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Twelve tips for teaching a comprehensive disease-focused course with a global perspective: A sickle cell disease example

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Abstract

A disease-focused course entitled “*Understanding Sickle Cell Disease: A Biopsychosocial Approach*” addressed the complex nature of SCD using patient-centered, global and interdisciplinary approaches. Sickle cell disease (SCD) is a rare inherited blood disorder that requires multidisciplinary care. Worldwide 20–25 million individuals have SCD, which is associated with a shortened lifespan due to many medical complications and social and behavioral health challenges. Health care professionals often have limited knowledge of SCD as they typically learn about it within the context of their own disciplines. This article provides twelve tips for educators that can be used to develop a similar course on any disease, with considerations for both low- and high-resource countries. The tips were devised from personal experience and available literature. Through these twelve tips, we provide a practical framework for increasing knowledge of complex diseases like SCD using a comprehensive elective course.

Introduction

There is often limited time in healthcare core curricula to study diseases in depth (Jenkins et al. 2001; McCleskey et al. 2009). While core curriculum is essential in providing students with foundational knowledge needed for their progression in their disciplines, a disease-

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based elective course can give students the opportunity to learn about areas outside of their disciplines' core curricula. Additionally, a disease-based course can offer students the opportunity to: (1) develop a comprehensive understanding of an illness in an array of contexts including psychosocial and ethical issues, (2) contextualize the disease from a global perspective, and (3) advance their interdisciplinary communication skills. In this essay, we present 12 tips to educators wishing to develop and teach a comprehensive, disease-focused elective course. Using sickle cell disease (SCD) as an exemplar, we discuss tips based on our own experiences that are generalizable to other contexts including low and high resource environments.

The case of sickle cell disease

SCD is a rare inherited disorder of the red blood cells that affects 20–25 million people worldwide (Aygün and Odame 2012; Mulumba and Wilson 2015), primarily individuals of African, South Asian and Mediterranean descent (WHO 2011). SCD is associated with a wide range of complications including stroke, vaso-occlusive crisis, leg ulcers and acute and chronic pain (Yawn et al. 2014; Bortolusso Ali 2015); all contributing to a severely shortened lifespan (Wierenga et al. 2001; Lanzkron et al. 2013). The global burden of SCD is rising due to increased survival in low- and middle-income countries and migration to high-income countries, warranting the need for increased global health intervention and public health planning (Grosse et al. 2011; Piel et al. 2013). SCD has been declared a public health priority by the World Health Organization (SCD Coalition 2017).

SCD requires multidisciplinary, comprehensive care by teams comprising physicians, genetic counselors, social workers, nurses, nutritionists, psychologists, hematologists, public health workers and other specialists (Okpala et al. 2002). Care for people with SCD is complex, and interdisciplinary education is critical to improve healthcare provider knowledge. Individuals with SCD often report that providers lack adequate knowledge to treat them (Jenerette et al. 2014). In addition to lack of knowledge about SCD, health-care providers often possess negative attitudes toward individuals with SCD that stem from racism and disease stigma (Freiermuth et al. 2014; Adeyemo et al. 2015); and these attitudes influence care, including resulting in longer wait times and less adherence to analgesic guidelines (Glassberg et al. 2013; Freiermuth et al. 2014; Jenerette et al. 2015). The compilation of high global prevalence, complex medical characteristics and psychosocial issues present in SCD make it an excellent exemplar for a disease-based comprehensive elective course with a global focus.

The twelve tips presented explore the teaching methodology for a comprehensive course: “*Understanding Sickle Cell Disease: A Biopsychosocial Approach*.” The 13-week graduate level course met once a week for 3 hours and provided an overview of SCD from a global perspective, including content on genetics, epidemiology, pathophysiology, medical complications, psychosocial and ethical challenges and health service utilization (Table 1). Faculty and student participants included representation from graduate and undergraduate nursing; arts and sciences disciplines such as African and African American studies, biology and cultural anthropology; and public and global health programs. An integrated curriculum was employed. Integrated curriculum refers to the unification of subjects frequently taught

separately (Brauer and Ferguson 2015). The need for integrated education in healthcare has been identified globally in numerous reports by the Association of American Medical Colleges, the General Medical Council in the United Kingdom, the Association of Faculties of Medicine of Canada, the Australian Medical Council, and the Inquiry on Medical Education in Sweden (Brauer and Ferguson 2015). We discuss other modalities to consider when implementing such a course in low resource environments.

Tip 1

Utilize existing infrastructures within the university

Creating and executing a comprehensive disease-focused course requires a great deal of time, planning, and organization. Taking advantage of existing infrastructures (e.g. partnerships, research and healthcare teams and/or programs) within the university can facilitate this process and minimize duplication of effort. The infrastructure and resources available at each institution varies. A careful assessment of who and what might be available for the course will help provide a realistic picture of the outstanding needs. We utilized relationships cultivated through a collaboration supported by the Duke Global Health Institute to ascertain shared interest in developing the SCD course and identify students committed to taking the course. It is important not to overlook existing infrastructures, resources and opportunities that can facilitate course development. Further networking is required for institutions that do not have established infrastructure. Tips for networking and garnering support for the course includes identifying faculty with shared interest to collaborate with and seeking organizational and individual partnerships with other institutions.

Tip 2

Identify multidisciplinary course faculty and lecturers

Faculty from the Schools of Nursing and Medicine, and the College of Arts and Sciences (departments of African & African American Studies and Biology), codirected the SCD course; both faculty were researchers specializing in areas of SCD. The varied backgrounds represented by the course coordinators and invited expert guest lecturers provided students with diverse perspectives. This is important because the effects of SCD, like many chronic illnesses, transcend the healthcare setting.

Despite potential coordination challenges, there are many benefits to having experts from different disciplines codirect a disease-focused course. Faculty can provide unique perspectives when preparing, developing, and leading the course. Multidisciplinary coordination when developing the course can lead to an interdisciplinary curriculum that addresses nuanced topics and illuminates how different professions complement each other. Codirectors can pool resources, especially as they identify faculty to guest lecture. When developing the course curriculum, identify faculty in different disciplines across campus, institutions and countries who are experts in the disease, but bring different areas of scholarship and practice. Disciplines available at a single institution may be limited, so it might be necessary to connect with individuals outside of the institution offering the course.

Internet and smartphone use is steadily increasing in countries with both developing and developed economies and has been implemented into healthcare and education (Traxler and Kukulska-Hulme 2005; Chib et al. 2015). Low-cost technology, including email, phone, webinars and video-calling can be used to connect with potential faculty and guest lecturers. Video-calling can also be used to facilitate lectures when there are time or financial constraints preventing face to face lectures. Free application software such as Skype and Google Hangouts make it possible to voice and video call individuals across the globe at no cost.

Tip 3

Anticipate technological and logistical issues

We faced several technical and logistical issues related to scheduling and enrolling students in the SCD course. By working with the appropriate online registration support staff, we were able to resolve these issues. Technological and logistical problems are to be expected and can impact recruitment, enrollment, educational technology and course evaluations. These issues can disrupt even well-constructed plans. It is important to prepare and have alternative plans. While educators should always anticipate such issues, complications can increase when coordinating courses across disciplines, departments, and institutions. Strategies for minimizing technical and logistical issues in the conception phase of the course include: (1) utilizing multiple methods of recruitment, (2) maintaining contact with students that have expressed desire to enroll in the course, (3) forewarning and seeking the help of appropriate personnel in areas of potential concern, and (4) knowing the relevant departments or offices to contact for particular needs. Valuable strategies in the implementation phase include: (1) having multiple means to communicate with students, whether through an online learning system, phone, or email; (2) being flexible and adaptable; and (3) being proactive in encouraging students to complete course evaluations. Additional issues may arise when using technology to communicate. Always have a backup communication method. For example, if a guest lecturer cannot be reached via video conference, perhaps a phone call can be used instead. It is important to know what technology is available and use the most appropriate mechanism. For instance, in many countries, WhatsApp and Viber are the preferred phone applications for making free international video and voice calls, while other countries use WeChat or KaKaoTalk.

Tip 4

Recruit students from multiple and diverse disciplines

Eight students – three graduate and five undergraduate students – enrolled in the SCD elective course and contributed to stimulating discussions and fruitful debates. Faculty can recruit students from their own programs and departments to enroll in the course. Students feeling intimidated to take an elective course originating from outside of their own discipline or program may be more comfortable if the course includes faculty from a discipline they are familiar with. Having students from a wide variety of disciplines provides them with the opportunity to engage with students from disciplines they would not normally encounter. Learning in multidisciplinary classrooms promotes a culture of respect and collaboration.

Finally, opening the course to students outside of the hosting department can increase student enrollment, as it is sometimes difficult to obtain a sufficient number of students for elective courses. In environments where it is difficult to coordinate multidisciplinary enrollment, students from different disciplines can interact with each other through activities coordinated by faculty, for example debates and symposiums, or online course-work, such as discussion boards.

Several methods can be used to recruit students from multiple disciplines and increase student enrollment. We developed and distributed a flyer to key individuals in various academic programs across campus. We discussed the course with leaders of academic programs. We cross-listed the course with nursing, cultural anthropology, African and African American studies, and global health to increase participation. Cross-listing makes it easier for students from a variety of disciplines to find the course. Utilizing existing infrastructure, such as relevant organizations and clubs, can also be helpful to identify students that may be interested.

Tip 5

Incorporate a biopsychosocial framework

The onset and progression of disease involve the interaction of biological, behavioral, and social factors. In SCD, as in many other chronic diseases, individuals suffer from a wide array of medical complications that are influenced by social and behavioral factors. It is important to understand the joint and separate effects of these factors on disease management and outcomes. We organized the entire course using the biopsychosocial framework (Borrell-Carrió et al. 2004). This framework can be applied to a variety of chronic diseases and contexts. It uses a holistic approach to understanding the effect that disease and illness have on personhood, by considering the influence of combined biological factors (genetic, medical), psychological factors (personality, behaviors), and social factors (culture, demographic characteristics) (Borrell-Carrió et al. 2004). These various determinants –especially social, cultural, behavioral factors – will vary markedly by setting and it is critical to understand the influence of this variability on disease outcomes. For example, in low-resource environments, social determinants of health such as poverty and access to care may have huge influence on health outcomes. Individuals with a chronic disease in these settings may have limited access to treatments because they are unavailable or very limited.

Tip 6

Use a global approach

By exploring SCD through a global lens, we provided students with an opportunity to learn how SCD is viewed and managed across the world. Students explored literature in different populations and countries. Rich discussion surrounding disease pathology, the relevance and impact of race and racism, disease stigma, and health disparities resulted from using a global perspective to understand SCD. Students discussed the state of the science and healthcare regarding SCD, and explored their own ideas about possible solutions to gaps in the

literature. The use of a global approach enhances the interdisciplinary study of a disease. Students can learn how a disease is viewed and managed in and outside of their country of reference. Differences between treatment and resources between high and low resource environments should be discussed at length. Approaches to employing a global framework include: (1) inviting national and international experts by maximizing their ability to participate through webinars, phone conferences or available taped lectures, (2) incorporating relevant research and clinical findings from outside of institutions' countries of origin, (3) assigning readings that represent global perspectives, (4) and encouraging students to integrate global viewpoints into their coursework.

Tip 7

Incorporate a focus on policy

We had several discussions about healthcare policy and its influence on SCD morbidity and mortality rates in high and low resource environments. Namely, newborn screening for SCD and prophylactic penicillin treatment in children with SCD are vital policies that have increased survival into adulthood in countries with both high and low resources. We discussed the importance of these policies; successes, failures and barriers to policy implementation in different countries; and potential ways implementation can be improved. Relaying the significance of policy and how to engage with government when implementing science is a crucial focus that should be implemented in every disease-focused course. It is also important to discuss how policy may affect "which" actual healthcare providers are available and how their scope of practice may be different depending on the resources available in a country. Some countries may rely heavily on lay healthcare workers or ministries and international nongovernment organizations to provide healthcare.

Tip 8

Provide opportunities for students to interact with and learn from patients

We created several opportunities for students to learn from people living with SCD. Persons with SCD were approached through faculty contacts and a local SCD support group. The first day of class a panel of five people with SCD introduced the course by speaking about their life experiences with SCD, including childhood, dating and marriage, pregnancy and employment. For most classes, at least two persons living with SCD were present. This innovative approach proved to be a mutually beneficial experience. Patients learned more about SCD, and students benefitted from their participation. Patients were included in group work and discussions. Students consulted with patients outside of class time to gain insight into their final group projects.

Patient perspectives in the classroom can provide human voices to a disease-focused course. In the United States, patient-centeredness has been identified as one of the six domains of quality for the Institute of Medicine in the United States (Epstein et al. 2010; IOM 2015). In 2010, the Patient-Centered Outcomes Research institute (PCORI) was established in the United States to address challenges that patients face when addressing their complex health concerns (PCORI 2012). Consequentially, there have been initiatives to increase patient-

centeredness in healthcare education. When healthcare students learn using a patient-centered approach it allows them to (1) contextualize a condition within the setting of patients' daily lives, (2) better recognize patients' needs and (3) to recognize the complexity of providing care (Oswald et al. 2014). Regardless of the country of practice, or whether practicing in a low or high resourced environment, the patient perspective is critical. If patients believe more in non-Western Medicine and non-pharmacologic therapies, it is important to understand this and incorporate these perspectives into how and what we communicate when working with patients.

Patient participation can be developed using several methods including organizing a patient panel, inviting a patient to be a guest lecturer, or simply inviting the patients to sit in on the class and participate in class discussions and activities. Another way students can interact with patients is through a clinical immersion experience. Even a brief 2–3-hour experience in a clinical setting—such as a primary healthcare facility or a doctor's practice can enhance the learning experience in a disease-based course. We recommend tailoring the clinical experience to the environment and disease. For instance, in some situations it may not be ideal for several students to visit clinic simultaneously and students may need to be scheduled in groups of 1 or 2. Ensure that patients who agree to help educate students are respected by: (1) informing them that they are not obligated to answer all of the questions asked by students or faculty; (2) notifying them of what the topic of the class will be beforehand or providing them with the syllabus; (3) providing parking passes or other compensatory necessities; and (4) accommodating medical needs as appropriate.

Tip 9

Enable students to learn from one another using assignments that inspire creativity

There are tremendous opportunities for students from different backgrounds to gain knowledge from one another. We incorporated student-led lectures and discussions as well as group work into the curriculum as a course assignment. This promoted learning from peers by allowing students to help, share, and advance efforts in each other's learning. Students shared knowledge from their disciplines and engaged with others outside of their spheres of expertise. Students worked closely with course faculty to develop content and lead a topic each week; faculty provided one hour of content on the topic each week. Students searched the literature, facilitated discussion of course content, and developed an interactive activity, such as case studies and charrettes, to reinforce the knowledge gained. Another way to inspire creativity is through group work. Students in our course worked in groups on a creative and original final project for the class. In an effort to raise awareness and reduce stigma surrounding SCD, one group developed easily digestible infographic and video to inform the general public about SCD. Another group identified the need for and developed an online set of modules designed to teach employers about living and working with SCD and the related accommodations needed for employees with SCD.

Giving students the opportunity to use the knowledge gained in the course and applying it creatively can be powerful. Projects such as videos, infographics, websites, brochures, awareness campaigns and apps can be innovative ways for students to demonstrate mastery of content and achievement of course objectives or learning outcomes. Encourage students

to use their projects to address issues that have not been fully explored, and to pursue projects that can be used outside of the classroom. When guiding students as they decide on their creative assignments, urge them to pursue unique projects that embody the essence of the course or specific aspects of the course. Instruct students to integrate key course concepts into their project and target a specific audience. Assigning creative projects in groups can also provide students with another opportunity to learn from each other. This strategy of using creativity to enhance teaching and learning can be applied in any setting with use of whatever resources are available.

Tip 10

Consider students' diverse backgrounds

In our SCD elective, students represented nursing, biology, global health, anthropology, and other disciplines at the graduate and undergraduate levels. It was important to plan course activities with this diversity in mind. Students may have limited knowledge of medical subjects and terminology or might not have encountered certain concepts. This can be a barrier, but can also provide even more opportunities for students to learn from each other. It is important to acknowledge when lectures may include unfamiliar terminology; this can alleviate feelings of alienation. Encourage students to ask questions when they encounter unfamiliar topics. Be aware of the culture, hierarchy, and climate of the institution and patterns of student engagement; and act accordingly. Closely monitor student behaviors and encourage participation.

Tip 11

Facilitate dissemination of products of course assignments

Disease-focused comprehensive courses can be an ideal opportunity for students to pursue projects that they may not be able to in their core curriculum (Harirforoosh and Stewart 2016). Students also have the opportunity to network with faculty from multiple disciplines and work closely with them in small classroom or online environments. For some students, this can spark an interest in research, desire to publish an article, or to disseminate materials developed for a creative project. Disseminating web-based creative projects can help facilitate learning in future courses in all environments, but especially low resourced ones. Academic gain aside, publishing can also teach students a lesson about the importance of distributing knowledge in the scientific community and how knowledge dissemination can lead to improvements in the lives of people suffering from diseases globally. Students should: (1) identify a target audience and journal when writing papers, (2) choose a topic relevant to the target journal and audience, and (3) use author guidelines for the journal when writing the paper. Maintain contact with students after the end of the course and guide them through the process of publication or dissemination of class assignments.

Tip 12

Promote lifelong learning

An interdisciplinary environment can yield many opportunities to instill the value of lifelong learning into students. Multidisciplinary classrooms allow students to have rich discussions that illuminate nuance. It is important to explore sensitive and complicated topics in elective courses as there is often not enough time in core curricula to examine these topics in depth. In our SCD elective, we had rich discussions surrounding racism, medical ethics, infertility, policy, health disparities and equity. To foster and facilitate discussion of difficult and sensitive topics: (1) do not shy away from subjects when they arise organically; (2) challenge students to explore nuances when their questions do not have finite answers; and (3) use the literature and real-life examples to guide class discussions and encourage students to do the same. It is highly likely that difficult topics will emerge when approaching diseases from an integrative medical, behavioral and social framework and a global perspective.

Elective courses are the perfect environments for students to get out of their comfort zone and broaden their world view. Students will study the global burden of a disease, rather than just its impact in their community. Students will be challenged to think about how an illness impacts the whole person, rather than just the disease process. Students will have the opportunity to develop practical skills and habits, such as staying up to date on literature in all relevant disciplines and engaging in interdisciplinary communication. Encourage students to apply what they learn in practice by using examples of interdisciplinary teams interacting with individuals with complex diseases. Foremost, a comprehensive disease-focused course allows students time to learn about how illness impacts individuals holistically. By engaging with course material in depth and interacting with other disciplines, students can have a unique learning experience that allows them to employ creativity and explore their potential passions, whether that be policy, education, medicine, or a combination of their choosing.

Conclusions

Our elective course entitled “*Understanding Sickle Cell Disease: A Biopsychosocial Approach*” addressed the complex nature of SCD employing patient-centered, global, and interdisciplinary approaches. Using our SCD elective as an example, we have presented twelve tips for developing a disease-focused, interdisciplinary, and comprehensive elective course. These tips are useful for healthcare educators that wish to address knowledge gaps in core curricula. In SCD, these knowledge gaps often result in poor patient-provider communication, negative provider attitudes towards individuals with SCD, and poor quality of care (Haywood et al. 2013; 2014; Freiermuth et al. 2014). We believe that the use of elective courses to address knowledge and awareness gaps that exist for many diseases can improve healthcare provider skills and attitudes, such as communication, self-reflection, critical thinking, open-mindedness, and empathy.

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Table 1**Course Topics and Objectives.**

Topics	Objectives
Course overview	<ul style="list-style-type: none"> ✓ Introduce faculty and students. ✓ Provide a course overview including in-class structure, assignments, and grading. ✓ Assign students to group for group projects and dates for leading the student-led discussions. ✓ Provide a brief review of how to find and search for scientific papers and types of scholarly papers that can be selected for first assignment (final paper). ✓ SCD Panel: Individuals living with SCD. Open discussion of what it is like to live with SCD and how the healthcare community can best interact with people with SCD.
Epidemiology	<ul style="list-style-type: none"> ✓ Review basic epidemiologic constructs relative to SCD ✓ Compare and contrast the epidemiologic differences of SCD globally
Genetics	<ul style="list-style-type: none"> ✓ Identify genetic underpinnings of SCD. ✓ Understand inheritance, state versus trait, differences and global variation between SCD genotypes, and how genetics influences patient outcomes and disease trajectory.
Acute and chronic pain	<ul style="list-style-type: none"> ✓ Identify the prevalence of acute and chronic pain experienced by individuals with SCD. ✓ Distinguish multiple etiologies of chronic pain. ✓ Discuss treatment of both acute and chronic pain.
Pathophysiology and medical complications	<ul style="list-style-type: none"> ✓ Inter-related pathophysiology and medical complications of SCD.
Racism and disease stigma	<ul style="list-style-type: none"> ✓ Examine how racism and disease stigma are related in persons with SCD globally. ✓ Understand the intersection between stigma related to race and stigma related to disease, misconceptions related to SCD and addiction, and impact of stigma on health care decision-making and treatment in a global context.
Ethical and social implications	<ul style="list-style-type: none"> ✓ Examine the relationship between social and cultural factors and well-being in individuals with SCD and their families in the United States and selected other countries. ✓ Understand how social environment influences disease-related outcomes, and how SCD is viewed across different cultures. ✓ Identify and discuss two common ethical dilemmas that occur when treating individuals with SCD.
Psychological complications	<ul style="list-style-type: none"> ✓ Identify psychological complications associated with SCD. ✓ Differentiate the frequency and type of psychological complications experienced and how they differ among demographic factors. ✓ Distinguish and critique various psychosocial therapies needed, kinds of treatments and interventions that are currently in use, and how psychological treatments compliment medical treatments.
International speaker	<ul style="list-style-type: none"> ✓ Examine the medical treatment, conceptualizations and psychosocial impact of SCD in Jamaica.
Quality of life	<ul style="list-style-type: none"> ✓ Understand how SCD impacts quality of life across the lifespan, and how quality of life can be improved through various social, psychological, and medical interventions.
Health service use and cost	<ul style="list-style-type: none"> ✓ Compare and contrast health service utilization, including healthcare provider delivery differences of SCD in the United States and selected other countries. ✓ Examine the financial costs associated with SCD from the individual, national, and global perspectives. ✓ Understand how and what resources are available for patients with SCD to pay for treatments, barriers to care, and what is being done domestically and internationally to improve care.
Student Presentations and Course Wrap up	<ul style="list-style-type: none"> ✓ Students present their final paper topics and groups present their creative projects. ✓ Reflect on the course.