

INTERNATIONAL MEDICINE RESEARCH

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To know or not to know: Disclosure of terminal illness status to cancer patients in South Korea

Introduction:

Most Western physicians and patients believe as ethical the idea that patients deserve to know their diagnosis. Disclosure of terminal illness is believed to be critical for patient input in their medical care and the decision-making process from that perspective.¹⁻³ Patient awareness of terminal illness has been shown to help maintain patient autonomy in medical decision-making. Failing to disclose terminal illness may inhibit open discussion of best care options and can lead to increased disagreements in care.⁴ Most patients in Korea indeed prefer to be involved in making medical decisions; however, there is still a significant minority – nearly 30% – that prefers not to be involved.⁵ This may reflect a cultural trait, in which Korean, and East Asian cultures in general, entrust their families or physicians with treatment decisions.⁶⁻⁷ We expect that most patients and caregivers will prefer patient involvement in decision-making.

Specifically within the field of oncology, 80% of Korean physicians preferred to disclose a patient's terminal cancer to the patient,⁸ and almost all patients and caregivers believed that patients should be informed of terminal illness.⁹ A basic reason cited was that the patient should have a right to know the truth about their medical condition. Other reasons mentioned included resolving unfinished business, taking appropriate care of themselves in cooperation with healthcare professionals, and relieving themselves and their families of the burden of useless treatments.⁹ Whether the patient paid for treatment costs also played a factor in preferences in disclosure. Patients and family caregivers are more likely to prefer disclosure of terminal illness if the patient is paying the treatment cost, highlighting the economic burden of disease.¹⁰ We hypothesize that the majority of families and physicians who disclose terminal illness do so on the grounds of the patient's right to know the truth.

However, there are some patients, families, and physicians who prefer not to disclose a patient's terminal status. Some families and physicians may protect patients from the bad news to give them hope for the future. Telling them the bad news might discourage the patient from fighting the disease. Patients who object to being told the truth reflect this idea, viewing the

disclosure as meaningless and conveying a sense of helplessness.^{9, 11} A cultural perspective on nondisclosure unique to Asian cultures is that the sense of filial responsibility may lead to family members keeping burdensome information from patients and making end-of-life decisions on behalf of the patient.¹² We hypothesize that caregiver families who choose not to disclose terminal illness will express desires to protect the patient, but will express anxiety that the patient will find out about their terminal status.

Despite the general recommendation of disclosure, the true rates of disclosure of terminal illness in Korea are not as unanimous. One study by Yun et al (2010) reported that only 58% of patients in an oncology ward and 83% of family caregivers were aware of the patient's terminal status. This study also reported that 30% of patients who were not told of their terminal illness eventually correctly guessed it from their worsening condition.¹⁰ Another study by Ahn et al (2013) reported that roughly two-thirds of terminal patients admitted to palliative care services in Korea were aware of their terminal illness.⁴ These rates were, however, actually higher than in some Western studies, where the percentages were 30-40% for patient awareness, and 80% for family caregivers.¹³⁻¹⁶

Patient emotional responses to learning of terminal illness are varied, ranging from sadness, depression, grief, denial, anger, stress, fear, worry, guilt, regret, and loneliness. Interestingly, the manner in which the bad news is learned has an effect on the emotional response. Patients who learned of their terminal status indirectly, whether by chance or by guessing from their own worsening condition, experienced more severe distress and lower quality of life.¹¹

Objectives:

This study aimed to investigate motives for disclosure or nondisclosure of a patient's terminal illness status in South Korea, and the emotional outcomes of disclosure or nondisclosure. The research questions specifically investigated were: 1) What are the primary driving factors for caregivers and physicians disclosing or not disclosing a patient's terminal status in South Korea? 2) What are the decision-making dynamics among terminal patients, caregivers, and physicians in South Korea? 3) How does disclosure or nondisclosure of terminal illness to patients impact the patient-family relationship within this setting?

Anticipated motives for disclosure of terminal illness include families' and/or physicians' belief in the patient's right to know of terminal illness, the desire for the patient to be a part of his/her own medical decision-making process, and a necessity for dialogue on end-of-life arrangements. Motives for nondisclosure may include protection of the patient against bad news or an unhappy death. For patients who know of their terminal status, decision-making was anticipated to be a mutual and equitable process among all three parties involved; conversely, it was predicted that the families of patients who are unaware of their terminal status would be the primary decision-makers. From the Western perspective, it'd be expected that the majority of patient-family relationships would not be negatively impacted by disclosure of terminal illness, but that nondisclosure may lead to anxiety for those caregivers who choose not to share that information with their patients.

Results:

Results were divided into four broadly themed categories – disclosure, decision-making, relationships, and patient age.

Disclosure

As expected, common reasons cited by physicians, caregivers and patients in favor of disclosure of a terminal cancer patient's terminal status were of the patient's basic right to know his/her own health situation, patient participation in treatment and medical care, and necessary preparations for the end of life.

All physicians who were interviewed believed that terminal patients should eventually receive the news that they are indeed terminal. Most physicians preferred to disclose a patient's terminal status to the caregiver first, citing an implicit duty of the caregiver to be the ultimate decision-maker on whether to disclose to the patient or not. The most difficult aspect of disclosure commonly noted was the idea that the physician was delivering emotionally damaging news; several physicians even felt a personal responsibility for the failure of cancer treatment. Physicians also mentioned examples of patients who, when not told of their terminal status, probably guessed it anyways from their declining health.

Caregiver opinions on whether to disclose or not varied. Reasons cited for non-disclosure included a potential loss of hope for a patient still receiving treatment, and unnecessary stress/burden. There were several instances of non-disclosure only initially – a unique reason cited was a lack of courage on the part of the caregiver. Several caregivers, whether or not they disclosed immediately or after a prolonged duration, requested the physician to disclose a patient's terminal status. Of note, a particular difficulty cited of non-disclosure was that caregivers emotionally suffered when the patient was in pain but was unaware of the cause.

All patients interviewed were fully aware of their own terminal status. Several patients mentioned that they found out by “accident” – they either guessed their condition or overheard a conversation revealing their terminal status. Most patients were in favor of knowing of one's own terminal status. One particularly revealing reason cited in favor of disclosure was that a patient wanted to mentally “control” the disease and more actively fight it in a psychological capacity. This seemingly contradicts a preference of caregivers not to disclose out of fear that the patient would lose hope or give up on any treatment they might still be receiving.

Decision-making

Physicians generally regarded their role in end-of-life (EOL) decision-making to be one of explaining all treatment and/or palliative options and recommending a best course of action. Caregivers and patients were in unison regarding their perceived roles in a patient's medical care. With respect to palliative options, such as whether to leave the hospital or enter hospice, patients were the decision-makers if they knew of their own terminal status; when patients were unaware

of their terminal status, caregivers tended to take the dominant role in medical decision-making for the patient.

Regarding continued treatment, caregivers and patients tended to defer to the recommendation of the physician. A common theme was that caregivers and patients lacked the medical knowledge to seek an alternative, with several patients even expressing dissatisfaction at the gulf of knowledge between physicians and caregivers/patients. As one interviewee noted, “doctors are the law. We do as they tell us.” Non-informed medical decision-making seemed to be the prevailing theme with regards to treatment.

Relationships

Physicians expressed regret at the tenuous physician-patient relationship in situations in which the patient was unaware of his/her terminal status. Physicians felt that they were not able to have an honest conversation with these patients, having to provide roundabout explanations to questions that patients might have.

Patients and caregivers expressed significant frustration at both the Korean medical system and at physicians for inaccessibility. As the time allowed for patient visits at many major hospitals is about five minutes, patients and caregivers alike felt that they received insufficient detail about the patient’s status throughout the disease process. In addition, they were unable to have questions about the patient’s medical care answered, compounding the paucity of medical information available to patients and caregivers.

Patient age

Physicians noted a greater tendency of caregivers to hide a patient’s terminal status with older patients – specifically when the caregiver was the child of the patient. Some possible reasons suggested by physicians were that the emotional trauma experience by older patients would be overwhelming, that patients would be unnecessarily burdened, older patients’ mental incapacity to understand diagnosis, and protection of parents from bad news as a manifestation of filial piety. A majority of caregivers indeed reflected these physician views. Several physicians also noted that both patients’ and caregivers’ emotional reactions to hearing news of terminal illness were more muted for older patients, possibly a reflection of death being less unexpected at an older age.

Conclusion:

While interviewed patients and physicians were near-universal in their opinions that the patient should know of his/her own terminal status, the ultimate decision of disclosure in South Korea is the responsibility of the caregiver. Caregiver responses suggest that this decision is a case-by-case one, with a multitude of relevant factors. Interviewees acknowledged that a patient’s age was a major consideration in the decision to disclose, and also influenced reactions thereafter. Interviewees revealed that the Korean healthcare system greatly impacts medical knowledge available to patients and caregivers, and thus end-of-life and treatment decision-

making. These influences notwithstanding, patients' experience of terminal cancer and role in their own medical care rests largely on caregivers' decisions to disclose or not.

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INTERNATIONAL MEDICINE RESEARCH

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ASSESSING CLINICAL IMPROVEMENTS OF RECONSTRUCTIVE SURGERY IN PATIENTS WITH ADVANCED SPINAL DISEASE IN ETHIOPIA

Abstract:

Spinal deformities due to congenital defects and / or TB or HIV infections pose a challenging public health issue for patients in developing nations such as Ethiopia. These abnormalities can lead to decreased lung function, inability to perform physical tasks, and social stigmatization for those afflicted. Surgical procedures have been shown to be effective in improving clinical outcomes for these patients; however, a systematic analysis of patient's perceptions on surgical outcomes is lacking. In this prospective cohort study, students from the University of Rochester administered a questionnaire to 77 post-operative spine patients seen by Dr. Rick Hodes in Addis Ababa Ethiopia (36 in the summer of 2013, and 41 in the summer of 2014). Preliminary data showed that patients (average age 16.3 years \pm 2.8 years) who had a surgical spinal procedure on an average of 15.6 months (\pm 7.3 months) before enrollment reported improvement in terms of self-perception of health, ability to perform daily activities, and decreased pain interference during the day and while sleeping. This study aimed to show how, and by how much, post-operative spinal patients' lives have changed since their surgery.

Background / Introduction:

Ethiopia, Africa's second most populous country, has a disproportionately high incidence of communicable diseases due to the public health challenges faced by its predominantly impoverished population. This includes poor access to safe drinking water and proper housing, as well as poor food sanitation¹⁰. As a result, incidence rates of malaria, HIV, and tuberculosis (TB) have continued to increase over the past decade. In particular, TB has become a growing public health concern in the country, with the World Health Organization (WHO) estimating a prevalence of 210,000 (170,000 – 250,000) affected individuals and a mortality rate of 18 per 100,000 individuals in 2012¹¹.

While TB typically affects the lungs, the bacteria can also invade and inflame the intervertebral joints of cervical and upper thoracic regions of the spine. This can result in a severely crippling spinal deformity called Pott's disease, manifesting as vertebral collapse and, if

left untreated, kyphosis. While this condition occurs in approximately 1% of patients with TB, the steady rise in prevalence of TB in developing nations makes this disease a growing global health issue^{5,9}. Moreover, as one meta-analysis suggests, other causes of non-traumatic spinal cord injuries (NTSCI) disproportionately affect Ethiopians including those caused by congenital defects, HIV infection (17% of the total NTSCI's studied), tumor-related / degenerative cases (22%) and myelitis (4%)⁸.

Suggested indications for surgical intervention for patients with Pott's disease and other non-traumatic spinal cord injuries include neurological deficits due to compression of the spinal cord (present in 10-43% of patients), spine instability due to a kyphosis exceeding 40 degrees, resistance to TB drugs, and paraplegia⁹. A retrospective study investigating data from 694 patients in Turkey with Pott's disease found that decompressive surgery plus anti-TB chemotherapy remains the best mode for treatment of the disease¹². In patients with less severe cases (i.e., without neurological disorders and a kyphosis less than 30 degrees), indications for surgery are not as clear. In one retrospective study, 70 cases of adult patients with spinal TB not associated with kyphosis or neurological deficits in India were reviewed, and 69 out of 70 patients were successfully treated with conservative medical therapy alone⁷. Moreover, the literature on surgical management of Pott's disease in children is mostly limited to retrospective case studies. One retrospective study reviewed 64 pediatric patients who were treated surgically for Pott's disease found that 72% of subjects improved in grade according to the Kumar and Kalra clinical scoring system, while 28% remained constant or worsened in grade following surgery⁴. The need for prospective, observational data assessing post-surgical outcomes in both pediatric and less severe adult cases of Pott's disease is evident.

Dr. Rick Hodes, a University of Rochester alumnus, has been working in Addis Ababa, Ethiopia for the past two decades and is currently the senior consultant at a Catholic mission dedicated to treating patients with a variety of diseases, including TB-induced kyphosis. Dr. Hodes utilizes surgical interventions to treat patients with advanced forms of this disease, and the patient testimonials, as well as before and after images (see Figure 1), clearly show how this treatment has positively impacted patients' quality of life and overall daily functioning³. However, a systematic, scientific analysis of the clinical outcomes experienced by these post-operative patients is lacking.

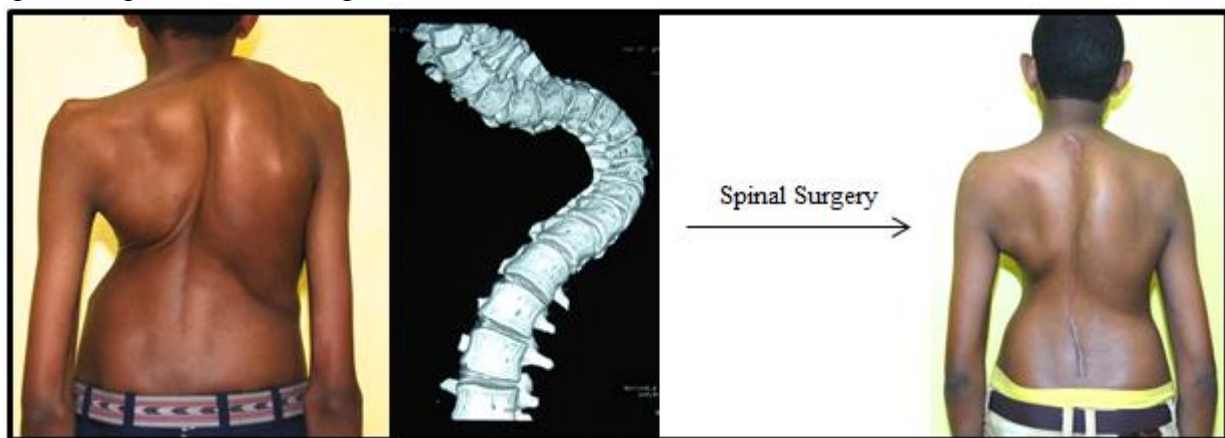


Figure 1: Typical spinal patient pre- (left two images) and post-surgery (right image)

Objectives:

The primary aim of this prospective cohort study was to quantitatively assess the clinical outcomes of reconstructive spinal surgery performed on Dr. Hodes' patients with severe spinal disease in Addis Ababa, Ethiopia, utilizing a self-administered questionnaire developed in the summer of 2012. We sought to examine how this clinical intervention affected a patient's quality of life, physical and psychosocial function, sleep hygiene, and neurological function.

Methods:

Eligible patients were identified using the clinic's database of all postoperative spine patients. Patients were ineligible if they were under 8 years old and / or had surgery less than six months ago. They were called and asked if they would be willing to return to clinic to learn about and potentially participate in the study. The study was explained and informed consent obtained before enrollment. Surveys were administered by the researchers, translated with the help of a volunteer at the clinic, and filled out individually by the subjects.

Our survey, the 'Preliminary Retrospective Questionnaire: Post-Kyphoscoliosis Corrective Surgery', was developed in 2012 and consisted of 29-items modified from the SF-36⁶ and SRS-22¹ surveys. This modified survey, which was translated into Amharic, aimed to quantitatively assess improvements in quality of life and general physical/psychological functioning of patients who have received corrective spinal surgery. The questionnaire was broken down into seven broad categories: 1) general improvements since the surgery, 2) limitations of activities, 3) effect on work or other activities, 4) pain, 5) feelings/emotions, 6) sleeping, 7) neurologic function, and a final open ended response asking the subject to 'list suggestions for improvement on your medical care.' Categories 1 through 7 utilized an ordinal scale.

Survey responses were entered into and analyzed in Microsoft Excel. Frequency distribution of subject age, gender, time since surgery, previous TB treatment, and response to questions was calculated. Scoring of modified responses to the SF-36 and SRS-22 items were performed following previously established guidelines^{1,6}.

Results:

Demographics

During the summers of 2013 and 2014, 79 patients were enrolled into the study. Two were excluded from analysis since they were younger than 8 years old. Of the 77 eligible participants, 48% (n=37) were male with an average age of 16.9 years (SD = 3.3 years). 83% (n=64) had spinal surgical procedures performed in Ghana, Africa, 12% (n=9) had spinal surgical procedures in Ethiopia, Africa, and the remaining 1% (n=4) had surgeries in other locations (Dallas, TX or Vancouver). The average time since surgery upon study enrollment was 26 months (SD=24.7 months) and 10% (n=7) of patients had received TB treatment prior to study enrollment.

Demographic	
	<i>Mean (SD)</i>
Age	16.9 (3.3)
Time since surgery (months)	26.0 (24.7)
	<i>Percent (n)</i>
Male	48.1% (37)
Previous TB Treatment	9.9% (7)
Surgery in Ghana	83% (64)

Table 1: Participant demographics

Survey Responses

According to survey results, 77.6% of participants reported very good to excellent health, and 92% reported their health is somewhat to much better now than before surgery. Similarly, 71.4% reported a lot of change in the shape of their backbone and 100% reported somewhat to a lot of change in their backbone as compared to before surgery. The mean responses for selected questionnaire items are given in Table 1. Patients reported that their health, ability to bath and dress self, shortness of breath while performing tasks, and the amount of bullying or teasing they received due to their deformities all on average much better than before surgery and pain interference with daily activity and ability to sleep without back discomfort was somewhat better than before surgery.

Response	Mean (SD)
Self-perception of health as compared to before surgery	1.3 (0.7)
Ability to bath or dress self	1.2 (0.5)
Shortness of breath after surgery	1.4 (0.7)
Pain interference with daily activities	1.6 (0.9)
Amount of bullying/teasing experienced	1.4 (0.7)
Ability to sleep without back discomfort	1.6 (0.9)

Table 2: Mean participant response regarding change in overall health, pain, and social experiences since before surgery. Scale: 1 = Much better now than before surgery, 2 = Somewhat better now than before surgery, 3 = About the same, 4 = Somewhat worse now than before surgery

Interestingly, there was a significant decrease in shortness of breath while performing tasks ($p < .0001$) and a significant decrease in sleep interference due to back pain ($p = .0014$) compared to before surgery. While patients on average reported less bullying compared to before surgery, the change was not significant.

Conclusions:

This study provides insight into spinal patients' perceptions of their health and clinical outcomes following a spinal surgery procedure in a third-world setting. Overall, these patients have shown improvement in their health, a decrease in their physical pain, and improvements in their spinal shape. Ideally, this quantitative analysis can provide physicians and surgeons with a deeper understanding of expected clinical outcomes when treating spinal deformities with surgical therapies and shed light on patients' experiences before, during, and after their surgeries.

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INTERNATIONAL MEDICINE RESEARCH

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Needs Assessment and Piloting of Adolescent Sexual Health Intervention in Yantaló, Peru

Background:

Yantaló is a small, jungle community in the San Martin region of Peru with limited access to health care and a corresponding lack of resources to address public health issues such as the high prevalence of STIs and adolescent pregnancies. Dr. Luis Vasquez founded the Yantaló Peru Foundation with the intention of increasing Yantaló's access to health care as well as catering specifically to the health needs of the community. As part of this goal, he hopes to provide sexual health education classes geared especially towards the young adult subset of the population. Research on sexual health educational interventions has shown that interventions can have behavioral impacts on participants when the interventions have clear messages that are reinforced and culturally informed. These behaviors can include delayed sexual intercourse initiation, decreased sexual risk behaviors, increased contraceptive use, and reduced incidence of STI transmission and unwanted pregnancies.

Objectives:

The objectives of our sexual health education study in Yantaló were to qualitatively assess the baseline sexual health knowledge of our adolescent target population, to establish a framework for teaching sexual health in the new clinic in Yantaló, and to pilot an easy-to-use and effective curriculum for sexual health education that would continue to be used after we left.

Methods:

We taught ten 90-minute sexual health workshops in the local secondary school, Colegio Dionisio Ocampo Chavez, to approximately 280 students. Seventy of these students between the ages of 12 and 17 were enrolled in our research study. In order to participate in the study, participants needed to have a completed permission form from their parents, to sign the assent form provided to them at the beginning of our workshop, and to complete both a pre-workshop survey and a post-workshop survey which provided us with information about the participant's demographics as well as their level of sexual health knowledge. All of the data were de-identified

and each permission form, assent form, and survey was linked with a unique participant number to allow for paired analysis and tracking of study forms. Data forms were stored in a locked room when not being used.

The sexual health workshop was composed of 10-15 minute block lessons covering topics including sexual anatomy and physiology, safe sex practices, STI information and prevention, contraceptive use, and a condom demonstration and practice activity. The first 15 minutes of each class were used to give information about the study, obtain consent, and administer the pre-survey, and the final 15 minutes were used for the post-survey and to answer anonymous questions about sexual health written on notecards distributed at the start of the class.

Results:

Quantitative results are still pending. Qualitatively, many adolescents enjoyed the use of visual diagrams and hands-on activities included in the class. They also responded with thoughtful and persistent questions during the final anonymous question-and-answer time at the end of class. In the lower grades, we were not allowed by the school to do a formal condom demonstration and we received several questions as to whether one could get diseases from using condoms, etc. Both students and teachers asked questions concerning STIs and expressed interest in further instruction on the subject.

Conclusions:

Initial analysis demonstrates the importance of teaching about sexual anatomy, sexually transmitted infections, and contraception to adolescents aged 12 to 17 in Yantalo, Peru. Older children generally demonstrated limited knowledge of these three areas despite a concrete sexual health curriculum in school. The largest deficits were seen in anatomy, while the greatest interest and the majority of anonymous questions concerned contraception and condom use. There were also significant deficits in knowledge about STIs which led to increased interest and frequency of questions both during this lesson and in the anonymous question-and-answer portion of the class.

Overall, after the workshop, students showed modest gains in knowledge based on test parameters. Barriers to the workshop's effectiveness included using a short answer test format, as well as limited time in a 1.5 hour class. In order to assess the effectiveness of this workshop, we would recommend changing the format of the surveys to be multiple choice (to achieve a higher response rate) and to change the content of the questions to see if the participants understand and have mastered the most critical learning objectives. If implemented, the alterations to protocol could ensure that comparing the pre-test and the post-test could be an evaluation method of the curriculum and format. We also recommend completing all forms of consent / assent and any IRB form tracking prior to class times.

The goal of our single class curriculum was to teach critical concepts, skills, and information about reproductive health including recognizing common signs and symptoms of STIs and how to access appropriate medical care, which types of contraceptives are effective and how to use them, and how to have consensual and safe communication in a relationship. If the course accomplished these goals, it can be used by volunteers to teach in rural schools or clinics to impart critical knowledge along with an anatomical and physiologic context while

simultaneously allowing for greater access to the workshop by limiting it to a single instructional period.

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INTERNATIONAL MEDICINE RESEARCH

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Perceptions of Food Inequality and Community Interventions in Rural Malawi

Introduction

Food insecurity, defined as existing “when all people at all times [do not] have access to sufficient, safe, nutritious food to maintain a healthy and active life,” has been an issue for many countries in Sub-Saharan Africa (1). In Malawi, food insecurity became a serious issue in the early 2000s as the result of growing problems that had been building since the early 1980s (2). Several reasons have been proposed to explain the food insecurity problem, including farming practices, political policies, agricultural issues, and a high dependence on foreign aid (3). This food crisis has had a large effect on the overall health of the country. The country has a high infant mortality rate of 53 deaths per 1,000 births, as well as a low life expectancy at birth (54 years) (4). Additionally, Malawi also has a high adult prevalence of HIV, affecting 10.0% of the population.

In the last decade, the food insecurity problem in Malawi has gained the world’s attention and international efforts have begun to try and improve the situation. However, the implementation of these efforts has struggled greatly over the past decade. One of the many problems faced is the lack of planning and research to address the root of the issue. One study writes, “Humanitarian assistance has become the *de facto* policy of a world that is unwilling to take decisive action to address the underlying causes of global poverty...Providing humanitarian aid is at best a small part of what we should do to address the plight of the poor. It is not the solution to global poverty” (5). Studies have only recently begun looking at how to solve the actual problem of famine, both globally and specifically in Malawi. These studies have shown that the problem is not simply that governments do not have enough funds. In fact, giving funds directly to the government has been shown to be ineffective and sometimes detrimental due to government corruption and the lack of knowledge of what to do with these funds (5). Programs also often focus on interventions that are easier for aid workers, rather than providing heavier emphasis on cultural norms. Messer and Shipton write, “The question throughout Africa is not just how to ensure that Africans produce more food, but how to help ensure that people in Africa

have the means to acquire food and other necessities by their own chosen means” (6). Specifically, practices and resources that already exist in the community must be examined. As rural communities make up 80% of the population in Malawi, proper research, must involve going into these rural communities, examining the normal practices, and begin learning cultural norms within the community. Then, these normal practices should be examined in a more holistic approach, looking at the overall trends within the community. Only after this has been completed can aid workers begin implementing new strategies and practices that can become part of everyday life within the community (8). This approach will lead to a more sustainable intervention, ultimately decreasing a community’s reliance on international aid.

Objectives

We focused on the perceptions of individuals residing in the community. The purpose of this research project included three major objectives. First, we looked to identify perceptions directed towards the timeframe of food insecurity. Next, we wanted to identify available assistance currently in place among community members. Lastly, we wanted to determine perceptions of community food insecurity vs. individual household insecurity.

Methods

The survey was administered in several villages in the Ntcheu district of Malawi between June and July of 2014. Food insecurity levels and perceptions were measured based on a four-page survey. The survey was translated from English to Chichewa by a translator on site, and then back translated by a second translator to ensure consistency in wording. The first section of the survey was ten questions that asked about food insecurity perceptions at both an individual and community level. The same ten questions had been asked to the participants at two prior timeframes (January/February 2014 and June/July 2013). The second section focused on collecting qualitative information regarding an individual’s experience with food insecurity. Individuals were also asked about their food insecurity perception scores from the two previous timeframes in relation to the third collection. The third section consisted of diet diversity questions. The final section collected income and employment information for the household. Questions for the survey were developed from current research literature on the topic.

Forty households were surveyed, and were drawn from a sample of ninety individuals that had been interviewed during previous timeframes. Inclusion criteria required that the individual surveyed must be considered the head of household, and a minimum age of 18. Participants were selected based on convenience sampling, requiring that they were at home and available to sit for an interview. The survey was read orally in Chichewa by a translator, and then responses were orally translated back to English for the interviewers. Responses were hand recorded on the surveys.

Results

Results of the study are pending. Current analysis shows that individuals perceive themselves to be less food insecure than the community (based on quantitative scoring through survey questions). This has been consistent between the dry and rainy seasons. Analysis from the qualitative section of the survey indicate that a variety of factors influence participants’ responses. Common themes from the qualitative questions include ganyu (working in neighbors’ fields for food or money), planning, family, coping mechanisms, and preventative mechanisms.

Conclusion

Food insecurity is a complex problem, with a variety of contributing factors. As such, these factors must be considered when trying to define a population as food insecure. This is especially true when determining if a household is food insecure. Heads of households may state they are less food insecure than others in the community, but could still be food insecure and in need of assistance. Current and future interventions must take this into account before implementing new strategies and programs in Malawi.

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Local Community Response to a National Public Smoking Ban in Ladakh, India

Introduction

While tobacco control has seen great international success as a public health measure over the last 5 decades, India is expected to lose more than 1.5 million lives per year due to tobacco (ITC Project, 2013; Ng, et al., 2014). Recently, India has actively engaged in tobacco control efforts and is considered an international leader in tobacco control policy. In 2008, the government enacted a nation-wide ban on public smoking (ITC Project, 2013). Nevertheless, the in-country diversity makes it challenging to create acceptable programs for the variety of specific, local populations. The region of Ladakh is one such population area in India.

Objectives

This project investigated a local public response to a national ban on smoking in public areas in Ladakh, a culturally diverse and geographically remote region of Northern India. This mixed methods community-based participatory research explored knowledge and attitudes, observed enforcement, and perceived harms and benefits of the ban through quantitative survey and in-depth qualitative interviews. The research is hypothesis generating rather than hypothesis testing and will be useful in informing tobacco control experts in India of the scope of reactions nationally, as well as guiding collaborating partners in Ladakh in the local enforcement and supplementation of this policy.

Background

The 2008 ban is not well known among certain sub-populations of the Ladakhi community – specifically tourists and merchants – and is inconsistently enforced (Dara et al., 2012). Other findings beyond Ladakh show “systematic heterogeneity in the attitudes and behaviors of smokers and non-smokers” regarding tobacco control policy (Poland et al., 2000). This work suggests that distinct patterns can be used to design specific interventions for different types of smokers and non-smokers, and calls for further research to investigate the heterogeneity of attitudes regarding policies and behaviors towards them. Further, these findings have significant implications and raise interesting questions about how public knowledge and attitudes may affect local implementation of a national policy, and how this affects community members. How national policies are practiced on the local level and supplemented with community-based interventions requires empiric data and calls for a community-engaged approach of investigation.

Ladakh, India lies in the mountainous northern province of Jammu and Kashmir, and was extremely isolated until the later half of the twentieth century when it saw a large increase in basic infrastructure and tourism. The rapid development of Ladakh has had major effects on

public health, including an increase in access to biomedical care, but also to harmful goods like tobacco. Ladakh's unique path of development raises interesting questions regarding how a national tobacco control policy might be played out on the local level. After rapid globalization occurred in the 1970s, a Ladakhi movement for regional political autonomy began. Some outside observers characterize this movement as a local fight against the damaging influence of Western development, while others argue that it embraces development and seeks to fight instead against the state government, which holds Ladakhi development back (Norberg-Hodge, 1991; van Beek, 2000; Chin, Dye & Lee, 2008). These complex political factors are further complicated by the Ladakhi economy's reliance on tourism. Opposing forces of globalization and local autonomy create an interesting environment to explore how national policy inspired by international sanctions (WHO FCTC, 2014) is applied on the local level.

This project explored the local perspective of the national policy in Ladakh, both to gauge its effectiveness and acceptability in the community and to contribute to literature that informs tobacco control experts in India on the scope of attitudes nationally. Data was gathered through survey and interview data using a community-engaged approach that continued the University of Rochester's collaborative partnership with the local health department and hospital. At this point in project development, this work was hypothesis generating rather than hypothesis testing, and will lay groundwork for future research in this area.

Research Design and Methodology

This research used mixed methodology combining in-depth qualitative interviewing with a brief quantitative survey to identify attitudes and awareness regarding smoking policies among people of the general Ladakh population, as well as among itinerate merchants, business owners, other community members and tourists in Leh, Ladakh. Preliminary study findings were presented at the Leh Department of Health before departure from Ladakh.

A critical component of this work was the application of principles of community-based participatory research (CBPR) to project development and implementation. CBPR is a collaborative approach that actively engages communities in a research process, utilizing the unique strengths of communities and academic institutions in the process and outcomes of research (University of Washington, 2013). It is specifically well designed to study and develop solutions to health care issues within the context of social, political and economic systems (Israel, Schulz, Parker & Becker, 2001). As a part of the application of these principles in my research, I hired a local Ladakhi college student, Punchok Namgial, as a research assistant. This gave my work a more authentic cultural context and increased research capacity in Ladakh.

Survey Protocol

The survey instrument was adapted from an existing instrument used by the International Tobacco Control (ITC) Policy Evaluation Project (ITC Project India Surveys, 2013). ITC is a partnership between international health organizations and policymakers in over 20 countries, including India, whose goal is to measure the psychosocial and behavioral effect of national level tobacco control policies (ITC Project, 2013). Survey questions used as a template are from the tool used in four states in southern India, which is specifically designed for Indian populations. Finalized questions were developed in collaboration with partners at the Leh Department of Health and Punchok Namgial, the study's hired research assistant.

A convenience sample of 52 adults were surveyed, including shop owners, restaurant managers, taxi drivers, tourists, Internet café managers, and local people in the streets of Leh.

Surveys were administered in English, the common language of tourists, businessmen, and professional Ladakhis, and responses recorded by myself with pen and paper. The hired research assistant, who is tri-lingual in English, Hindi and the local language of Ladakhi acted as a translator when necessary. Data was entered into an Excel spreadsheet on a password protected computer, and analyzed using the statistical program R.

In-depth Interviewing Protocol

10 in-depth interviews were conducted. Interviews were conducted in English when appropriate and the research assistant translated in the local Ladakhi language and Hindi when needed. Informants were recruited using purposive sampling. Interview questions explored general knowledge and attitudes, observed enforcement, and perceived benefits and harms regarding the ban, and were developed in collaboration with the Leh Department of Health and Punchok Namgial. Interviews were not recorded.

Results

Data analysis is ongoing, however some preliminary analyses have been completed.

Survey Results

60% of respondents expressed knowledge of the policy banning public smoking. Respondents' perceptions of the existence of smoking policies varied. For restaurants: 57.7% of respondents reported that smoking was banned in all indoor areas, 25.0% reported that smoking was not allowed in some indoor areas, and 3.8% reported no rules or restrictions in restaurants. Respondents answered that smoking should not be allowed in various public places: public transportation (92.3%), hospitals (90.3%), schools (88.5%), restaurants (82.7%), and restaurants (65.3%). 42.3% of respondents believed that smoking should be banned in all outdoor eating areas.

In-depth Interview Results

Many respondents expressed approval of the law and suggested that the local government should enforce the law more strictly. Most respondents expressed that enforcement of the law would help both smokers and non-smokers but few perceive direct harm from second-hand smoke.

Conclusions

The population represented by this sample shows low knowledge of the existence of this policy and reports low observed enforcement, especially in restaurants. However, respondents do express belief that smoking should be banned in many public places. In-depth interviews show that the ban does have support in the community and many respondents recommend stricter enforcement of this policy and express an attitude that the policy must be supplemented with education about the health risks of smoking. Perceptions of second-hand smoke are rare and suggest that community-based education is required to engage non-smokers in advocacy for their own health regarding the enforcement of this policy. Further analysis is ongoing.

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INTERNATIONAL MEDICINE RESEARCH

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Medical, Health Sciences, and Social Work Students' Perspectives on the Health of Disadvantaged Minorities and Community Outreach in Hungary

Introduction:

Despite universal healthcare coverage in many countries of Europe, some populations are still left at the margins and excluded from this basic human right. The Roma remain the most disadvantaged and underserved minority across Europe.¹⁻³ It is estimated that 5-10 million Roma people live in Europe, with the highest concentration living in the Central Eastern Europe countries of Romania, Slovakia, Bulgaria, and Hungary.⁴ The extremely poor health outcomes of the Roma are reflective of their highly marginalized status in society. On average, Roma people have a life expectancy 10-15 years less than non-Roma people in Hungary.⁵ Roma infants in Hungary are twice as likely to be born prematurely and be underweight at birth.⁶ Forced sterilization of Roma women without informed consent is still practiced.^{1,5-7} Furthermore, rates of communicable and non-communicable diseases are significantly higher amongst the Roma than in the general population.^{1,5-7}

These health issues are further exacerbated by their lack of access to education, healthcare providers, and high unemployment rates. The Roma usually reside in very poor, segregated living conditions and face discrimination in the health care system.^{1,4,5} Their communities lack basic sanitation services, adequate housing, and access to health care services. Documented discrimination against the Roma by healthcare providers resulting in significantly lower quality of care has not improved in recent years.^{1,5-7}

In Hungary, the perspectives of medical, health sciences, and social work students regarding the Roma and other disadvantaged minorities have not been studied. Although there has been some investigation of healthcare provider attitudes towards the Roma, there has been no such study of this within the medical student and social work student population. The student participation and/or interest in working with disadvantaged populations is also understudied. These groups of students have a great opportunity and capability to affect change in the outreach to the Roma population and other underserved groups. Medical student-run clinics in the United States have already been successful at providing quality healthcare to underserved and disadvantaged populations.⁸⁻¹⁰ This model may also be applicable to

another context. Furthermore, as shortage of physicians in primary care worsens, the need for students who understand health disparities and how to address them in practice is also paramount. These circumstances lend themselves to an excellent opportunity to examine the perspectives of medical students and social work students in Hungary regarding the health of disadvantaged minorities and community outreach.

Objectives and Hypothesis:

This study aims to quantitatively and qualitatively explore the perspectives of medical student and social work students with regards to the health of disadvantaged minorities and community outreach in Hungary. The research questions that we would like to address are: 1) What is the knowledge of medical and social work students on the health disparities of disadvantaged minorities, specifically the Roma, in Hungary? 2) What is the students' participation and involvement in community outreach with disadvantaged minorities? 3) What do students propose as solutions to the healthcare disparities faced by the Roma and other minorities?

We anticipate that the social work students will have had greater contact and experience with disadvantaged minorities, and thus have a better understanding of the health care issues that these populations face and a greater involvement in community outreach with the Roma and other minorities. We also hypothesize that medical students will suggest different solutions than social work students to remedy the healthcare disparities faced by minorities. We believe that medical students will have had less training in sociological factors of health, and thus be less aware of the magnitude of the effect that they have on the health of a population. Therefore, they may be more likely to emphasize genetic or biological factors of disease and respective treatment. On the other hand, we believe social work students will emphasize the social determinants of health and measures to improve these conditions as a means to better health for minorities.

Methods:

This multi-method approach used surveys and focus group interviews to collect data. The site of the study was the University of Szeged Faculty of Medicine in the Great Southern Plain of Hungary. The subjects of the study were students in their final 3 years of schooling from the Faculty of Health Sciences and Social Studies (in the Social Work program) and from the Faculty of Medicine. The survey was translated by Edit Paulik, M.D., Ph.D. and Andrea Szabo, Ph.D., DrPharm. In addition to approval by the RSRB, the survey was approved by the University of Szeged Ethical Approval Committee. After explanation of the purpose of the survey, paper copies of surveys were distributed to students at the end of the semester and their participation was completely voluntary. Completed and uncompleted surveys were returned to investigators in envelopes. If students were interested in participating in the focus group interview, they were asked to leave contact information on a separate page from the survey.

The focus group interviews were organized with a small number of students who and two investigators. After explaining the purpose of the interview and receiving verbal consent, the interviews were audio recorded. Discussion in the focus group interview revolved around expanding upon topics that were elucidated in the survey. The focus groups will be organized and conducted in accordance with methodology outlined by McLafferty¹⁸ and Kitzinger¹⁹ in their respective analyses of focus group methodology.

Results:

A total of 143 surveys were collected from students of the University of Szeged. Of the respondents, 67% were between the ages of 22-24 (inclusive). The majority of respondents (68%) were female. There were 91 medical students, 31 health sciences students, 18 social work students, and 3 nursing students who completed the survey. Almost all students surveyed were in their 4th year of study (94%) and 67% were Hungarian. A total of 14 students were interviewed for the focus groups interviews.

The results are divided into three sections, corresponding to the three main research questions of this study.

1) What is the knowledge of medical and social work students on the health disparities of disadvantaged minorities, specifically the Roma, in Hungary?

A large majority (75% of respondents) ranked the Roma people as having the worst health outcomes. However, only about half of respondents (51%) indicated that they believed access to healthcare was equal for all people in Hungary. Regarding life expectancy, 80% of respondents indicated that they did not believe life expectancies at birth are the same for all groups of people in Hungary. The majority (67%) of respondents believed that a healthy lifestyle was the most important factor affecting health outcomes, followed by not smoking or drinking alcohol (10%), having a healthy family history and living in a safe neighborhood (both 7%). Only 18% of respondents believed that access to healthcare was the most important factor in disease outcomes for the Roma people.

2) What is the students' participation and involvement in community outreach with disadvantaged minorities?

The majority of students (66%) believed that there were volunteer opportunities at the University, but 41% of respondents believed that there were few opportunities. Despite these opportunities, 85% of students reported never participating in volunteer activities. Furthermore, 69% of students believed that students should be more involved. When asked if they would be interested in volunteering if there were more organized volunteer opportunities, only 9% said they would be very interested and 61% said they would be somewhat interested. When asked about how effective they believed community outreach to be in affecting change, 20% responded very effective and 64% responded somewhat effective. However, 50% of respondents said that addressing healthcare disparities is very important.

3) What do students propose as solutions to the healthcare disparities faced by the Roma and other minorities?

When asked which governing body or community organization should be held most responsible for addressing healthcare disparities, 56% reported the national government, 1% reported community organizations, and 27% reported the healthcare system. However, 57% of students believed that the community organizations were the ones doing the most to address healthcare disparities. About 73% of respondents believed that students should be very responsible or somewhat responsible for addressing healthcare disparities in Hungary. Students seemed to largely believe that good health outcomes are mostly due to positive lifestyle factors, rather than access to healthcare.

The results of the interviews largely supported the results garnered from the surveys. Further statistical analyses of the data are pending.

Conclusions:

Students recognized the marginalized status of the Roma people and understood that they suffered more from poor health outcomes than the rest of the population in Hungary. However, it was not clear whether students believed that the Roma people had equal access to healthcare as the rest of the population. From the interviews, there was a lot of discussion surrounding the universal healthcare system of Hungary. After some talk, students seemed to discover some pitfalls of the system, by which the Roma people get lost in the system.

Respondents reported that there did exist some volunteer opportunities for students at the University of Szeged. In the interviews, many students expressed the belief that these opportunities were scarce and ambiguous. Volunteer participation was very low amongst the respondents, but they expressed some interest in participating in volunteer work if there were more organized and interesting volunteer experiences. Students reported the biggest barrier to participation was time. Students didn't want to work for free when they already had a lot to worry about with academic responsibilities. There was the

understanding amongst many students that addressing healthcare disparities is important, and that community outreach is fairly effective at improving these problems.

Students believed that the national government and the healthcare system should be most responsible for addressing the issues that the Roma people and other minorities in Hungary face. Only 2 respondents said that community organizations should be responsible, yet 57% believed that community organizations were doing the most, presenting some ambiguity here. Students placed a lot of responsibility on outside organizations, which might explain the low participation rate in volunteer work and the low motivation to participate in volunteer work.

At the University of Szeged, the students surveyed demonstrated a strong knowledge of the health disparities that the Roma people face. However, this knowledge didn't always correlate with the principle causes responsible for these differences in health outcomes. Students also expressed interest in participating in volunteer work, but cited several barriers to participation, mainly the lack of interesting and organized activities and the lack of time. Students believed that the government and healthcare system should be the most responsible for addressing the differences in health outcomes for the Roma people and other minorities, but did not place themselves as students responsible for this.

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