contact them through hospital-based directories. Of the clinicians who did participate, the vast majority worked in the same hospital division as the authors, and thus, may have been more committed to the study and accessible to the study team. We speculate that outside community providers did not enroll or complete surveys due to time constraints, as this was a factor that had been identified in our earlier qualitative work or perhaps because of lack of familiarity or alliance with the study [26]. As well, clinicians may have ignored surveys related to patients who were no longer in their care. Future studies may need to provide more engagement with providers ahead of recruitment.

To address the loss to follow-up seen in prior multisite studies conducted by the NEDQIC, we aimed to recruit primary care physicians of patient participants. By engaging primary care physicians, we hoped to obtain ongoing objective measures of recovery even if patient participants had stopped being seen by Adolescent/Young Adult Medicine. Primary care clinicians proved to be particularly difficulty to recruit and maintain in the study. This may be due to time, clinical burden, or infrequent requests for research participation. By design, our registry had the ability to follow patients, with additional parent input, even when they were no longer in the care of the specialized ED program. However, without participation from primary care physicians, we were relying on patient and parent report of weight recovery.

Our cohort had moderate but acceptable rates of attrition with more than 2/3 of participants responding to surveys at 12 months. This was in keeping with other studies of youth [25]. We found bias in response rate by age and gender with younger participants and males being less likely to respond compared to older and female participants. This is important given the relative dearth of evidence for males with eating disorders compared to females. We found no bias in reporting by either diagnosis or markers of severity, reasons we had concern could influence response (e.g., if an individual had worsening symptoms they may be reluctant to acknowledge so).

There are limitations to this study that must be acknowledged. First, this cohort was recruited from an ED treatment program and many of the patient participants had existing relationships with the program and the clinicians. This may have influenced their willingness to participate. Response to recruitment may differ in non-clinical settings. We were also unable to compare those patients who enrolled to the general population enrolled in our eating disorder program on characteristics such as demographics and illness severity. Thus, we cannot be sure that participants do not differ from non-participants in some meaningful way. As well, our cohort represents treatment-seeking youth with EDs and may differ substantially from those who do not seek treatment. Non-treatment seeking youth with EDs is an important and under-studied group of individuals and future studies are needed to understand how their experiences may be better represented in ED-related research.

We are encouraged by our ability to recruit and maintain a cohort of patients with eating disorders as non-disease specific longitudinal cohort studies have demonstrated the benefits of establishing a database of patients to conduct long-term quality research. The Nurses Health Study (NHS) [27], the Australian Longitudinal Study on Women's Health (ALSWH) [28, 29], and the Growing Up Today Study are examples of longitudinal studies that have addressed their primary aims while also providing data instrumental to public health research for decades and across generations. Longitudinal registries of patients with EDs have the capacity to

similarly provide significant insights into the risk factors and optimal treatment strategies for patients with EDs while also providing data that can be used to address additional epidemiologic and other research questions. Established cohorts have additional benefits: for example, our experience in being able to the RECOVERY cohort to answer timely questions such as those related to the COVID-19 pandemic and its impact on individuals with eating disorders [30, 31].

Significant improvements in care have been achieved in non-ED fields through the sharing of experiences and pooling of research data across multiple sites. For example, retrospective studies of cohorts of individuals with cystic fibrosis (CF) have identified important predictors of survival [32, 33]. Prospective studies using pooled cohorts of patients with CF have identified clinical markers of function, trialed new therapeutics, and have identified infectious organisms impacting individuals with CF [34–36]. Similarly, the field of pediatric hematology-oncology has mapped best therapies by pooling data from centers around the globe [37–40]. In demonstrating feasibility at one site, we hope to similarly extend our cohort to other sites to build on knowledge similar to other fields. Yet at our single site, we demonstrated feasibility in recruiting a robust sample of youth with a variety of eating disorders and the ability to maintain engagement with a large percentage of participants for more than a year.

Conclusions

The RECOVERY study is the first multi-reporter, prospective registry of adolescent/young adult ED patients. Now that enrollment strategies have been tested at a pilot Adolescent/Young Adult medicine site, it can be adapted as a multi-site study. This study, in concert with our earlier qualitative study, provides early lessons, particularly that a registry of ED patients is indeed feasible. Future studies will need to devise new recruitment strategies for clinicians such as incorporating research staff onto clinical sites. Alternatively, a cohesive electronic medical record could provide clinical data from a multi-disciplinary team, obviating the need to recruit and maintain multiple clinicians. This study provides evidence that adolescents and young adults with EDs can be enrolled in a long-term study over multiple years that exceeds the treatment time at any individual program or practice. Data provided through this registry will be invaluable in identifying prevention and treatment strategies.

Abbreviations

ED	Eating disorders
NEDQIC	National ED Quality Improvement Collaborative
AN	Anorexia nervosa
RECOVERY	Registry of eating disorders and their co-morbidities OVER time in Youth
EDE-Q	ED examination questionnaire
EDQoL	ED quality of life measure
EDY-Q	ED in youth questionnaire
CES-D	Center for Epidemiological Studies Depression Scale
GAD-7	Generalized anxiety disorder-7 questionnaire
ARFID	Avoidant restrictive food intake disorder
BN	Bulimia nervosa
BED	Binge eating disorder
NHS	The Nurses Health Study
ALSWH	Australian Longitudinal Study on Women's Health
CF	Cystic fibrosis

Acknowledgements
Not applicable.

Author contributions
Drs. Forman, Woods, and Richmond conceived of the RECOVERY study. Dr. Richmond oversaw the analysis and oversaw and produced the first draft of the manuscript. Drs. Farbman, Woolverton and Ms. Santoso were research assistants who were integral to the development of the RECOVERY study. Dr. Farbman was an integral part of writing the initial draft. Ms. Milliren conducted all analyses and aided in interpretation of results. Dr. Kells helped to refine the analysis and revised the manuscript. The authors had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. SF, EW, and TR conceived of the RECOVERY study. TR oversaw the analysis and oversaw and produced the first draft of the manuscript. EF, GAW and MS were research assistants who were integral to the development of the RECOVERY study. EF was an integral part of writing the initial draft. CM conducted all analyses and aided in interpretation of results. MK helped to refine the analysis and revised the manuscript. The authors collaborated fully on drafting of the manuscript. No one was provided a grant or honorarium to produce this manuscript. Each author has seen and approved the submission of this version of the manuscript and takes full responsibility for the manuscript.

Funding
Funding for this study came from the Appleby Family Fund.

Availability of data and materials
The datasets generated and/or analysed during the current study are not publicly available due to privacy concerns but are available from the corresponding author on reasonable request. No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate
Approved by Boston Children's Hospital's Institutional Review Board.

Consent for publication
Not applicable.

Competing interests
Dr. Richmond is on the Clinical Advisory Board of Arise.

Author details
[1]Division of Adolescent/Young Adult Medicine, Boston Children's Hospital, 333 Longwood Ave, LO 645, Boston, MA 02115, USA. [2]Department of Pediatrics, Harvard Medical School, Boston, MA, USA. [3]UMass Chan Medical School, Boston, MA, USA. [4]University of Rochester, Rochester, NY, USA. [5]Department of Pediatric and Newborn Medicine, Brigham and Women's Hospital, Boston, MA, USA.

Received: 10 March 2024 Accepted: 29 August 2024
Published online: 27 September 2024

References

1. Hambleton A, Pepin G, Le A, Maloney D, Touyz S, Maguire S. Psychiatric and medical comorbidities of eating disorders: findings from a rapid review of the literature. J Eat Disord. 2022;10(1):132. https://doi.org/10.1186/s40337-022-00654-2.
2. Herpertz-Dahlmann B. Adolescent eating disorders: update on definitions, symptomatology, epidemiology, and comorbidity. Child Adolesc Psychiatr Clin. 2015;24(1):177–96. https://doi.org/10.1016/j.chc.2014.08.003.
3. Ward ZJ, Rodriguez P, Wright DR, Austin SB, Long MW. Estimation of eating disorders prevalence by age and associations with mortality in a simulated nationally representative US cohort. JAMA Netw Open. 2019;2(10):e1912925. https://doi.org/10.1001/jamanetworkopen.2019.12925.
4. Austin A, Flynn M, Richards K, et al. Duration of untreated eating disorder and relationship to outcomes: a systematic review of the literature. Eur Eat Disord Rev. 2021;29(3):329–45. https://doi.org/10.1002/erv.2745.
5. Fichter MM, Quadflieg N. Six-year course and outcome of anorexia nervosa. Int J Eat Disord. 1999;26(4):359–85. https://doi.org/10.1002/(sici)1098-108x(199912)26:4%3c359::aid-eat2%3e3.0.co;2-7.
6. Arcelus J, Mitchell AJ, Wales J, Nielsen S. Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies. Arch Gen Psychiatry. 2011;68(7):724–31. https://doi.org/10.1001/archgenpsychiatry.2011.74.
7. Streatfeild J, Hickson J, Austin SB, et al. Social and economic cost of eating disorders in the United States: evidence to inform policy action. Int J Eat Disord. 2021;54(5):851–68. https://doi.org/10.1002/eat.23486.
8. Forman SF, Grodin LF, Graham DA, et al. An eleven site national quality improvement evaluation of adolescent medicine-based eating disorder programs: predictors of weight outcomes at one year and risk adjustment analyses. J Adolesc Health. 2011;49(6):594–600. https://doi.org/10.1016/j.jadohealth.2011.04.023.
9. Monge MC, Forman SF, McKenzie NM, et al. Use of psychopharmacologic medications in adolescents with restrictive eating disorders: analysis of data from the national eating disorder quality improvement collaborative. J Adolesc Health. 2015;57(1):66–72. https://doi.org/10.1016/j.jadohealth.2015.03.021.
10. Kapphahn CJ, Graham DA, Woods ER, et al. Effect of hospitalization on percent median body mass index at one year, in underweight youth with restrictive eating disorders. J Adolesc Health. 2017;61(3):310–6. https://doi.org/10.1016/j.jadohealth.2017.03.020.
11. Forman SF, McKenzie N, Hehn R, et al. Predictors of outcome at 1 year in adolescents with DSM-5 restrictive eating disorders: report of the national eating disorders quality improvement collaborative. J Adolesc Health. 2014;55(6):750–6. https://doi.org/10.1016/j.jadohealth.2014.06.014.
12. De Young KP, Kambanis PE, Bottera AR, et al. Identifying duration criteria for eating-disorder remission and recovery through intensive modeling of longitudinal data. Int J Eat Disord. 2020;53(8):1224–33. https://doi.org/10.1002/eat.23249.
13. le Grange D, Lock J, Loeb K, Nicholls D. Academy for Eating Disorders position paper: the role of the family in eating disorders. Int J Eat Disord. 2010;43(1):1–5. https://doi.org/10.1002/eat.20751.
14. Field AE, Sonneville KR, Micali N, et al. Prospective association of common eating disorders and adverse outcomes. Pediatrics. 2012;130(2):e289–95. https://doi.org/10.1542/peds.2011-3663.
15. Hudson JI, Hiripi E, Pope HG Jr, Kessler RC. The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. Biol Psychiatry. 2007;61(3):348–58. https://doi.org/10.1016/j.biopsych.2006.03.040.
16. Richmond TK, Woolverton GA, Mammel K, et al. How do you define recovery? A qualitative study of patients with eating disorders, their parents, and clinicians. Int J Eat Disord. 2020;53:1209–18. https://doi.org/10.1002/eat.23294.
17. Fairburn CG, Beglin SJ. Assessment of eating disorders: interview or self-report questionnaire? Int J Eat Disord. 1994;16(4):363–70.
18. Engel SG, Wittrock DA, Crosby RD, Wonderlich SA, Mitchell JE, Kolotkin RL. Development and psychometric validation of an eating disorder-specific health-related quality of life instrument. Int J Eat Disord. 2006;39(1):62–71. https://doi.org/10.1002/eat.20200.
19. van Dyck Z, Hilbert A. Eating disorders in youth-questionnaire. Deutsche version. Leipzig: Universität Leipzig; 2016.
20. Radloff LS. The CES-D scale: a self-report depression scale for research in the general population. Appl Psychol Meas. 1977;1(3):385–401.
21. Spitzer RL, Kroenke K, Williams JB, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med. 2006;166(10):1092–7.
22. Stockings E, Degenhardt L, Lee YY, et al. Symptom screening scales for detecting major depressive disorder in children and adolescents: a systematic review and meta-analysis of reliability, validity and diagnostic utility. J Affect Disord. 2015;174:447–63. https://doi.org/10.1016/j.jad.2014.11.061.
23. Löwe B, Decker O, Müller S, et al. Validation and standardization of the Generalized Anxiety Disorder Screener (GAD-7) in the general population. Med Care. 2008;46(3):266–74. https://doi.org/10.1097/MLR.0b013e318160d093.
24. Whitney DG, Peterson MD. US national and state-level prevalence of mental health disorders and disparities of mental health care use in children. JAMA Pediatr. 2019;173(4):389–91. https://doi.org/10.1001/jamapediatrics.2018.5399.
25. Gold MA, Tzilos GK, Stein LA, et al. A randomized controlled trial to compare computer-assisted motivational intervention with didactic educational counseling to reduce unprotected sex in female adolescents. J Pediatr Adolesc Gynecol. 2016;29(1):26–32. https://doi.org/10.1016/j.jpag.2015.06.001.
26. Richmond TK, Woolverton GA, Mammel K, et al. How do you define recovery? A qualitative study of patients with eating disorders, their parents, and clinicians. Int J Eat Disord. 2020;53(8):1209–18. https://doi.org/10.1002/eat.23294.
27. Bao Y, Bertoia ML, Lenart EB, et al. Origin, methods, and evolution of the three nurses' health studies. Am J Public Health. 2016;106(9):1573–81. https://doi.org/10.2105/ajph.2016.303338.
28. Loxton D, Tooth L, Harris ML, et al. Cohort profile: The Australian longitudinal study on women's health (ALSWH) 1989–95 cohort. Int J Epidemiol. 2018;47(2):391–392e. https://doi.org/10.1093/ije/dyx133.
29. Field AE, Camargo CA Jr, Taylor CB, et al. Overweight, weight concerns, and bulimic behaviors among girls and boys. J Am Acad Child Adolesc Psychiatry. 1999;38(6):754–60.
30. Vitagliano JA, Jhe G, Milliren CE, et al. COVID-19 and eating disorder and mental health concerns in patients with eating disorders. J Eat Disord. 2021;9(1):80. https://doi.org/10.1186/s40337-021-00437-1.
31. Lin JA, Hartman-Munick SM, Kells MR, et al. The impact of the COVID-19 pandemic on the number of adolescents/young adults seeking eating disorder-related care. J Adolesc Health. 2021;69(4):660–3. https://doi.org/10.1016/j.jadohealth.2021.05.019.
32. Holtrop M, Heltshe S, Shabanova V, et al. A prospective study of the effects of sex hormones on lung function and inflammation in women with cystic fibrosis. Ann Am Thorac Soc. 2021;18(7):1158–66. https://doi.org/10.1513/AnnalsATS.202008-1064OC.
33. Linnane B, Walsh AM, Walsh CJ, et al. The lung microbiome in young children with cystic fibrosis: a prospective cohort study. Microorganisms. 2021;9(3):492. https://doi.org/10.3390/microorganisms9030492.
34. Collaco JM, Blackman SM, Raraigh KS, Morrow CB, Cutting GR, Paranjape SM. Self-reported exercise and longitudinal outcomes in cystic fibrosis: a retrospective cohort study. BMC Pulm Med. 2014;14:159. https://doi.org/10.1186/1471-2466-14-159.
35. Cipolli M, Fethney J, Waters D, et al. Occurrence, outcomes and predictors of portal hypertension in cystic fibrosis: a longitudinal prospective birth cohort study. J Cyst Fibros. 2020;19(3):455–9. https://doi.org/10.1016/j.jcf.2019.09.016.
36. Kapnadak SG, Dimango E, Hadjiliadis D, et al. Cystic Fibrosis Foundation consensus guidelines for the care of individuals with advanced cystic fibrosis lung disease. J Cyst Fibros. 2020;19(3):344–54. https://doi.org/10.1016/j.jcf.2020.02.015.
37. Major A, Palese M, Ermis E, et al. Mapping pediatric oncology clinical trial collaborative groups on the global stage. JCO Glob Oncol. 2022;8:e2100266. https://doi.org/10.1200/go.21.00266.
38. Willis DN, Huang FS, Elward AM, et al. Clostridioides difficile infections in inpatient pediatric oncology patients: a cohort study evaluating risk factors and associated outcomes. J Pediatr Infect Dis Soc. 2021;10(3):302–8. https://doi.org/10.1093/jpids/piaa090.

39. Gupta S, Alexander S, Pole JD, et al. Superior outcomes with paediatric protocols in adolescents and young adults with aggressive B-cell non-Hodgkin lymphoma. Br J Haematol. 2022;196(3):743–52. https://doi.org/10.1111/bjh.17862.
40. Soeteman M, Kappen TH, van Engelen M, et al. Validation of a modified bedside Pediatric Early Warning System score for detection of clinical deterioration in hospitalized pediatric oncology patients: a prospective cohort study. Pediatr Blood Cancer. 2023;70(1):e30036. https://doi.org/10.1002/pbc.30036.

Publisher's Note