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In this case study, faculty from Communication Studies, Biological Sciences, and Management & Information Systems combined resources of six courses and 172+ students in a health-related service-learning project during Fall 2010. The project focused on Cystic Fibrosis (CF) concluding with one public event that attracted audience members from several Appalachian Central East Ohio counties. The project's primary goal was to disseminate CF-related information to a large number of university students and to residents of the surrounding communities in a multiple-dimensional presentation in order to give voice to a relatively small segment of the population, people living with CF and their caregivers, who feel stigmatized by the general public's lack of knowledge about CF. The multi-dimensions of the 3-hour production event included a talk from an expert CF researcher, a student-written and -enacted play, "A Life with Cystic Fibrosis", student posters, and caregivers at information tables. Student learning occurred in each dimension and at each stage of the project.

This article describes the details of the project process: people, planning, and construction. It concludes with the connections developed between the students and the CF information, impact on all involved and considerations for future projects.

Introduction

Cystic Fibrosis (CF) is a debilitating and typically fatal disease that affects the respiratory, digestive, and reproductive systems of the body (Torpy, Lynm, & Glass, 2009). The definition of CF, according to A.D.A.M. Medical Encyclopedia at the National Library website, MedlinePlus,

Cystic fibrosis (CF) is caused by a defective gene, which causes the body to produce abnormally thick and sticky fluid that is mucus. This mucus builds up in the breathing passages of the lungs and in the pancreas, the organ that helps to break down and absorb food. This collection of sticky mucus results in life-threatening lung infections and serious digestion problems. The disease may also affect the sweat glands and a man's reproductive system.

Cystic fibrosis is the most common deadly genetic disease of Caucasians in the United States, with approximately 1 in 29 persons being carries (bearing one of the two copies of the mutated gene needed to develop the disease). It is especially prevalent in those of Northern and Central European descent (A.D.A.M. Medical Encyclopedia, 2012). Nationally, it afflicts about 30,000 persons (Torpy et al., 2009), and is considered by many to be an "orphan disease."

The term "orphan disease" implies two separate but related concepts. It has been used to describe diseases that are neglected by doctors. However, more specifically the term "orphan disease" is used to designate diseases that affect only small numbers of individuals (so-called health orphans). There is no satisfactory definition of an orphan disease. In the USA, it is defined as one that affects fewer than 200 000 individuals. (Aronson, 2006)

Orphan diseases receive only a small fraction of the governmental or private funding and research priority by pharmaceutical companies enjoyed by other more familiar and widespread diseases such as cancer and cardiovascular disorders, Alzheimer's and Parkinson's diseases, and even influenza. CF is often under-reported in medical disease databases since it is non-contagious. The only recording agency for CF is the National Cystic Fibrosis Foundation that gathers data of self-reports from CF caregivers and cystic fibrosis treatment centers.

An important concern of the parents of children with CF is a stigmatization of the disease that prompts them to protect children from ignorance about the disease by others (Farrell, LaPean & Ladouceur, 2005; Evers-Kiebooms, Denayer, Welkenhuysen, Cassiman, & Berghe, 2008). While school personnel are required to give special attention to CF patients who must frequently cough vigorously in order to breathe, use inhalers, and are not able to compete in sports when they are not feeling well, general education about the disease is uncommon (Mullet, 2010). The best way to decrease or counteract this stigmatization of the disease is to provide accurate information to educate others in the CF person's life (Wilford & Fost, 1990).

The Kent State University at Tuscarawas campus serves the counties of Tuscarawas, Carroll, Holmes, and Coshocton in East Central Ohio of the northern section of Appalachia (Appalachian Ohio, 2012; Appalachian Regional Commission, 2012a & 2012b). These four counties, home to over half of the campus's students, are among the eight counties in Ohio considered "distressed" by the County Economic Status in Appalachia, FY 2012 (www.arc.gov/maps). Almost 30% of the students attending the campus, as well as the members of the local community, have a higher risk for being CF gene carriers than the national average since most are of German, Italian, Hungarian, and Polish heritage (A.D.A.M. Medical Encyclopedia, 2012; Appalachian Regional Commission, 2012).

The adverse effects of CF on the residents of the campus's community are greater than those experienced by persons of similar ethnic background living in the counties situated immediately to the north, west or south due to a lower average family income, higher unemployment rates, lower general level of education, and further distance to the nearest CF treatment centers in Akron and Cleveland, Ohio (50 and 144 miles, respectively) (U.S. Government, 2011; MapQuest, 2012a). For emergencies, the nearest general hospital is in campus's town (5 miles) and has a respiratory unit, but the closest large facility having over 200 beds requires a trip of over 28 miles (MapQuest, 2012b). During the last years of the nation's recent and ongoing depression, many people of this corner of Appalachia experienced compounded woes as the few manufacturing plants operating in the area pink-slipped workers and shuttered the plants (U.S. Government, 2011). Not just plant jobs were lost, but their spin-off jobs (such as plant maintenance workers, restaurant workers and owners) ceased along with loss of residents leaving the region in order to find jobs elsewhere.

CF caregivers/parents in this East Central Ohio region thus have less ability to meet the very high costs associated with the care of a person living with CF. In addition to the financial and time burden of transporting those living with the disease to the proper medical facilities and CF treatment centers, caregivers must also provide 5-6 daily full meals in order to permit the consumption of the 4000-5000 calories required per child, the administration of multiple medications and several daily treatments of 20-30 minutes on very expensive and specialized machinery, and the 2-4 week stays at CF treatment centers

for what the patients of CF themselves label "tune-ups" every 3-6 months. These items cost approximately one million dollars per child from birth to the age of 21 (Mullet, 2010). Many affected families include more than one child living with CF that requires the efforts of multiple family members. People living with CF exist in a precarious position at the best of times: they need their family caregivers and extended family to support their medical and emotional concerns. In the current economic climate, if the main income producer loses their job, those persons with CF have to either stay in a long-distance relationship with the parent looking for work in other locations or travel with the parent or parents in order to receive the required daily physical treatments. Because of the added stress on caregivers and families at this time, community support is particularly valuable and vital to ease the stress of coping with a chronic and painful medical condition that shortens life expectancy to an average of 37 years (Cystic Fibrosis Foundation, 2010a).

Given the extra challenges of the people living with CF and their families in this economically challenged area of Appalachia and the importance of community support, there is an especially great need to bring an awareness of the disease and the special needs of those affected by it. One effective means of fostering understanding of the dire circumstances of the CF patient and their families is to begin with a public awareness campaign by the leading institution of higher education. The authors devised a service-learning project as a vehicle to disseminate the CF-related knowledge. Such an informational campaign would shed new light into the dark corners of the daily existence of a small but largely ignored population of CF patients while introducing college students, many of whom are future nurses, to develop empathy for patients who are often lost to the healthcare community. The project could ultimately impact whole families and their supporting groups by demystifying the disease and informing the community of how best to aid those living with it.

To achieve the authors' informational and educational purposes, four major goals were crafted. The first goal of the project was to introduce, increase and promote understanding and compassion for CF patients, their caregivers, and the medical personnel who treat CF patients by informing the general public about the disease. Though a small number of people are genetically carriers of the gene, CF, patients living with CF deserve a place and not ignored or misunderstood.

A second goal was to inform students about the disease and its impact on family, community, and society. The mission of the university is to educate their students about the interconnectional nature of society members, both small groups and large. Beyond facts and figures, each person impacts others along their life journeys.

The third goal of the service-learning project was to provide educational material to the general public that might encourage funding for research to find a cure for CF or extend and improve the CF patient's life. The community partners of The Cystic Fibrosis Foundation, The Cystic Fibrosis Treatment Center of Akron Children's Hospital, and a CF volunteer supplied the Biological Science and Communication Studies professors with many of the previously available CF publications used in fund-raising events in the local area to be displayed at the ending presentation.

A fourth and final goal was to provide opportunities for networking among and between CF researchers and CF caregivers, and build relationships between CF researchers and education professionals, and to increase interactions between the campus and the surrounding community.

The service-learning project involved three faculty members of Kent State University at Tuscarawas from Biological Sciences, Business Administration, and Communication Studies working together to create a multidisciplinary project for students in six of their respective courses. The project focused on a specific disease, CF, with the intention of broadly disseminating health-related information to 172 students and the general public. Kramarae's (1981) Muted Voice Theory is used in this study to explain lack of voice of a small group of the population needing understanding and compassion from the rest of society.

As with most case studies, the use of theory brings the case study application into perspective for the reader. This case study used Kramarae's (1981) Muted Voice Theory, a critical feminist theory that underscores the lack of voice by minority groups (Kramarae specifies women as the minority) as a means to assist understanding of why some small groups of people need assistance from a larger voice, in this instance the voice of 172+ students and over 120+ audience members in a university setting. Many persons living with CF chose to not be identified or labeled as a CF patient because of the stigmatization associated with having any disease, having a disease that kills, and having high cost needs from the scarce resources available in smaller rural communities. By choosing to not be identified, they are in fact invisible. But now, by being invisible they are without a voice or a face. Communities, including those in CE Ohio, that are often characterized by a lack of industry for employment, low income due to few learned skills, high school dropout rates, and single-parent families are subjected to intense competition for income and support by others. The stigma of CF reduces the income possibilities by the massive time required of the caregiver to the CF patient that affects job performance, increases job absences for doctor appointments, CF treatments, and the treatments that patients with CF label "tune-ups". The caregiver and the CF patient are limited in job opportunities and job advancements.

A second theory, Rogers' (1983) Diffusion of Innovations, addresses the need for educating others in order for change to be possible and explains the process of acquiring information and then deciding what to do or not do with that information. When people are exposed to a message transmitted directly to one or more than persons, it is called face-to-face, the richest form of information transmission with the most possibility for speaker influence (Verderber, Verderber, & Sellnow, 2012). This face-to-face intervention was the delivery of student speeches in the classroom and the other public venue of the public awareness event play and during the times before and after the play in which audience members interacted with one another, with the CF researcher, with biology students presenting their posters, and with university personnel.

The assessment of outcomes using pre- and post-tests of general student knowledge about the disease, by the responses of the general public, and by the repeated use of educational material produced during the project by CF volunteers is described.

Finally, the lessons learned from such a large and involved multidisciplinary servicelearning project are discussed so that that may be applied in projects by our group and others in the future

The Project: Service-learning Experience for Students with a Public Awareness Campaign for Community Partner-The Cystic Fibrosis Foundation

The parts of the project include (1) a single unifying service-learning topic, (2) links to other courses, and (3) the planning, construction, and delivery of a public awareness campaign. The other issues that influenced the topic of the project and its direction were the central location of the regional university campus in the tri-county area, a medical condition that is generally underfunded and relatively unknown to the general public due to the small number of patients and the muted voice of those with CF (a medical condition), and the collaboration of 172 students in six different courses across three disciplines. Changes in student understanding of CF was assessed in the Communication Studies and Biological Science classes at the beginning and end of the project.

The initial work on the project began eight months prior to the start of the semester with numerous meetings between the three professors, several meetings with the campus dean, three critical off-site meetings with community partners, and a series of interviews with volunteers and caregivers. At the beginning of the semester, the communication professor and the biology professor visited the business management class three times to assist students in the final event organization and direction. The biology professor came to all four of the communication classes and delivered her lecture via story and power point lecture with discussion at the end. The three professors visited community partners at their locations three times during the semester at week 1, 8, and 9. The Cystic Fibrosis Foundation is a nonprofit organization that is the single best source for information about the disease to those living with CF, their caregivers and the general public. It also has raised the majority of the money that has funded research efforts resulting in adding over three decades to the CF patient's average lifespan and vastly improving quality of life (Cystic Fibrosis Foundation, 2010a, 2010b). The Cystic Fibrosis Treatment Center of Akron Children's Hospital is one of the premiere providers of care to those living with CF.

The key to the project was the willingness of all the students to learn new information and apply it into tangible products of speeches, posters, and a play. There were six groups of students in the project from the following courses: three sections of lower-division basic speech class with 75 students, one upper-division speech class with 12 students, one lower-division biological science class with 70 students, and one upper-division business management class with 15 students for a total of 172 students.

The Biological Science faculty member supplied one Biological Structure and Function class, a beginning science course for the pre-nursing program. At week 3 of 16, this biological science professor gave one 45-minute CF lecture to all Communication Studies students with handouts of the lecture power point slides and references, used extensively by the speech students in their major speeches given in weeks 12-14. The lecture began with a fictional story to give details and emotion to her involvement with CF. Throughout the semester, the biology students were required to research the effects of CF on various body parts until at the 8-week point, they researched specifically assigned topics concerning the biology aspects underlying CF and were quizzed by the Communication Studies students during one 30-minute group interview. At week 13, the biology students were given in-depth 39-part worksheets on genetics of CF, the exact mechanisms in which CF damaged organs, the newest medications and therapies available, and how they acted. In week 15 at the presentation event, the Biology students created and displayed original

posters about the effects of CF on the functioning of the body organs and the types of treatment currently used.

While not trained in medical issues, the students in the upper-division speech class became mentors to teams of lower-division speech students on the speech process rather than on medical syndromes, medical conditions, or exact scientific terminology. They coached their teams on the speech-creation process for their first CF speech of information, which provided general information about the disease, and assisted the teams in creating their visual aids in the final speech of persuasion that involved advertising a fundraising event for the Cystic Fibrosis Foundation (Cystic Fibrosis Foundation, 2010a, 2010b). The upperdivision speech students created and acted in a seven-part play titled "A Life with Cystic Fibrosis" at the public awareness event using personal interview material from people living with CF who did not wish to be identified in the play or in any references and CF caregivers who generously provided their years of experience in multiple personal interviews, also wishing to remain anonymous. All speeches by the communication studies students and the public event gave voice to the concerns and life issues of those affected by CF as explained by Muted Voice Theory (Kramarae, 1981), in a manner that was designed to influence audience members as well as student participants as viewed from Rogers' 1983 Diffusion of Innovation Theory.

The latter theory was incorporated in the project by the delivery of student speeches in the classroom and the other public venue of the public awareness event. In addition to the stage performance, there were three additional venues at the latter event that allowed audience members to interact with one another, with CF researcher, with biology students, and with university personnel. The biology students presented information about the disease on posters prepared during the project, volunteer caregivers sat at information tables for people to ask questions about CF and being a caregiver to people living with CF and the keynote speaker mingled with the audience to answer any questions he could about current research in CF and possibilities for cure someday. The speaker was a hometown native of the small town next to the university who had been inspired to follow his interest in CF due to a childhood experience of having a friend who died of CF.

When the students in the event play presented their information to the audience, there was a 50% chance of acceptance (i.e. changing their mind about the topic) according to adaptation possibilities (Rogers, 1983). That acceptance depends on whether the audience members (1) believed the speaker(s), (2) were moved from neutral to sympathy or empathy, (3) decided to act on the message, (4) thought that the speaker and the receiver in the audience were a common social system (shared the same values) and (5) thought that their common social system required or demanded a positive or negative response such as viewing the people living with CF in a favorable light (Rogers, 1983).

A third faculty member and his Strategic Management capstone course business students coordinated the ending presentation event. The tasks of the Strategic Management teams were to: (1) collaborate with the Communication Studies professor for creating the event program handout, (2) register all audience members as they entered the building, (3) record demographic data from the audience members and store it in electronic spreadsheet for use in future research articles and permit networking of interested parties, (4) assist Biology students with displaying their posters, (5) assist audience members with seating in the auditorium and address any of their concerns, and (6) remove all registration materials and other event items at the conclusion of the evening.

Service-learning as a tool

Since the project's goals required students to talk to the general public, it was a perfect fit for a service-learning (experiential learning) experience. The concept of service-learning offers the promise of illustrating a segment of life that is completely other-oriented, giving of one's talents and skills to provide for others with no other motive than it is the right thing to do for one's community. Degelman (2000) defines that motive/reason as civic responsibility or citizenship education. In this small community that encompasses deepseated issues of chronic underemployment and quick response to economic downturns and national recessions, service-learning projects offer windows to what would otherwise be silence on community and family concerns.

Once the community learned about interest in cystic fibrosis, the grapevine talk quickly found some community members who knew people living with CF, had a family member living with CF, or was a person living with CF. Those community members came forward to speak to the students at a very private level, sharing their life stories one-on-one. The students came into class with parts of these stories and presented them in a manner that protected their sources but nevertheless provided clear examples of what people living with CF had to do to keep alive and in relatively good health.

The service-learning community partner, The Cystic Fibrosis Foundation, assisted with books, movies, and brochures discussing different concerns that new parents of people living with CF needed to know, providing information about agencies that the parents needed for financial support and medical centers that the parents needed to locate and which helped to establish relationships with the medical personnel.

The Impact and Outcomes

The impact of the service-learning project on those attending the public presentation as well as the students involved in the project was determined by a combination of anecdotal evidence, by the results of the pre-and post-tests, and by the further usage of project material by the CF community.

The most effective means of transmitting a message of a personal nature, such as an inherited disease like CF, is to use the grapevine within a close-knit family oriented community as was done by the students in the project, predominantly young people of the community who are 18-26 years old. By relating personal stories during classroom discussions over the last eight years, these and similar students have shared their lives: they live at home with their parents, work in local businesses, and have had close personal relationships with each other since kindergarten. Rogers' (1983) theory relates these established lines of communication as the strongest to influence.

Rogers' (1983) theory acted through the presentation material in the play, striking a solid note with the audience as evidenced during the reception afterwards when they poured out of the auditorium and stayed in the lobby area for the next hour until encouraged to move out into the foyer area next to the front doors. Audience members sought out the student actors, the event speaker—an expert CF researcher, and caregivers sitting in the library area as they talked to other caregivers and viewed the biology students' posters. Receiving the information, acting on it, and telling others are components of the clear path of persuasion that extends from the speaker to the receiver of the message. The student-actors in the play, "A Life with Cystic Fibrosis," matched the audience's needs of visual reinforcement of the positive message of hope and a future. With the intent to be blatantly

obvious, the principal characters in the play were named Hope, born with CF, who had a daughter, Faith, born with CF.

In accordance with Rogers' (1983) Diffusion of Innovation (Information) theory, the project helped the message receivers, in this case the audience members, to understand the importance of a close relationship between the actors and themselves. With a shared community history, the students' message was constructed with the right elements of the traditions, values, and beliefs that are clearly present in this community of family and friends.

One caregiver from a town south of the university came to the event hoping to find others to join a support group for respite and was able to locate and speak with another caregiver at one of the information tables (Anonymous, 2010). This simple communication interaction was Muted Voice Theory in action which speaks to those who want to find others to order to share their own story, to listen to other stories, to look for hope, and to plan for the next day that might grant a little bit of sunshine in an otherwise gloomy future.

The value of the information imparted by the student groups became evident during the reception time of the final presentation event when audience members congregated around CF caregivers who had come to share their stories. Audience members asked questions and took away brochures as they encircled a vendor of CF respiratory equipment who had set up an information table in the registration area. The CF researcher who spoke at the event, Dr. Mitchell Drumm, had five caregivers for different patients, numerous medical treatment personnel, and two CF patients (as mentioned earlier) gathered around him at the reception (Drumm et al., 2005). Beyond the presentation, the expert researcher reported that two audience members who are not allowed to drive themselves due to religious convictions later toured his research laboratory at Case Western Reserve University and initiated better forms of transportation to treatment centers as a result of their new base of information.

Since this presentation, a CF volunteer has used eight of the biology student posters in multiple fundraising events to augment her informational speeches. Very recently, the 22-year old star of the presentation play became pregnant with her second child and had the CF needle test, as she said "just in case." She said she had recently became "more aware of certain relatives" in her life and wanted to take every precaution for her new child. The stigma of CF had caused family member to hide or not share important medical facts about a branch of the family until she asked them direct questions about children who had died very young with CF in the 1930s.

The impact of transmitting the information about CF was multi-layered and multi-directional that included people, organizations, and institutions. The multi-layers consisted of the 172 students in the service-learning project, the friends and families of those students, other students outside of their friends and family circles to whom the students spoke, and other people interacting with the students during the semester. The multi-directions were within the eight campus university system, the Cystic Fibrosis Foundation system, the Akron Children's Hospital CF Treatment Center in Akron, OH, the thousands of people who read about the final event in The Bargain Hunter newspaper on December 6, 2010, The Times Reporter newspaper on December 9, 2010, and the 129 people who registered on the final presentation event at the college on December 9, 2010 (Holmes, 2010; Times-Reporter Staff, 2010).

Three days before the presentation event, the local newspaper, The Bargain Hunter, ran a cover page article on the upcoming event with quotes from two of the professors,

three actors, and the public relations coordinator at the regional university campus. The following week, the event was again featured including photographs from the play and the Case Western Reserve University CF researcher, Dr. Drumm, who informed the audience of new forms of treatment being developed by the research funded by the Cystic Fibrosis Foundation (Haddow, Paomaki, Bradley & Doherty, 1998; Drumm et al., 2005; and Evers-Kiebooms et al., 2008). Dr. Drumm's presentation was particularly well received by the community, both due to his much-acclaimed research in the field (Drumm et al., 2005) and because he grew up in the small Appalachian town next to the college campus. The picture of Dr. Drumm and his mother was accompanied by a story of her deep roots in the community and church that exhibited the strong family orientation of the area. It is important to note that The Bargain Hunter is distributed free of charge to all residences in the central county of the three county area serviced by the university and The Times Reporter serves eight communities in the county of the university plus four adjoining counties.

On the morning of the presentation event, The Times-Reporter newspaper, the only daily paper in Tuscarawas County, ran a small box article embedded in the local "Events to Do" column. While it was not as personal as The Bargain Hunter article and photos, nevertheless, several audience members mentioned the ad as a factor in their attendance that night (Times-Reporter Staff, 2010).

The most heartwarming discovery of the case study was that the project was a success with the final presentation having an audience containing caregivers and medical personnel, reports of audience satisfaction, and effective transmission of information to a large number of students. Audience satisfaction was evidenced by comments made to the faculty members following the presentation as well as notes written to the campus dean, Dr. Andrews, and faculty members. Several days after the program, a mother of two children living with CF wrote the following note of appreciation:

I wanted to say thank you for what you and your students have done to bring attention to Cystic Fibrosis and the challenges those living with the disease face very day. I was so impressed when I saw the final project presentations and the Kent [State University at Tuscarawas] campus. During a couple of scenes of the drama, I actually had to fight back tears. The check-in process was smooth and the posters were so impressive. It was an awesome evening. Thank you for investing your time and talents in such an important mission to bring awareness to Cystic Fibrosis. (Anonymous, 2010)

Dissemination of knowledge to students was evidenced by the responses of communication students and biology students to a CF knowledge test administered at the beginning and end of the semester. Based on the results of the pre- and post-tests, student knowledge increased significantly, with an overall score of 30% on the CF pretest vs. over 80% on the post-test (unpublished data). Interestingly, the increase in topic-related knowledge was nearly equal in the communication studies and biology classes and both low and high performing students scored over 80% on the post-tests. This is particularly interesting due to the differences in student populations—students of all interests vs. future health care practitioners. The following semester, an unannounced post-test was administered again to a group of the same biology students in a microbiology course. Surprisingly, the number of correct responses from this group was nearly identical whether given at the end of the project or given the next semester (87% vs. 86% correct responses).

Thus, despite nine months of massive preparation time and scheduling meetings, the large number of alternations made in the preparation and schedule, difficulties arising with

accountability, and student complaints about "hard work, extra beyond the syllabus", we still had a final presentation event that attracted a medium-sized audience who remained talking in the reception area until asked to leave by university personnel. Not just student-actors and their parents but rather an extremely high interest group comprised much of the audience and subsequently inquired as to when we would be giving another such presentation.

On another level, while only a small percentage of Americans (approximately 30,000) have the disease, it affects an exponential number of people, including the CF patient's family, caregivers, medical personnel, and friends. The close-knit nature of families in this region means that people have long-standing histories with each other and are aware of who has CF: many area residents personally know one or more children living with the disease. Several students in the service-learning project mentioned knowing at least one person with CF. From one of these connections, a 17 year-old woman living with CF came forward during the semester after talking to one of the project's students. She volunteered to speak to a joint gathering of students from the different courses participating in the project. She and her primary caregivers, father and grandmother, traveled two hours to this meeting, bringing one of the large pieces of equipment that she uses to clear out her lungs as a demonstration aid during her speech.

Problems and Lessons Learned

Scheduling meetings for three full time professors and community partners was difficult and future projects would be simplified by using a time management program. An unanticipated problem involved confusion regarding discipline jargon, requiring the participants to learn to both speak in unfamiliar terms and to alter and adapt their own means of communication in order to lessen misunderstandings and "misspeak" moments. Different disciplines also have different goals and expectations in that what was "good enough" for one professor was not tolerable for another. The interaction among such disparate disciplines increased the professional standards for the three faculty and their students while facilitating communication with those uninitiated to the field. This finding should prove useful to all involved in their day-to-day interactions beyond the educational realm.

While eventually proving to be only a minor glitch, the Communication Studies/Biology student 30-minute interviewing section of the project was completely chaotic as the biology students had not anticipated or prepared for the types of questions asked by the communication studies students. Few of the Communication Studies students managed to glean useful interviewing responses from their assigned team of Biology students. In order to maximize the value of the information and the ease of its exchange between classes meeting at different times, the next year's project used taped information from biology students designated by topic, accessed by communication studies students from the library reserve desk.

Conclusion

This section of the region of Appalachia has low education levels, scarce sources to gain mid-range or high-income employment, and no public transportation at all. At this regional university campus, most of the students are first generation college students whose parents hold high school diplomas as their highest educational level and whose grandparents generally completed only the 8-10th grades. Area businesses do not rely on the local residents having more than a high school diploma to be eligible for the jobs within the

companies. Low education level and entry-level pay for local jobs creates financial and informational gaps with regard to medical issues and treatments. The difficulty of finding the means and personnel for transporting CF families to medical facilities is further complicated by the great distance to the nearest CF treatment center, in turn creating a deep crevice in access to health care providers for treatment of the disease. An important additional concern is the stigmatization of living with CF, primarily due to lack of information about the disease.

Now however, no less than 172 students have accurate information about CF and its impact on persons' lives. Most of the biology students hope to enter the nursing field and may encounter persons affected by CF in the future. As a service-learning project, we have served the needs of an under-represented population and brought their story to a large population of students. As least some of these students will have increased understanding and empathy for those people who are generally ignored by society as being too few in number to be considered important in this increasingly callous age that values the cost to benefit ratio over individuals' lives. There is some antidotal evidence that compassion and understanding has indeed been imparted at a beginning level as evidenced by classroom talk and the passion (exhibited by the extra out-of-class time) the students demonstrated to produce a play called "A Life with Cystic Fibrosis."

The increased level of information students received traveled beyond them into their circles of influence. All have families and friends whom they texted, tweeted, and facebooked about this topic and further, into their social network of other "friends" of friends on Facebook who read the postings "on the wall." The exponentially expanded explosion that is truely social networking shows the promise of civic engagement within their community and demonstrates hope for acceptance of patients living with CF in spite of the location within the Appalachian region that is isolated from easily accessed urban resources.

With this project completed, the authors continued the concept to the next year with the theme of domestic violence. The students from the domestic violence project gave speeches to students at the local junior and senior high school health classes that generated a greater number of audience members than the cystic fibrosis project.

Future themes will cover prescription drug abuse and obesity. Both themes are extremely serious health issues for this area that need to be more attention on the after effects and costs to the person and society. To highlight one concern at a time is useful as to not overwhelm but to help the public become aware of the health consequences directly.

The authors' goals to inform and educate were met when the community partner thanked the university in a letter addressed to the three professors and their students in raising awareness about the CF fundraising events.

References

A.D.A.M. Medical Encyclopedia. (2012). *Cystic fibrosis*. Retrieved April 2, 2012 from http://www.nlm.nih.gov/medlineplus/encyclopedia.html

Appalachian Ohio. (2012). Retrieved February 17, 2012 from http://www.firstohio.com Appalachian Regional Commission. (2012a). *Counties in Appalachia*. Retrieved February 16, 2012 from http://www.arc.gov/appalachian region/Ohio.asp

Appalachian Regional Commission. (2012b). *Maps of Appalachia*. Retrieved February 16, 2012 from http://www.arc.gov/maps

- Aronson, J.K. (2006). Rare diseases and orphan drugs. *British Journal of Clinical Pharmacology* 61, 3, 243-245.
- Cystic Fibrosis Foundation. (2010a). 2010 *Annual Report*. Website viewed February 15, 2012 at www.cff.org
- Cystic Fibrosis Foundation. (2010b). Find a chapter. Retrieved February 18, 2012 from http://www.cff.org/aboutCFFoundation/Locations/Find/aChapter/index
- Degelman, C. (2000). Fostering civic responsibility through service learning. Website of National Service Sources viewed February 14, 2012 at http://www/nationalservicerosources.org/
- Drumm, M.L., Konstan, M.W., Schluchter, M.D., Handler, A., Pace, R., Zou, F.,
 Zariwala, M., Fargo, D., Xu, A., Dunn, J.M., Darrah, R.J., Dorfman, R.,
 Sandford, A.J., Corey, M., Zielenski, J., Durie, P., Goddard, K., Yankaskas, J.R.,
 Wright, F.A., Nowles, M.R., Gene Modifier Group. (2005). Genetic modifiers of lung disease in cystic fibrosis. New England Journal of Medicine 353,14, 1443-1453.
- Evers-Kiebooms, G., Denayer, L., Welkenhuysen, M., Cassiman, J. & Van den Berghe, H. (2008). A stigmatizing effect of the carrier status for cystic fibrosis? *Clinical Genetics* 46, 5, 336-343.
- Farrell, M.H., LaPean, A. & Ladouceur, L. (2005). Content of communication by pediatric residents after newborn genetic screening. *Pediatrics* 116, 6, 1492-1498.
- Haddow, JE. Palomaki, G.E., Bradley, L.A., & Doherty, R.A. (1998). Letters to the editor on screening for cystic fibrosis. *The Journal of the American Medical Association* 279, 14. 1068.
- Holmes, J. (2010). "Cystic Fibrosis Awareness Presentation", December 6, 2010. Sugarcreek, OH: *The Bargain Hunter*.
- Kramarae, C. (1981). Women and men speaking. Rowley, MA: Newbury House.
- MapQuest. (2012a). Website of maps and distances. Retrieved April 4, 2012 from http://www.mapquest.com.
- MapQuest (2012b). Retrieved April 28, 2012 from http://www.mapquest.com/directions.
- Mullet, M. (2010). Lecture on CF as a person living with CF. October 10, 2010 at Kent State University at Tuscarawas, New Philadelphia, OH.
- Rogers, E.M. (1983). Diffusion of Innovations. NYC, NY: Free Press.
- Times-Reporter Staff. (2010). "Events to Do" on December 9, 2010. New Philadelphia, OH: The Times Reporter.
- Torpy, J.M, Lynm, C., & Glass, R.M. (2009). Cystic fibrosis. *Journal of the American Medical Association* 302, 10, 1130.
- U.S. Government. *U.S. Census Report of 2010.* (2011). Washington, D.C.: U.S. Government Printing Office. Website viewed on February 15, 2012 at http://www.2010.census.gov/
- Verderer, R.F, Verderer, K.S., & Sellnow, D.D. (2012). COMM2. Boston, MA: Wadsworth.
- Wilford, B.S. & Fost, N. (1990). The CF gene: Medical & social implication for heterozygote detection. *The Journal of the American Medical Association 263*, 20, 2777-2783.

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