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Proposal for a University of Akron Chronic Condition Support Group

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Proposal for a University of Akron Chronic Condition Support Group

Honors Project

School of Nutrition and Dietetics

The University of Akron

Kendra Taylor

Spring Semester 2018

Table of Contents

Introduction.....	1
Rationale.....	1
Chronic Conditions and Adolescents.....	1
The Gap.....	3
Transitions in Healthcare.....	3
The College Experience.....	5
University Intervention.....	7
UA Chronic Condition Support Group.....	8
Introduction to the Organization.....	8
Organization Framework.....	8
Organization Affiliation.....	10
Organization Objectives.....	11
The Program.....	12
Weekly Meetings.....	12
Monthly Educational Lessons.....	13
Program Logistics.....	15
Organization Leaders.....	15
Members.....	17
Resources.....	17
Marketing.....	18
Program Evaluation.....	19
Conclusion.....	20
Resources.....	21
Appendix A: Pre- & Post Survey.....	23

Introduction

With constant advancements in modern medicine, new opportunities are opening up to those diagnosed with chronic conditions during childhood and adolescence. Children who would have died early on due to their life-altering medical conditions are now living well into adulthood, with approximately 500,000 youth with chronic conditions turning 18 years old each year in the United States.¹ Despite them having similar high school graduation rates as their peers, students with one or more chronic condition are only half as likely to graduate from college after starting.¹ Data on this specific population while in college is very limited, but what is available theorizes that lack of peer support, inadequate access to local healthcare and disease management resources, and diminished health-related quality of life negatively influences the ability of these students to succeed in college.¹ The purpose of this proposed chronic condition support group is to help students with unique hardships and difficulties related to living with chronic medical conditions throughout their time at The University of Akron, and ultimately, increase their retention, degree progression, and graduation, and build self-efficacy for transitioning into a career.

Rationale

Chronic Conditions and Adolescents

While there are variations in the exact definition, it is commonly accepted that the term “chronic condition” is describing a health state which requires ongoing physical and psychological adjustments for health management by the affected person and consistent interactions with the health care system throughout an individual’s life or for an extended

period of time.^{2,3} Chronic conditions usually cannot be cured by taking medication, nor do they just disappear over time, thus requiring ongoing medical treatment and lifestyle intervention.^{2,3} Those chronic conditions that are first diagnosed before a patient is 19 years old are commonly referred to as Childhood Onset Chronic Conditions (COCCs).⁴ Examples of COCCs include, but are not limited to, cancer, diabetes, congenital heart disease, cystic fibrosis, seizure disorders, and sickle cell disease.^{5,6}

It is currently estimated that 15% of adolescents, aged 10-19, in Western countries suffer from COCCs, amounting to over 6 million adolescents within the United States.^{7,8,9} And with the drastic advances in modern medicine over the past four decades, many of these youth who would have previously passed away early in life are now living well into adulthood.¹ For example, life expectancy for a child born with sickle cell disease was approximately 14 years in 1970, but has now progressed to an estimate of more than 40 years.⁶ In fact, an increase in survival rate has been seen across almost every childhood onset chronic condition, with estimates of more than 90% of adolescents with COCCs living past the age of 20 years old.⁶

Currently, more than 500,000 adolescents with COCCs turn 18 years old each year in the United States.¹ For many adolescents, a logical step at this age milestone is to attend a college or university in order to obtain the knowledge needed to have a specialized vocation or career and a fulfilling life. Though data is limited regarding the prevalence of chronic disease among college students, The Commission on the Future of Undergraduate Education reports that nearly 90% of high school graduates are attending college within 8 years.^{1,10} With high school graduation rates being nearly identical for adolescents with COCCs as that of their healthy peers, it could be argued that colleges and universities likely have a similar prevalence rate of

students with COCCs as the national adolescent average of 15%.^{1,8} However, one study examining a population of college students found that one third of respondents reported having some sort of life-long illness.¹ More research is needed to identify more precisely the prevalence of chronic conditions among those enrolled in U.S. colleges and universities.

The Gap

Despite having similar high school graduation rates, the National Longitudinal Study of Adolescent Health indicates that adolescents with one or more COCC are only half as likely to graduate from college as their healthy peers.¹ This discrepancy has been associated with the increased difficulties faced by students with chronic conditions in colleges and universities.¹ While these students generally possess similar academic ability and motivation, they are at an increased risk for physical and psychological barriers to learning ranging from medical symptoms, fatigue, and pain to feelings of loneliness and isolation from their peers as well as the added responsibility of managing their medical care.⁸

Transitions in Health Care

Adolescence and the transfer into college is a significant developmental transition on its own, marked by increased self-identity, growing independence, and additional responsibilities.¹¹ For those with COCCs, however, additional challenges are faced with their transfer from a pediatric-style healthcare model to that of adult care which requires much more self-management of their chronic condition.¹¹ The Institute of Medicine and *Healthy People 2020* identify this healthcare transition for adolescents with COCCs as crucial to their future health and psychosocial outcomes.¹² However, since those with COCCs would rarely

survive to adulthood only decades ago, the transfer of adolescents into adult-oriented care through healthcare systems remains to have notable deficits and has just recently begun to be researched.¹²

The experiences, attitudes, and feelings of adolescents during this healthcare transition has been shown to be very similar across almost all diagnoses.¹¹ The level of care and professionals experienced in the pediatric care setting are generally described as informal, individualized, and comfortable.¹¹ The relationships with pediatric professionals generally start early in life and form into close relationships, with many describing their healthcare providers as being like family members to them.¹¹ The adult care setting feels quite different, with doctors and nurses seeming more impersonal and diseased-focused, making it very hard to establish close, comfortable relationships.¹¹ This often results in young adults feeling like their questions burden healthcare professionals and consequently, in them being unwilling to ask important questions pertaining to their condition and decision-making.¹¹

In the pediatric care environment, the clinicians generally negotiate treatments and care for adolescents with COCCs through their parents, with little involvement from the patient.¹¹ With the transition to adult care, however, adolescents are now expected to be autonomous and independent, challenged with making their own healthcare decisions.¹¹ Many do view this change as a logical step towards independence and feel excited to achieve responsibility and be on their own, but they often report feeling unprepared and express a need for additional guidance and support.¹¹ The increased maturity and responsibility needed to take care of their own health, many young adults do not feel ready for.¹¹ After transfer to adult care, they become solely responsible for scheduling appointments and follow-ups, picking up and

remembering to take medications, self-monitoring symptoms, and the overall management of their condition.¹¹ Some are able to adjust to these challenges with minimal effort, but many others find it scary and stressful.¹¹ This stressful period in the adolescent's life can lead to failure to comply with treatment protocols which can lead to poor health outcomes.¹³ Even more unfortunate, some adolescents, wanting a break from constant disease-focused routines, choose to drop out of medical care altogether at this transition point.¹¹

The College Experience

In addition to the significant changes in healthcare that students with COCCs are experiencing, many are faced with challenges associated with starting tertiary education at a college or university as well. More and more adolescents with childhood onset chronic conditions are entering college each year, yet there is still a major gap in our understanding of how their college experiences differ from that of their healthy peers, causing the significant difference in graduation rates, and research has only just begun.¹ Considering that academic ability and motivation have been determined to be equal across both populations, researchers have turned to health-related quality of life, social support, and lack of local health care as potential areas of discrepancy.¹

Health related quality of life (HRQoL) is a measurement of how much a person is limited in daily activities by their physical or mental symptoms.¹ One study surveyed college freshman with COCCs and their healthy peers to examine the correlation between HRQoL and feelings of loneliness.¹ Results showed that participants with COCCs had a significantly more impaired HRQoL, being approximately 43% lower than that of their peers.¹ Additionally, it was shown

that the degree of HRQoL corresponds with feeling of loneliness, with the students with COCCs reporting higher levels of loneliness by about 29%.¹ Additional research has found that students with chronic conditions have a two to three fold increased risk for depression, further decreasing their HRQoL from what the effects of their medical conditions already had.⁸ Furthermore, 20% of students with chronic conditions reported missing 1-5 days of class per week, and 4% reported missing 6 or more.¹

To investigate the potential link between social support and college attainment, researchers examined the relationships that students with COCCs possess.¹ Having peers with similar chronic conditions was found to be positively influential and provided helpful opportunities to discuss feelings, share experiences, and reduce overall anxiety.¹¹ However, a study examining the peer relationships of college students with COCCs found that only 7% reported knowing more than one other student with a chronic condition and 57% reported knowing none.¹

Having established local healthcare providers and disability assistance are very important in the management of COCCs.¹¹ With the transition into college, many students are not only transitioning into adult healthcare, but also moving to unfamiliar areas.¹ This can cause a discontinuation or disruption in the medical care that had been previously established. When surveyed, only 11% of college freshman with COCCs reported having a local doctor, either general practice or specialist.¹ Additionally, most campuses have disability support services to assist students with health and physical issues, but only 15% of students with COCCs report utilizing these services.¹

University Intervention

As previously mentioned, many barriers exist to educational attainment of students that are enrolled in colleges and universities with chronic health conditions. These include decreased health related quality of life, lack of peer support, and the new-found responsibility of self-management of their conditions. With students that have chronic conditions being only half as likely to graduate from college as their healthy peers, interventions are necessary to mediate through these barriers and help bridge the gap in educational attainment.

The University of Akron has the opportunity be one of the first universities to help students with chronic conditions have the same ability to complete their education as the remainder to the school's population. The UA Chronic Condition Support Group has been designed to directly address these identified barriers and provide the information and support needed to overcome them. It has been planned to work alongside what is currently being done in healthcare and the services already established at the university to allow for the most effective management of chronic disease for The University of Akron's student population. The following section contains the developed intervention, in the form of a student organization that can easily be adopted at The University of Akron to improve the graduation rate of UA students with chronic conditions.

UA Chronic Condition Support Group

Introduction to the Organization

UA Chronic Condition Support Group (CCSG) is an organization dedicated to assisting students with chronic health conditions as much as possible while enrolled at The University of Akron. CCSG's mission is to improve educational attainment for The University of Akron students with chronic conditions through peer social support, collaboration with healthcare providers and resources, and techniques to improve self-management of conditions. CCSG aims to work alongside current healthcare initiatives and campus resources to overcome the barriers to academic success that students with chronic conditions often experience in college.

Organization Framework

The organization has been developed using the Chronic Care Model (CCM) as a framework. The CCM is a well-established approach to chronic conditions utilized by most health care systems that incorporates patient, provider, and system level interventions into the successful management of diseases.¹⁴ This model has been shown effective in the management of chronic diseases when utilized in both the healthcare and community setting.¹⁴ The comprehensive, multisystem approach of the CCM makes it ideal for working with susceptible populations like adolescents with chronic conditions.¹⁴

The CCM consist of six distinct concepts for effective health care delivery and management which have been adapted for use outside of the healthcare setting. These six concepts and how they are incorporated into the UA Chronic Condition Support Group are listed below.

- Organization: Leadership is committed and visibly involved, supports change and improvement, and creates incentives to improve care management.¹⁴
 - The leaders of CCSG will be dedicated to its mission and continually incorporate new research into each meeting that supports effective self-management.
- Clinical information systems: Data is kept of trends of the individuals and the health and improvements of the overall population.¹⁴
 - Data will be collected at the beginning and end of each academic year and monitored for improvement individually, as a group, and from year to year.
- Delivery system design: Effective, efficient, coordinated care and information is delivered through the use of a multi-disciplinary team, planned interactions, and regular meetings.¹⁴
 - Regular meeting will be conducted according to a set schedule, led by a team of facilitators made up of various healthcare disciplines.
- Decision support: More educated decisions are made through the communication of evidence-based guidelines and information about care options.¹⁴
 - New research and evidenced-based treatment/management options will be shared by the facilitators both during educational meeting and when questions arise during support group meetings.
- Self-management: Individualized support, education, and empowerment for self-care is provided through the use of goal setting, identification of barriers, and the implementation of plans to overcome barriers.¹⁴

- At the end of each meeting, every group member will set a goal for the following week, identify barriers that might interfere with achieving their goal, and formulate a plan to combat the acknowledged barriers.
- Community resources: Resources in the surrounding community are utilized to provide peer-support, coordination of care, and community-level interventions.¹⁴
 - Members will be informed of many resources available, both on campus and in the community, that can assist them in the successful self-management of their health condition.

All of these six concepts were used in the formation of CCSG's leadership team, curriculum, and meeting design. Additionally, these concepts will continue to be the framework for which all future implementation and operations will be conducted.

Organization Affiliation

UA Chronic Condition Support Group will be affiliated with The University of Akron through registration in the Student Organization Resource Center (SOuRCe). SOuRCe is the department at The University of Akron that legitimizes all student organizations and connects the student organizations to other resources on campus. SOuRCe can provide all of their organizations with many free resources including leadership training, meeting locations on campus, marketing services, a nonprofit fund account, and up to \$3,000 in funds per year for organization activities. The availability of these important resources at no cost is the main reasoning behind formatting this program as a student organization as opposed to affiliating with a specific department on campus as a health program. Through this affiliation, CCSG can

more effectively assist students within The University of Akron and more readily utilize resources already available on the campus.

Organization Objectives

The overarching goal of UA Chronic Condition Support Group is to increase educational attainment for students at The University of Akron with chronic conditions through peer social support, collaboration with healthcare providers and resources, and techniques to improve self-management of conditions. This goal will be accomplished by achieving the following objectives:

Objective 1: By the end of each academic year, at least 90% of the members of CCSG will be able to identify at least 2 other students at The University of Akron that have chronic conditions who they can turn to for social support when asked on year end program evaluations.

Objective 2: By the end of each academic year, at least 90% of the members of CCSG will be able to list at least 2 campus resources available to assist them with the management of their condition when asked on year end program evaluations.

Objective 3: By the end of each academic year, 90% of members of CCSG will have at least a 20% increase in confidence in their ability to self-manage their condition when asked on year end program evaluations.

Objective 4: By the end of each academic year, the average HRQoL score for all of the members of CCSG will increase by at least 20%, calculated using the CDC HRQoL Questionnaire.

The Program

UA Chronic Condition Support Group will consist of weekly meetings for all members of the organization to provide peer-support and education to assist in self-management of conditions. Each weekly meeting will be in the style of a facilitated peer-support meeting. Once a month, a discussion-based educational lesson from a set curriculum will be delivered following the support group.

Weekly Meetings

Each weekly meeting will be structured in a roundtable or circle type fashion, with all participants and group facilitators facing each other in their seats. All meetings will begin with an ice-breaker style activity that includes participation from all present in the room, including organization members and leaders. The intent of this is to help the members become familiar with each other in order to form a more comfortable relationship that facilitates open and honest discussion with one another. Additionally, this will assist any members that may enter the group after the start of the academic year cycle in familiarizing themselves with those already in the group.

Upon completion of the icebreaker, the facilitators will then prompt those in the group to share either what caused them to struggle or what was positive that happened within the last week. This will hopefully spur a discussion among the members of the group and, with the

help of the facilitators, allow for positive feedback. During this time, both the facilitators and additional group members have the ability to make suggestions for coping with struggles that the members express. Through this, open and honest discussion should be formed with topics varying from week to week depending on where the discussion is led by the group. Every week will be different in regard to the content of the discussion because it is meant to be based on current life events and situations.

Towards the end of each weekly session, the facilitators will prompt the group to wrap up the discussion, and the facilitators will lead the group in setting realistic goals for themselves for the following week. To initiate this, each member will discuss how effectively their goal from the week before was accomplished. After discussing past goals, each person will take a few minutes to define and write down a goal for the following week. Each member will then tell the group their goal, say what barriers lie in their way of achieving it, and describe how they plan to overcome those barriers.

Monthly Educational Lessons

Educational lessons will be provided once per month, following the support group meetings, by the organization officers. The lessons will be structured so that the first three months of every academic year will have lessons from a set of topics that is repeated yearly to provide this valuable information to every student, regardless of their year in school and with the organization. For the remaining five months of the academic year, the organization officers will present new topics that have been decided on and planned by them. Those that have been members for longer than a year may not wish to attend each of the set-curriculum lessons, but

will have the opportunity to learn new information in the months that have newly-developed lessons.

CCSG Set-Topics		
Month	Topic	Points to Discuss
1	Adjusting to University Life	<ul style="list-style-type: none"> • Campus Resources the can help <ul style="list-style-type: none"> ○ The Office of Accessibility ○ The Nutrition Center ○ Health Services ○ Any other resources that could be beneficial • How to talk with professors about their condition and potential absences • Any additional areas of concern that members have regarding adjusting to college
2	Importance of Healthcare	<ul style="list-style-type: none"> • The importance of having a local physician in management of chronic conditions • What each member of healthcare team can contribute to condition management including: <ul style="list-style-type: none"> ○ Physicians/ Specialists ○ Dietitians ○ Nurses ○ Therapies ○ Social Workers ○ Mental Health Professionals • The importance of regular follow-ups and communication between embers of the healthcare team
3	Treatment Decisions	<ul style="list-style-type: none"> • How to ask your doctor the hard questions • Where to find evidenced-based literature regarding various treatment options • The decision-making process and tips on making an informed decision

Program Logistics

Organization Leaders

The organization leaders will consist of a faculty advisor, four officers, and two to four facilitators. Ideally, all of the group officers will have been members of CCSG prior to holding their position in office. Though this is not a requirement, it would be helpful in ensuring that the group operations are most beneficial to the members if the officers have prior experience in the organization. The facilitators will preferably be members of The College of Health Professions and/or be obtaining a degree in a health-related field. Ideal majors would be nursing, dietetics, social work, speech-language pathology, or any other major with classes pertaining to disease processes and management. Potentially, students could be offered volunteer hours or clinical hours for their participation as facilitators of this organization as an added benefit for them. Each of the leadership positions and their description are listed below.

- Faculty Advisor
 - Sign off on all documents needed for SOuRCe registration or use of resources
 - Obtain any approval needed through the Institutional Review Board and ensure confidentiality of information collected
 - Be available for any needs that the student officers and facilitators may have
 - Approve educational lessons for monthly delivery
 - Attend at least one meeting per semester
- Officer 1: President

- Oversee relations with SOuRCe and handle all meeting logistics such as booking a meeting room and deciding on meeting times
- Help to determine yearly and monthly meeting schedule/topics
- Officer 2: Vice President
 - Develop and/or disburse all surveys and data collection methods used to evaluate program effectiveness
- Officer 3: Treasurer
 - Manage all funds of the organization, apply for funding and reimbursement when needed, and purchase any materials needed for the organization
- Officer 4: Secretary
 - Handle all marketing and promotion needed for the organization
 - Keep record of all data collected on group demographics and progress through survey methods
- Facilitators (2-4)
 - Lead active discussion during weekly meetings
 - Assist in the planning and execution of all education lessons
 - Collaborate with the faculty advisor to obtain approval for educational lesson content.

Students are encouraged to stay in their positions as organization leaders for multiple years, if desired, so long as they remain enrolled at least part time at The University of Akron. It is the responsibility of the entire leadership members to identify replacements for any positions

that will be vacant the following academic cycle by the end of the academic year. The process of selecting new leadership will be left up to the leadership members to decide as they see fit.

Members

This organization will be open to all students, undergraduate and graduate, enrolled at The University of Akron at least part-time. Though the organization is intended to provide support for those students with chronic conditions, no health condition is required to be part of the organization. Upon signing up for the organization, each member will be required to sign a privacy pledge and a rules of conduct form, that will be created by the organization officers and facilitators. The privacy pledge is a pledge to not repeat any personal information shared within the group to anyone not belonging to the group, or in any setting outside of the group's designated meeting times. The rules of conduct form will list proper behaviors to ensure respect for each member of the organization emotionally and physically. Violation of either of these contracts could result in removal from the group.

Resources

SOuRCe provides a wide variety of resources that are available to meet almost every need the organization may have. SOuRCe will provide a reserved meeting room each week at the times designated by organization leadership. Chairs, tables, and all technology will be available free of charge within the meeting room. Additionally, a permanent workspace can be reserved for the length of each academic year, if the leadership wishes to use one, with free printing available for organization-related items.

For any other miscellaneous fees that the organization may come across (food, paper products, etc) SOuRCe allows the organization to submit requests for funds totaling up to \$1,500 per semester. The funds can be requested at any time during the academic year, and most requests are approved, so long as it pertains to the organization and would benefit its members.

Marketing

Recruitment of members is necessary to inform all students of the opportunity to be a part of this organization. CCSG will have a table each year at RooFest, which is an event on the Sunday before each academic year starts to highlight student organizations and volunteer opportunities. At the table, CCSG's leaders will have information available explaining what the organization is and what members could expect from being part of the organization. Additionally, there will be a sign-up sheet available for members who want to join that day, and handouts available for potential members that explain how to join.

After the academic year starts, there will be a variety of ways that CCSG will market itself. Information on the group will be available at the Office of Accessibility, the Wellness Center, the Nutrition Center, and any other University departments that would be able to refer students. Additionally, a weekly ad will run in the University's Zipmail with an explanation on what the organization is and how to join. Additionally, members will be encouraged to invite anyone that they feel would benefit from being part of the organization. Through these efforts, membership in the organization will hopefully continue to grow throughout the academic year cycles.

Program Evaluation

At each member's first and last meeting of every academic cycle, they will be asked to complete two separate surveys. The first survey will be the Pre- & Post Survey (see Appendix A) used to assess the members' peer relationships, knowledge of campus resources, and confidence in their self-management of their conditions. The second survey will be the HRQoL Questionnaire from the Center for Disease Control (CDC) to assess overall health related quality of life (HRQoL).¹⁵ This is a set of 3 separate surveys (14 questions total) that are used to calculate HRQoL across many populations.¹⁵ The administration of these surveys at the beginning and end of each academic cycle will determine if the objectives of the program have been met.

Objective	Party Responsible	When Evaluation will be Measured	Evaluation Measure
By the end of each academic year, at least 90% of members of CCSG will know at least 2 other students at The University of Akron that have chronic conditions.	CCSG Leadership Members	At the end of the academic year	Answers from the Pre- & Post Survey administered at the end of the academic cycle will be analyzed and the percentage of students listing a 2 or higher number on question 1 will be calculated.
By the end of each academic year, at least 90 % of members of CCSG will be able to list at least 2 campus resources available to assist them with the management of their condition.	CCSG Leadership Members	At the end of the academic year	Answers from the Pre- & Post Survey administered at the end of the academic cycle will be analyzed and the percentage of students listing at least 2 correct answers under question 2 will be calculated.
By the end of each academic year, members of CCSG will have at least a 20% increase in confidence in their ability	CCSG Leadership Members	At the end of the academic year	Answers to question 3 from the Pre- & Post Survey administered at the beginning and end of the

to self-manage their condition.			academic cycle will be analyzed and averaged. The averages from the beginning of the cycle and end of the cycle will be compared for improvement.
By the end of each academic year, the average HRQoL score for all of the members of CCSG will increase by at least 20%.	CCSG Leadership Members	At the end of the academic year	Answers from the HRQoL Questionnaire will be calculated to identify an average HRQoL for the group at the beginning and end of each academic cycle. The averages from the two instances will be compared for improvement.

Conclusion

While there have been dramatic increases in the life expectancy of those with COCC recently and higher rates of adolescents with chronic conditions are matriculating into colleges and universities, the graduation rate for students with chronic conditions is only half that of their healthy peers. The transition into adulthood and college life poses unique challenges such as decreased health related quality of life, lack of peer support, and the new-found responsibility of self-management of health conditions. Introducing UA Chronic Condition Support Group to The University of Akron can help solve these barriers to academic success through peer social support, collaboration with healthcare providers and resources, and techniques to improve self-management of conditions. If implemented, this could increase the college graduation rates of students with chronic conditions and help bridge the gap in educational attainment between these students and their peers.

Resources

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APPENDIX A

Pre- & Post Survey

1. How many University of Akron Students, not including yourself yourself, do you know who have a chronic condition?
2. Please list all of the resources at The University of Akron that you know of that are able to assist you in the self-management of your health conditions?
3. On a scale of 1-10, how confident are you in your ability to effectively self-manage your condition?

Not Confident

Confident

1 2 3 4 5 6 7 8 9 10