

College Health Service Capacity to Support Youth With Chronic Medical Conditions

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KEY WORDS

health care transition, young adults, college/university health, chronic medical conditions/special health care needs

ABBREVIATIONS

CMC—chronic medical conditions

IPEDS—Integrated Postsecondary Education Data System

YCMC—youth with chronic medical conditions

Dr Lemly designed the study along with Dr Weitzman, supervised data collection and analyses, and drafted the initial manuscript; Ms Lawlor carried out the data collection and reviewed the manuscript; Dr Scherer performed the analyses and reviewed and revised the manuscript; Ms Kelemen carried out initial study design and supervised data collection, and reviewed the manuscript; Dr Weitzman conceptualized and designed the study, supervised data collection and analyses, and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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WHAT'S KNOWN ON THIS SUBJECT: The population of youth with chronic medical conditions is growing and many attend college. Yet we know little about US colleges' capacity to identify and care for these youth, nor how transition guidelines and financing models should incorporate college health.



WHAT THIS STUDY ADDS: This is the first study to find that although many colleges can provide some clinical care for youth with chronic conditions, few colleges have systems to identify and track these students, elucidating gaps that pediatricians and institutions need to address.

abstract



BACKGROUND AND OBJECTIVE: Twenty percent of US youth have a chronic medical condition and many attend college. Guidelines for transition from pediatric to adult care do not address college health services, and little is known about their capacity to identify, support, and provide care for these youth. The objective of this study was to describe college health center policies, practices, and resources for youth with chronic medical conditions (YCMC).

METHODS: Survey of medical directors from health centers of a representative sample of 200 4-year US colleges with ≥ 400 enrolled undergraduate students. Patterns of identification, management, and support for youth with a general chronic medical condition and with asthma, diabetes, and depression, were investigated; χ^2 and Fisher exact tests were used to ascertain differences by institutional demographics.

RESULTS: Directors at 153 institutions completed the survey (76.5% response rate). Overall, 42% of schools had no system to identify YCMC. However, almost a third (31%) did identify and add to a registry of incoming YCMC on review of medical history, more likely in private ($P < .001$) and small (< 5000 students, $P = .002$) colleges; 24% of health centers contacted YCMC to check-in/make initial appointments. Most institutions could manage asthma and depression (83% and 69%, respectively); 51% could manage diabetes on campus.

CONCLUSIONS: Relatively few US colleges have health systems to identify and contact YCMC, although many centers have capacity to provide primary care and management of some conditions. Guidelines for transition should address policy and practices for pediatricians and colleges to enhance comanagement of affected youth. *Pediatrics* 2014;134:885–891

At least 20% of adolescents in the United States have chronic medical conditions (CMC) or special health care needs.^{1–3} This percentage is rising as a result of improving survival rates for children with chronic illnesses.^{2,4} Approximately 750 000 youth with CMC (YCMC) become legal adults each year.⁵ Overall, nearly 20 million students are enrolled in US colleges and universities,⁶ and many have CMC.^{6,7} For YCMC, going to college can be an important step in their development and transition to maturity and independence, but they remain at significant risk for health problems, educational disruptions, and lower graduation rates.^{8–12}

In college, YCMC must manage the full range of health-related tasks associated with their condition (attending doctors' appointments, taking medications, filling prescriptions, handling exacerbations) all while juggling the demands of college life. Yet they may be infrequently in touch with their home health care team, and disconnected from the college health service. Remaining engaged with the health care system is vital for YCMC. In college, they are vulnerable both to health problems directly related to their condition and to the effects of risk behaviors prevalent among college youth in general, including disruptions in sleep and poor diet,^{13,14} onset and intensification of alcohol use,¹⁵ and unprotected sexual activity.^{7,16} Therefore, the capacity of college health centers to identify and care for YCMC, and/or to coordinate care with a home health care team, may be a key component of a robust health care transition model.

Transition medicine, as defined by the Society for Adolescent Health and Medicine, refers to the purposeful, planned movement of adolescents and young adults from child-centered to adult-oriented health care systems.¹⁷ The American Academy of Pediatrics, American Academy of Family Physicians, and

American College of Physicians have provided explicit practice-level guidance for supporting health care transitions from pediatric to adult care,¹⁸ but with few references to coordination between pediatric and college health services in the guidelines, stating that “youth should either remain in their pediatric medical home or be well established in their adult medical home while receiving episodic care in these settings.”¹⁸ Because the transition to college may not be considered in the formulation of “health care transition,” neither youth going to college nor colleges receiving them may be adequately prepared to meet the needs of these students.¹⁹ In addition, because population and chronic care management may be tied to a home health care setting, payment for use of college health services by YCMC may not be included in insurance policies, despite the coverage extension to age 26 years under the Affordable Care Act.²⁰ To understand these issues and identify opportunities to strengthen practices important for the care of YCMC in college, we conducted a national study of policies, practices, and resources in use by college health services related to these youth.

METHODS

College Sample

We obtained a representative sample of 200 4-year, residential colleges in the United States with 400 or more enrolled undergraduate students. A complete list of all colleges that met these criteria was generated by using information available from the Department of Education's Integrated Postsecondary Education Data System (IPEDS), $n = 1397$. We conducted block-stratified random sampling by enrollment size, region, and public/private status to ensure appropriate representation of US colleges and universities. The targeted sample included 200 colleges, ~15% of eligible institutions. Fifty-one (26%) of the original

200 institutions did not have a health services director available during the study period and were replaced by another institution with matched characteristics; 33 (or 17% of the original sample) of these 51 institutions did not have an on-campus, school-run health center.

Survey Development

To develop the survey, we drew on national guidelines for pediatric- to adult-care transitions for YCMC.^{18,21} YCMC were defined as those who have a chronic physical, developmental, behavioral, or emotional condition and who also require more than routine health and related services. The following main health service domains were identified as important to transitions for YCMC in college: practices for identifying and tracking youth, information required before matriculation, available on- and off-campus medical services, peer and professional support services, and billing protocols for student health center visits. Feedback on survey measures was solicited from experts in health services research and from medical directors of a pool of college health centers that varied in setting and size (pilot institutions were excluded from the study sample). Additionally, the survey included brief clinical case examples to elicit comparative information about how an institution would identify and track youth with each of 3 exemplary CMC: (1) moderate persistent asthma on a controller medication, (2) type 1 diabetes using an insulin pump and an 8-hour drive from the current endocrinologist, and (3) major depression on antidepressant medication and requesting therapy. Measures of institutional characteristics also were obtained separately from publicly available data sources (IPEDS and Google Maps), including enrollment size (small schools with fewer than 5000 students, medium schools with 5000 to 10 000 students, and large schools with more than 10 000 students), region (East,

Central, South, and West/outliers as per IPEDS classifications), public versus private, religious affiliation, women's college, historically black college, and distances to nearest hospital and pharmacy.

In June 2013, medical directors at the 200 selected institutions were contacted initially by letter and E-mail and invited to complete a confidential online survey. Nonresponders also were contacted by phone (up to 3 times) and directed to the online survey. The survey was closed in mid-August 2013. In gratitude for participation, a small donation was made to the respondent's choice of 3 nonprofit organizations associated with youth health, mental, and chronic illnesses. Sampled institutions were each assigned a randomized study identification that was linked to their institutional characteristics. The Boston Children's Hospital Institutional Review Board exempted the study.

Data Analysis

Descriptive statistics were used to characterize the population and sample of schools. Differences in survey responses between institutional characteristics were assessed by using χ^2 and Fisher exact tests. All tests were 2-sided and significance level was set at .05. Analyses also were performed by using poststratification weights to account for survey nonresponse. There were no significant differences between unweighted and weighted results; therefore, the unweighted results are presented. All analyses were performed in SPSS (IBM SPSS Statistics, IBM Corporation, Chicago, IL) and SAS (SAS Institute, Inc, Cary, NC).

RESULTS

Of the 200 schools invited to participate, 153 completed the survey, a response rate of 76.5%. The 153 schools represented a cross-section of US colleges (Table 1). There were no differences

found between the responding institutions and source population (all eligible schools). Respondents identified themselves as student health directors/medical directors (80%), associate medical directors (2.0%), campus physicians/nurses (9%), or other student health administrators/coordinators (8%). Ninety-six percent of schools reported having an office of disability on campus.

Health Information Required for All Incoming Youth

Schools varied in their capacity to identify, contact, and support students with a nonspecific CMC (Table 2). The schools requested a variable amount of health information for incoming youth, with the highest percentage requiring immunizations (86%), a medical history form (completed by the student or parent) (71%), and proof of health insurance (59%). Fewer than half required a physical examination form or medication list. Medical history forms and immunization records were more likely to be required at private ($P < .001$ for both) and small schools ($P < .001$ for both) as compared with schools in other categories. Proof of health insurance, medication lists, and physical examination were more likely to be required at private ($P < .001$ for all), small ($P = .02$, $P <$

.001, $P < .001$, respectively), and Eastern schools ($P = .03$, $P = .04$, $P < .001$, respectively).

Identification and Contact of YCMCs

Schools reported varying levels of processes used to identify YCMC. Fewer than half (42%) of surveyed schools had no system to identify incoming YCMC. However, almost a third (31%) of schools reported creating a registry of YCMC on review of incoming health records, whereas 16% create a registry from information that students volunteer when/if they visit the health service. Private ($P < .001$) and small schools ($P = .002$) were more likely to report creating a registry of YCMC on review of incoming records. Approximately one-quarter of schools contact incoming YCMC to schedule an initial appointment or check-in. This outreach was more likely for schools that were private ($P = .02$), small ($P = .02$), or Eastern ($P = .01$).

Support Groups and Referral Relationships for YCMC

Twenty-eight percent of institutions have peer-led support groups for YCMC. Twenty-four percent of schools have health service-run support groups, less likely if small ($P = .02$). Eighty-two

TABLE 1 Characteristics of Colleges

	Eligible Schools, <i>n</i> = 1397, <i>n</i> (%)	Targeted Sample, <i>n</i> = 200, <i>n</i> (%)	Survey Responders, <i>n</i> = 153, <i>n</i> (%)
Public	527 (38)	75 (38)	59 (39)
Private	870 (62)	125 (62)	94 (61)
US geographic region			
East	388 (28)	55 (28)	52 (34)
Central	368 (26)	53 (27)	41 (27)
South	466 (33)	67 (34)	44 (29)
West/Outliers	175 (13)	25 (13)	16 (11)
Undergraduate enrollment size			
Small (<5000)	895 (64)	130 (65)	98 (64)
Medium (5000–10 000)	228 (16)	31 (16)	24 (16)
Large (>10 000)	274 (20)	39 (20)	31 (20)
Religiously affiliated	557 (40)	79 (40)	57 (37)
Women Only	45 (3)	7 (4)	6 (4)
HBCU	77 (6)	12 (6)	7 (5)

There were no differences between the targeted sample or the survey responders and the source population (eligible schools). HBCU, historically black colleges and universities.

TABLE 2 Identification, Contact, and Support of YCMC by College Health Services

	All <i>n</i> (%)	Status		College Size			Geographic Region			
		Private	Public	Small	Medium	Large	East	Central	South	West
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Health information required for all incoming students										
Medical history form (completed by student or parent)	109 (71)	80 (85) ^a	29 (49)	82 (84) ^a	15 (63)	12 (39)	42 (81)	29 (71)	29 (66)	9 (56)
Primary care provider records	2 (1)	2 (2)	0 (0)	2 (2)	0 (0)	0 (0)	2 (4)	0 (0)	0 (0)	0 (0)
Physical examination form	53 (35)	45 (48) ^a	8 (14)	46 (47) ^a	5 (21)	2 (7)	29 (56) ^a	9 (22)	13 (30)	2 (13)
Immunization records	132 (86)	89 (95) ^a	43 (73)	92 (94) ^a	20 (83)	20 (65)	49 (94)	32 (78)	39 (89)	12 (75)
Medication lists	69 (45)	56 (60) ^a	13 (22)	56 (57) ^a	9 (38)	4 (13)	30 (58) ^c	17 (42)	19 (43)	3 (19)
Proof of health insurance	90 (59)	69 (73) ^a	21 (36)	66 (67) ^c	11 (46)	13 (42)	39 (75) ^c	20 (49)	22 (50)	9 (56)
Identification of YCMC										
Registry (a list or database) created on review of incoming student records/medical histories	48 (31)	39 (42) ^a	9 (15)	40 (41) ^b	5 (21)	3 (10)	22 (42)	8 (20)	14 (32)	4 (25)
Registry created from information that students volunteer on visit to health service	25 (16)	16 (17)	9 (15)	18 (18)	3 (13)	4 (13)	10 (19)	5 (12)	7 (16)	3 (19)
No system of identification of students with CMC	64 (42)	29 (31) ^a	35 (59)	33 (34) ^b	10 (42)	21 (68)	14 (27) ^b	26 (63)	18 (41)	6 (38)
Other	31 (20)	22 (23)	9 (15)	19 (19)	7 (29)	5 (16)	10 (19)	6 (15)	10 (23)	5 (31)
Contact of YCMC										
Health service contacts incoming students with CMC to make initial check-in	37 (24)	29 (31) ^c	8 (13)	31 (32) ^c	3 (13)	3 (10)	20 (39) ^c	4 (10)	10 (23)	3 (19)
Support groups for YCMC										
Peer-led support groups	43 (28)	22 (23)	21 (36)	22 (22)	8 (33)	13 (42)	17 (33)	10 (24)	11 (25)	5 (31)
Health service-run support groups	36 (24)	19 (20)	17 (29)	17 (17) ^b	6 (25)	13 (42)	12 (23)	4 (10)	15 (34)	5 (31)
Referral relationships										
Established relationship with medical facility or specific providers for specialty referrals	125 (82)	73 (78)	52 (88)	78 (80)	21 (88)	26 (84)	46 (88)	30 (73)	36 (82)	13 (81)

n = 153 for all measures. Within each question, responses were "mark all that apply," so percentages may add up to more than 100. χ^2 and Fisher exact test comparisons of percentages are not significant unless noted as follows: ^a *P* ≤ .001; ^b *P* < .01; ^c *P* < .05. Differences pertain to all categories of the institutional characteristic.

percent of institutions have an established relationship with another medical facility or specific providers available for specialty referrals.

College Health Service Capacity to Address Youth With Specific CMC

When asked about specific CMC listed in the scenarios (Table 3), 28% of schools reported that they would identify and add to a registry an incoming student with asthma on review of the medical history, 38% would similarly identify a student with type 1 diabetes, and 35% would identify a student with depression. Private, Eastern, and small-enrollment schools were more likely than schools in other categories to report these practices for all 3 case conditions (*P* < .02 for all comparisons except depression, where region did not reach significance, *P* = .06). Few schools would contact these youth to arrange an initial appointment and check-in; 7% would contact the student with

asthma (more likely if private, *P* = .006), 25% would contact the student with diabetes (more likely if private, *P* < .001 and small, *P* = .009), and 19% would contact the student with depression (more likely if private, *P* < .001). Most schools reported they could provide primary care on-campus for all 3 case conditions: 84% for the student with asthma, 63% for diabetes (more likely if large, *P* = .05), and 72% for depression. Most schools reported they could manage asthma and depression on-campus (83% and 69%, respectively); half could manage type 1 diabetes on-campus (51%). There were no significant

differences by public/private status, enrollment size, or region in the reported ability to provide on-campus disease management for all 3 case conditions (except large schools were more likely to report ability to manage diabetes, *P* = .03).

Mental Health and Urgent Care Services

Nearly all (86%) schools have mental health counseling on campus; 56% of schools report having psychopharmacology and/or psychiatry available on campus. Most (82%) institutions provide weekday urgent care services, with

TABLE 3 Identification, Contact, and Management of Specific CMC by College Health Services

Student With:	Asthma, <i>n</i> (%)	Type 1 Diabetes, <i>n</i> (%)	Major Depression, <i>n</i> (%)
Identified and added to registry on review of medical history	42 (28)	57 (38)	53 (35)
Contacted by student health service to make initial check-in	10 (7)	38 (25)	29 (19)
Able to receive primary care within the student health system	127 (84)	95 (63)	108 (72)
Able to have specific medical condition managed by provider on-campus	126 (83)	76 (51)	103 (69)

few (6%) providing evening weekday urgent care services and/or weekend urgent care (10%); 17% of institutions do not provide any urgent care services (weekday or weekend).

DISCUSSION

College health services comprise an important and likely overlooked part of the health care ecosystem available to support YCMC. Nationally, most residential 4-year colleges have an on-campus, school-run student health service; ~1 in 6 do not. This is important because the median distance from home to college for students is 94 miles (25th percentile = 23 miles and 75th percentile = 230 miles),²² a distance that may impede travel home for urgent care and exacerbations. Whether going to college is accompanied by a transition at home from pediatric to adult care, starting college comprises an important shift in environment and autonomy for YCMC,¹⁹ representing a true if underrecognized health care transition.

Of colleges with a student health center, most report being able to provide primary care, mental health services, and medical management of select CMC. Nevertheless, proportionately few colleges can provide urgent care on evenings or weekends, limiting access to care when problems may arise. Relatively few colleges systematically identify and track YCMC, despite recent national guidelines emphasizing the importance of such components. The Center for Health Care Transition Improvement's 6 Core Elements include transition tracking and monitoring (identifying youth and creating a registry), transition planning, and transfer of care, including sending a "Transfer Package" (transfer letter and medical summary) to the new provider and encouraging direct communication between providers.^{21,23} Few surveyed schools required any prematriculation

documentation from an incoming student's primary care provider (such as a physical examination form or pediatrician records). Nearly half of surveyed schools did not have a system for identifying incoming YCMC, and only 1 of 4 schools contacts these youth to schedule an initial appointment or check-in; fewer do so for youth with asthma or depression. Identification of YCMC is necessary to target prevention initiatives to those at highest risk. For example, YCMC are known to be at higher risk of complications from influenza²⁴; therefore ensuring and tracking vaccination of this population would be a public health priority for college campuses. Private, small, and Eastern schools may be more likely to have systems to identify and contact YCMC because they may have greater financial resources or because they can more easily track relatively small student populations.

Prematriculation is an important time for schools to obtain student health information, and most schools require receipt of immunization records for incoming students. Given continued incidence of vaccine-preventable illnesses, such as meningitis, on college campuses, the Centers for Disease Control and Prevention and American College Health Association recommend that schools implement a comprehensive prematriculation immunization policy.²⁵ In many states, however, laws do not yet exist to enforce these recommendations. Most states have a mandate to require education about meningococcal vaccination for matriculating students, but only 16 states actually require meningococcal vaccination (or a waiver) for incoming residential students.²⁶

Nearly half of schools do not require proof of health insurance before matriculation. Historically, many young adults are uninsured or underinsured.²⁷ In 2009, 31.4% of young adults, ages 19

to 25 years, lacked coverage, nearly double the national rate for all ages.²⁸ In 2006, ~80% of college students had health insurance,²⁹ a percentage that is likely to continue to improve now that coverage under a parent policy can extend up to age 26.²⁷ However, it remains uncertain how these changes due to the Affordable Care Act may impact student health centers that are not typically designated as either primary care or referral within a geographic network. If expanded coordinated care is to include college health services, attendant financial arrangements must be addressed through payers, professional societies, and advocates.

Most schools report they can provide primary care for students with each of the 3 medical conditions used as case examples in the survey. Schools, however, lack outreach and tracking systems to engage and follow these youth. With regard to asthma, a substantial majority of schools reported being able to provide primary and specialty care on campus, but few schools identify and track these youth, and even fewer contact them about an initial appointment. Asthma affects 18% of older adolescents,³⁰ and is associated with substantial risk for disruption in school, work, and activities of daily life.³¹ The capacity of college health centers to manage asthma may be undermined by the potential for exacerbations related to stress,³² poor adherence,³³ and secondhand smoke exposure in dorms or parties.³⁴ Only approximately half of schools could manage diabetes on campus. The prevalence of diabetes (both type 1 and type 2) among youth is increasing.^{35–37} First-year college students with type 1 diabetes have been shown to experience difficulties managing their diabetes, in part because of difficulty finding appropriate care and changes in providers and routines.^{38–40} Thus, quality care of these youth will require advanced planning and

further support across health care settings (both before and during college). Mental health services were available on most campuses. Nearly 70% of schools indicated that they could manage major depression with pharmacological treatment on campus, and nearly all schools had on-campus mental health counseling, although just more than half of schools reported having psychopharmacology and/or psychiatry services on campus. The prevalence of mental health problems, such as depression and anxiety disorders, has been increasing among US college students.^{41,42} Psychiatric health disorders have been found to be associated with failure to complete college among college entrants.⁹ Eisenberg et al⁴¹ found that among US students with an apparent mental health problem, only 36% received any treatment in the previous year, with significant variability among schools. Service use was higher in private schools and smaller schools, thought to be in part because of a higher availability of resources per student. In a study of help-seeking behavior and access to mental health services at a large, midwestern university (with available on-campus mental health and primary care services), many students were unaware of or unfamiliar with service options.⁴³ Although many schools already have

mental health services, it will be important to increase the scope and availability of these resources and ensure student awareness.

This study had several limitations. Although the high response rate and close alignment of our college sample with the source population suggest minimal bias and encourage generalization to 4-year colleges nationally, community and technical colleges are not included in our sample and their experience may differ. The 3 case scenarios used in the survey do not represent the complete range of chronic conditions or learning or physical disabilities. Absent a previously validated survey instrument, we developed questions with expert input and based on the published literature. The survey was piloted and revised at multiple colleges to identify and clarify ambiguities. There are no published national guidelines regarding appropriate care of college students with chronic illness, and thus we cannot compare practices against an established standard. This current study serves as a snapshot of the policies and resources from the perspective of the college health service, not the student, parent, or the student's home primary care or specialty provider. In addition, offices of disability and other administrative services provide important

resources to support YCMC. Future work is needed to explore issues around financing visits and student health center communication with pediatricians and other providers.

CONCLUSIONS

This study highlights the need to further involve and integrate college health in the national discussion about improving health care transitions of YCMC. Many college health centers can provide care for YCMC and have existing referral relationships. Colleges should be encouraged to build systems to identify, monitor, and support these youth in alignment with pediatric providers. Evolving financing and care coordination models through payers, Accountable Care Organizations, and other networks should incorporate student health to prevent YCMC from falling between system-wide cracks. Elucidation of current capacity and resources is a necessary first step to ensure the delivery of appropriate and continuous care for these youth, enabling good health outcomes and academic and personal success.

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