**Aiding stigmatized others: A public health needs assessment in India**

Abstract

Needs assessments conducted in foreign countries present unique challenges, especially when the populations are poor, ill, and stigmatized. In India, greater than 100 million sick or aging people must navigate through corrupt government-provided or private healthcare services (Pai & Kumar, 2015). Illnesses, such as leprosy, malaria, tuberculosis, and AIDS still affect some of the nation’s poorest because of unattainable financial or social access to necessary treatments (Gadre, 2015; Roche, 2011). Some of the more fortunate untouchable members of society are adopted into rehabilitation communities, which provide housing and medical care for the rest of their lives. Those agencies rely on monetary or tangible donations to supplement income and provide resources their inmates require. Providing medical supply donations can alleviate some of the burden faced by caregivers. Efforts like these can influence reallocation of funds toward medications or other supplies, which may not be suitable for international partners to donate.

Approximately 100 million elderly and many more infirm people in India are subject to accessing healthcare through expensive private services or government-provided avenues, labeled as free, but with hidden price tags (Pai & Kumar, 2015). Those who cannot afford a barrage of unnecessary treatments and false reports are forced to forego treatments and suffer through diseases plaguing India’s poor, such as leprosy, tuberculosis, malaria, or AIDS (Gadre, 2015; Roche, 2011). Stigmatization of such diseases leads to social down-casting and isolation of people still in need of medical care (Raju, Rao, & Mutatkar, 2008). Faith-based institutions, such as one rehabilitation center, have been established in India to house and care for those rejected from their communities (Roche, 2011).

Private and government-sponsored healthcare is unaffordable for many Indian working class citizens (Pai & Kumar, 2015). Although nuns work for their duty to God, caring for the hundreds of inmates (the Indian term for patients) requires funding and supplies not readily available in India’s destitute suburbs (Roche, 2011). Donations, self-sustaining farming measures, and the operation of a nursery school provide the operating budget of the facility that provides free, lifetime care to inmates (Roche, 2011). Caring for so many with so few resources requires the support of outside agencies. In order to help sustain the center’s efforts, partnering agencies must know the diseases treated, types of supplies and equipment required, and the professional development needs of providers. This will allow for the development of essential interventions in ways which are culturally, medically, and economically feasible.

Providing care to the ailing destitute requires an understanding of the system within which patients attempt to seek care and the diseases requiring treatment. Comprehension of the current healthcare climate in India can influence future endeavors to assist those in hardship. By incorporating the needs of both individuals and the underlying healthcare system, resources and support can be organized to meet them.

 Healthcare services in India are primarily provided through the government or private agencies, but each sector is riddled with problems for patients requiring access (Pai & Kumar, 2015). Although dominant in health service provision, privatized care is often expensive and out of reach for the country’s poor and sick (Pai & Kumar, 2015). Government-run health services are advertised as free, but providers take opportunities to earn money for themselves through corrupt practices and ignore the perspectives of the patients (Dang & Vallish, 2015; Gadre, 2015; Pai & Kumar, 2015). The need for free and adequate care far exceeds the available resources (Pai & Jumar, 2015). Facilities run by missionaries and other nongovernmental organizations aim to fill this wide gap (Gautham et al., 2011; John, Rao, & Das, 2010).

 Physicians practicing in India revealed multiple forms of malpractice, such as prescribing superfluous medications or interventions for the patients or their conditions and getting kickbacks for referring patients to other, unnecessary specialties (Gadre, 2015). Representatives from pharmaceutical companies provide ‘medical education’ to healthcare providers, which results in the prescription of their medications, even if they are unnecessary (Gadre, 2015). Opportunities for revenue often take priority over patients’ needs and preferences (Dang & Vallish, 2015; Gadre, 2015).

 Elderly and infirm patients in India are underserved for myriad reasons, financial or otherwise. Patients nearing death are not typically given health services and, in the rare cases of care, only their physical health is considered (Chacko, Anand, Rajan, John, & Jeyaseelan, 2014; Pai & Kumar, 2015). Patient-centered outcomes and dignity while dying are currently seen to be unachievable goals, particularly in the dominating private healthcare system in India (Chacko et al., 2014; Dang & Vallish, 2015; Pai & Kumar, 2015). Shifting attention to accommodate patient perspectives, and spiritual, emotional, and social dimensions of health, is a necessary endeavor for healthcare professionals, but may not be possible until better regulation of the healthcare system is achieved (Chacko et al., 2014; Dang & Vallish, 2015; Pai & Kumar, 2015).

Disease-related needs assessments in India

 Stigmatized diseases are difficult to treat in India because of fear and inherent negative social views (Gautham et. al., 2011; John, Rao, & Das, 2010; Raju et al., 2008; Taneja, Dixit, Yesikar, & Sharma, 2013). Needs assessments for people in India with HIV/AIDS and leprosy have revealed the need for more comprehensive, holistic treatments for those with debilitating, chronic conditions (Gautham et. al., 2011; John et al., 2010; Raju et al., 2008; Taneja et al., 2013). Primarily, steps to increase awareness, accessibility to care (physically and financially), and creating social change to accept those conditions would increase care and decrease disability (Gautham et. al., 2011; John et al., 2010; Raju et al., 2008; Taneja et al., 2013). Women are less likely to seek early care for leprosy-related symptoms because of fears of losing time on travel, evaluation, and treatment that would otherwise be used to finish household duties. Women are also more likely to rely on the decisions of male family members to determine whether they can receive care (John et. al, 2010). Changing the healthcare and social systems so that people seek earlier detection, treatment, and prevention measures will lead to decreased levels of disability from curable leprosy or improvable HIV (Gautham et al., 2011; Taneja et al., 2013).

The rehabilitation center, founded by a Catholic missionary in the 1970s, is situated on 16 acres of land outside a major city in Southern India. The complex houses 104 ill persons, the 11 nuns who care for them, and a few support staff (Roche, 2011). The four dormitories originally housed inmates afflicted with leprosy, but, in recent years, a transition has added patients with HIV/AIDS, tuberculosis, deafness, blindness, as well as those with other, unspecified physical and mental conditions (Roche, 2011). Since most of the people admitted to the facility are indigent, no one is expected to pay for services at the facility, which becomes their life-long home (Roche, 2011). The facility also helps, when possible, to place family members in housing in a nearby village (Roche, 2011).

 The nuns work tirelessly to attend to the inmates’ social, physical, mental, and spiritual needs (Roche, 2011). Once inmates are remedied from their acute illnesses, those who are able, along with their capable family members, join the ranks of assisting with facility upkeep or tending to planted crops, the rubber plantation on the grounds, or the nursery school: all efforts for income and survival (Roche, 2011). Donations, both monetary and in-kind, sustain the facility and nuns continue providing necessary care to those people considered, in Indian culture, lower than untouchables (Roche, 2011; Jacob & Carlos-Paredes, 2008).

**Methods**

 Permission for the needs assessment was granted by the Institutional Review Board at a mid-sized US college, facility representatives, and stakeholders from a nearby Indian university. Two of the authors and eight undergraduate students to the site traveled to the site as part of a course in international public health research. One of the authors had previously visited the center and had taken note of needed medical and hygiene supplies, so the team traveled with 100kg of these and similar provisions to donate upon arrival.

 The head nun took the researchers on rounds of the facility, introducing every patient, presenting their conditions, and describing the treatments provided for ailments. Other nurses, helpers, and even the inmates interjected to demonstrate the use of equipment, provide background information of residents, and describe the daily functioning of the facility. Semi-structured interviews were conducted, with the use of an IRB-approved interview guide, with people integral to the functioning of the community. People were chosen for interviews through snowball sampling; each participant was recommended by other participants. Interviews were conducted in private locations near the areas the people were working in at the time. Questions focused on functionality, needs, and behavioral intentions for future need fulfillment.

 Observation of the facility and its functionality and 11 interviews took place during the three-day stay at the compound and in the days surrounding the visit with representatives of the Indian university who have regular contact. Interviewees included nuns, who perform as nurses, and support staff. A trained nursing assistant helper, a worker in charge of other hired helpers, and inmates who provide assistance to other inmates and perform daily tasks at the center also participated in interviews

**Results**

 The sisters spend most of their time and energy caring for inmates. When they find themselves lacking equipment, they use creativity to turn available items into devices they can use to help their patients. Blocks of woods are fastened to walkers to increase their height for taller patients’ use, coconut shells are nailed into trees to catch rubber milk, and newspaper is placed under bedding to soak up urine and preserve mattresses. Ingenuity, unfortunately, cannot address all needs. The facility is functional and mostly self-sufficient, but financial support is limited, so the nuns must be diligent about spending and fund-raising.

The greatest need for patients, identified by all workers, is medication. According to administrators, the majority of monthly expenses is centered on medications, which, despite being purchased at wholesale price through a local hospital, are still costly. Not only are prescription medications needed, over-the-counter medications, such as stool softeners, sleeping pills, and medications for gastrointestinal distress, are also frequently needed. Calcium, iron, and vitamins C and B are often used and B-complex is often administered via intramuscular injection.

Ointments are needed, in bulk, because there are at least 20 skin infections treated throughout the facility at any given time. Occasionally, expensive topical creams are used to reduce pain in patients with wounds or conditions that cause neuralgia. Dressings are used to cover wounds, prevent ointment from drying out, keep splints in place, and prohibit the spread of topical infections. Wounds are cleaned with iodine-based cleaners, but those sterilizing solutions are expensive and not always available. Splints are not often available, so, in one case, a ruler was bent and attached to a man’s foot with dressings to stabilize a fracture. Splints are useful for patients with paralyzed or otherwise dysfunctional extremities, to help them be more independent, ambulatory, and functional to the facility. One of the inmates who works in the facility said that her housemate would be able to walk if she had a brace for her leg, which was weakened by polio.

Increasing mobility of inmates can improve moods and allow them to take better care of themselves and others. Wheelchairs, walkers, and canes are necessary for some people to get out of bed and safely traverse the grounds. An exact number of canes and walkers needed was not available; the nuns specified a need for “many.” The current stock of canes and walkers includes those made by hand, as well as commercially-made walkers, which were purchased or donated, have been distributed to those residents most in need. Wheelchairs are especially important to the functionality of the facility because they help to maneuver those patients who would otherwise not be able to get out of bed to socialize, attend mass, and eat in a dining room with others.

For some, moving is very difficult because of disease-induced weakness or other sequelae that have left their extremities dysfunctional. The lack of lifting assistance to and from wheelchairs and commode chairs prompted the sisters to turn some of the wheelchairs into commodes. The sisters have requested six wheelchair commodes to use throughout the facility for those who have difficulty with moving, but still prefer to be out of bed and around other people. Current commode chairs are made from plastic lawn chairs and wheelchairs.

Patients who are unable or have difficulty getting out of bed or to a commode in time are in need of adult diapers in medium and large sizes. Bed linens are often nonabsorbent, so disposable chux pads, reusable lifting sheets, and soaker pads would protect the mattresses and bed frames and decrease urine odors. Rubber sheets are used, primarily, on the beds of those who cannot get out of bed at all, since there are not enough for each bed. Bed sheets are currently changed every 15 days, if the bed’s occupant is well, and every day, if the person is ill. Having more sheets available would be helpful because laundering takes time, particularly in monsoon seasons. Lifting sheets and absorbent pads can also be used to assist with moving patients who are unable to assist themselves because there are no devices available to do so. Staff lift patients by pulling on extremities, which can cause injury to both the patients and the medical personnel.

Patients who cannot get out of bed are served and, occasionally, fed by nuns, helpers, or able inmates. There are currently no tables available for helpers to place trays on, so bedside stands, preferably those on wheels, would be useful for those who are bed-bound to eat, be treated, and use for social situations. A minimum of five wheeled bedside tables would suffice, according to one nun because, most of the time, the majority of the inmates are able to get to the dining room to eat, either on their own accord, or through the use of wheelchairs or other ambulation-assisting devices.

Many informants requested the use of trolleys or wheeled carts to distribute medications and dressings. Currently, supplies are gathered from one area of the ward and carried to where they are needed and sometimes set on a bed or the floor. Having a cart with all of the supplies and equipment readily accessible will save time, prevent potential contamination, and make daily chores easier. Plastic boxes would be helpful for storing supplies and keeping them organized and protected from the elements. These boxes and trolleys would be used several every day to accomplish tasks.

Masks and gloves are needed to prevent workers in direct patient care from becoming ill, but also to prevent disease transmission to those with already-weakened immune systems. Currently, nuns and helpers go without masks, increasing their potential for contracting diseases spread through droplets. Disposable gloves are used between two and four times; they are washed between uses and draped over pipes in the wards to dry. These multiple uses are only done on “clean cases;” gloves used on known infections are thrown away immediately after use. A small supply of sterile gloves is available for use on invasive procedures, such as urinary catheter insertion and care of some wounds. Nurses and helpers reported they would throw the gloves away more often if replacements were available.

The sisters and trained helpers have the ability to treat many conditions at this facility and perform small procedures, such as suctioning, breathing treatments, and oxygen therapy. Suctioning and oxygen are primarily used in end-of-life care for comforting measures. According to one helper, “breathing is difficult in the last moments, so adding oxygen makes passing easier.” Currently, the center has two oxygen concentrators and each only delivers a maximum of five liters per minute. None of the patients are on oxygen all of the time, despite diagnoses that might require constant oxygenation in more developed settings. Oxygen is used only in the cases of dying or acute hypoxia. One patient is in need of intermittent oxygen application, so one concentrator remains in her ward. If another inmate requires oxygen administration, the concentrator (an estimated 20-pound unit) is carried, urgently, to the bedside from wherever it was previously located. More oxygen concentrators to provide at least one device per ward, as well as methods for delivering oxygen, such as nasal cannulas and nebulizers (for oxygen and aerosolized medication administration) are needed. The current practice is to wash and reuse disposable equipment, for use by other patients when their conditions require them. Stocks of nasal cannulas and nebulizers would allow the devices to be properly disposed of, as recommended by their manufacturers, and decrease the potential for pathogen transmission.

To assess for hypoxia, a pulse oximeter is needed for each ward. Currently, one is available for the entire facility and carried between wards when a patient requires its use. This monitor is useful to trend vital signs, as well as to evaluate the efficacy of medications when a patient is short of breath. At least one is needed for each ward, along with batteries to sustain proper function. Suctioning units are required, but one device per ward should suffice, according to the primary care nuns. Nasogastric tubes for use with suction units were also requested to help to decompress stomachs or provide enteral nutrition. Since these are difficult to clean and labeled as one-time use only, an abundance of these catheters would be appreciated.

Thermometers are also required throughout the facility. One is currently available at the facility for all 104 patients to share. More thermometers and probe covers can be used to gain a better assessment of temperature through oral or rectal routes.

When people are found to be acutely ill and remain at the facility for treatment, intravenous [IV] fluids, namely 0.9% sodium chloride, lactated ringers, or 5% dextrose in water, are administered for profound dehydration. Fluids are available for purchase through the local hospital and single-use IV administration sets and angiocatheters are also available through this channel. All fluids are administered via gravity-flow measures, so IV drip sets should accommodate this method. Butterfly needles, namely in 18ga-22ga sizes, are used to gain IV access in this facility; safety-style angiocatheters are requested because they are one-time use only devices and cannot be re-sterilized. Safety angiocatheters prevent accidental sticks and transmission of disease to healthcare providers.

Some medications must be administered intravenously, which requires the use of needles and syringes. The nurses reported acquisition of the hypodermic needles is easy; syringes, particularly in 2-10mL sizes, are difficult to access, so they are reused. Reusing syringes, although they do not directly touch patients, can still transmit pathogens because IV lines are directly connected to patients. Furthermore, syringes are difficult to clean, so cross-contamination between medications can be dangerous.

Patients with diabetes have their blood glucose levels assessed every 15 days when they are healthy because glucometers their testing strips are expensive. When diabetic patients are sick, their blood glucose levels are assessed daily, sometimes thrice, because of blood glucose sensitivity to infection. Blood glucose levels would be assessed more frequently if more testing strips, glucometers and lancets to obtain small blood samples were available. An alternate approach to digital glucometry is providing colorimetric strips – simple pieces of litmus paper – that can be compared to an accompanying legend to determine ranges of blood or urine glucose. Even though this method is not as accurate as digital glucometers, this method may be more sustainable and less affected by extreme temperatures.

Urinary catheters are useful for patients when they are ill or unable to get out of bed to a commode to urinate. Having direct measurement of intake and output is integral for measuring illness progression and improvement. Those who do not improve must be transported to a local hospital. Although the center has its own ambulance, the vehicle is used for transportation only and is not stocked. The facility does not have a cardiac monitor or defibrillator, so patients with cardiac dysrhythmias are transported to the hospital without intervention.

Basic equipment needs for this facility are similar to those in other healthcare facilities. Scissors, eye drops, and forceps could be used daily, as needed. Some of the equipment needs to be sterilized, depending on its manner of use, but there is no method of sterilizing equipment at the center, so the nuns clean what they have as best they can. Sterilization equipment could reduce potential pathogen transmission, precipitously.

Daily life at the facility promotes hygiene for all patients, regardless of their ability to get out of bed. Razors to shave faces are useful for the men. One patient was a barber before moving to the center 30 years ago. Despite his throat cancer (in remission) and amputation, he shaves as many of the men as possible throughout the day. Helpers and nurses shave the rest between their other care-providing tasks.

Staffing is a constant need at the center because there are so many patients and so few nuns to care for them. Each ward had one helper, a man in the men’s ward and women in the women’s wards. According to one of the nurses, the future looks bleak for getting new help because there are very few young nuns available in the diocese. She attributes this to society making people less service-minded and smaller families. Helpers who come from the local community are paid relatively low wages because the facility does not have much money. At least one more helper would be useful in each ward during the day, but funding does not allow for anyone else to be hired. Hired helpers must receive specialized training, available in the nearby city, to be able to safely lift and move patients, provide care, and dispense medications. People who are hired typically need to have their classes financed by the center, but those funds are unavailable. Patients care for themselves and each other after nighttime meals and medication dispensing; they can get the nuns if their services are needed overnight.

Classes for the inmates on good hygiene, their health, community life would also be helpful. When she is not too busy with other tasks, one of the nuns teaches these classes in the men’s ward to facilitate a better atmosphere. She says that the men tend to need more attention because many are alcoholics in withdrawal and some like to fight each other. Having someone to teach these classes throughout the campus would be beneficial to the overall atmosphere, but this is another expense the facility cannot afford.

Many of the daily chores are performed by the inmates. As they age, however, the tasks become more difficult for them to accomplish. Basic cleaning, such as sweeping, mopping, and picking up after meals are easier than the labor-intensive procedures of washing laundry by hand. Patients with polio-affected hands and arms, arthritis, or other disabilities to their extremities are often unable to do their own laundry, so other inmates help them. The ones who assist, however, are aging and have difficulty agitating and wringing out clothes to properly wash and rinse them and the nuns and helpers are often too busy with other tasks to help. A nurse proposed the supplement of at least one washing machine for the facility because the machine could wash several pieces of laundry at once and reduce labor-intensive work for those with disabilities. The appliance would have to be Indian-made to assure parts and repairs could be acquired in the future. A dryer is not necessary because laundry can be hung to dry inside or out, depending on the season.

Although most of the expenditures are on medications, food costs are also significant for the facility. The nuns and inmates eat meat once weekly because of its expense. They grow as much produce as they can at the facility and have symbiotic relationships with other centers in the diocese to obtain other goods. The only resource grown at the center in sufficient quantities is spinach. Other vegetables and fish (in season only) are purchased at a local market every week. Pepper creepers are abundant at the facility, so pepper is used for food preparation and sold for profit. Other fruits and vegetables grown at the facility are not in quantities sufficient enough to feed all of the inmates, so the ability to grow more in a vegetable garden or have more gardens, would mitigate some of the facility’s food expenses.

Several coconut trees occupy the grounds and, although some were knocked down by lightning, water-filled holes promote regrowth. The leaves from the coconut trees are scraped and sewn together by inmates to make brooms, each sold for 25 rupees. This method of income is necessary for sustainability, but more income techniques would be more beneficial to the facility, overall.

During the monsoon season, rain is collected in reservoirs for use in the dry season and, according to one of the inmates who performs several of the daily chores and cares for other inmates, “we need the rain for the food to grow.” She reported praying for rain because a “human can only pray for the best from God.” Water is needed at the center throughout the year, but the valuable resource is not always available. Water is not potable in all areas of the facility, so systems to purify water in all buildings and wards can prevent illness and reduce medical costs in the future. Water harvesting and purification methods should be explored.

The practices of rubber-making and biofuel creation conducted on the grounds of the center also aid in securing income, but, since product sales are outsourced, conducting those procedures on the grounds could increase profits by saving in transportation and service costs. The addition of dairy cows at the facility can increase manure production for biofuel manufacturing. Their milk can be used by the facility’s occupants and its harvesting could increase profits and improve self-sustainability. Since the cows eat coconut leaves, which are available in abundance on the grounds, cow maintenance would not be a concern.

**Discussion**

Participation in daily tasks by inmates, as well as the work performed by nuns and helpers, helps the overall functionality of the facility. Although the “needs are plenty,” according to one of the facility workers, “whatever comes in, in cash or in kind, is welcome.” Although there are grand needs, such as the ability to grow more produce to reduce food expenditures, purify water, and ease daily chores with the addition of appliances, initial resources should be focused on meeting the clinical needs of the 104 patients living at the facility. Monetary donations, disposable medical supplies, and durable healthcare equipment should be considered first-line support routes for rendering aid.

**Limitations**

This study was limited because the participants were chosen through convenience sampling and those volunteering to be interviewed. Although all participants spoke English, English was not their primary language and translation of some of the questions and answers proved challenging. Drawing pictures, using others to assist in translation, and showing examples of medications and medical equipment minimized most of the confusion. Time and cultural constraints also limited the scope of the study and the number of people interviewed. Living at the facility and participating in daily activities seemingly reduced emotional distance and improved trust between researchers and its residents. Subordinate nuns were more likely to defer to the opinions and beliefs of their superiors and inmates were more likely to refer the researcher to nurses or helpers to provide the needs of the facility, overall. This hierarchy made obtaining a wide variety of opinions and perspectives difficult.

**Delimitations**

This study was delimited to those engaged in work or those who facilitate working relationships with the center. Inmates who perform daily tasks vital for the continued functioning of the facility were interviewed, as long as they were able to provide consent for their own participation. Those who suffer from psychiatric problems or mental disability were deemed incapable of providing informed consent and, subsequently, did not participate. The interviews were only conducted over the three days spent at the center and the immediate days surrounding the visit.

**Conclusions**

 Any donations of money, supplies, or equipment would be appreciated by the people at the center because anything is more than they currently have. The enterprising nuns and helpers have found ways to help the facility function and to care for the inmates, so fulfilling their needs will only help them to perform their tasks more efficiently and improve the quality of life at the compound. Spending time at the center demonstrated the sisters, inmates, and workers are rich in the qualities they reported to be the most important: reaching out to the people in need, caring for them to the best of their abilities, and embracing them with love.

 Conducting needs assessments in similar facilities can be challenging, particularly for researchers from more developed countries and different cultures. Navigating issues of lacking resources, technology, and finances is an overwhelming task that feels nearly impossible, but any information gathered can be used to facilitate future programs and garner aid. Although heartbreaking, looking beyond deficits for an often-unseen view of humanity makes the task more meaningful and fulfilling.

Despite desires to address every uncovered discrepancy, sustainability, access, and efficiency of support should be prioritized. While conducting assessments, researchers must be cautious about addressing only the superficially apparent insufficiencies. Providing large pieces of equipment, medications, or staffing may be too expensive to continue funding or adequately deliver, so appreciating voids in dressings or antiseptic creams can provide necessary, albeit secondary, support to larger items or tasks. Quality of life concerns are paramount, particularly in stigmatized communities. Holistically appreciating the perspectives of all people within facilities can illuminate underlying concerns that those with more formal power do not readily reveal. All people, regardless of their roles and responsibilities in health institutions, presuming they are willing and able to consent, should be consulted for their views, opinions, and desires for their communities.

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