Healthcare of the rural aged in Andhra Pradesh, India

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Introduction

In the summer of 2010, an elderly man in West Godhavari asked me, "Now that you've met us, how are you going to help?" I could sense the frustration in his voice as he described his previous encounters with health care workers whose promises to alleviate his unaffordable monthly bills remained unfulfilled. He explained to me that as he grew older, he developed hypertension and diabetes requiring continuous treatment due to the chronic nature of both conditions. The cumulative cost of these medications put a financial strain on his family. This man was the first of many elderly villagers to voice such complaints to me.

In a little over four weeks, I traveled to ten villages in Andhra Pradesh (AP), India, with a team of CARE Byrraju employees. As a research intern for CARE, a non-profit organization (NPO), I formally interviewed ten aged villagers, their caregivers and the CARE Byrraju village doctors and nurses in each of six different villages. I also informally spoke with ten elderly individuals in each of the four other villages for a total of 100 interactions. My primary aim was to elucidate the most prevalent health problems and barriers to care that the elderly face in rural AP.

The motivations for my project were the rapid demographic changes seen across India, the inability or reluctance of aged individuals to seek regular medical assistance and the absence of programs targeting elderly care. Due to technological, medical and economic advances in India, the fertility rate has declined substantially from 5.5 children per woman in 1970 to four children per woman in 2009, and the life expectancy has improved significantly from 49 years in 1970 to 64 in 2009 (India, 2010). As a result, the aged population, defined as ages 60 and above, has increased to roughly 7.5% of the total Indian population as of 2001. Recent sociological changes, namely the increase in female employment and migration of young workers, have led to the disintegration of the joint family, an arrangement in which aged individuals typically live with their son and his family. This disruption of support systems, in combination with issues of immobility and increased dependence, particularly in rural settings, has exacerbated the poor health status of the growing elderly population (Pandey, 2009). Because the elderly often are unable to obtain paid work, most remain entrenched in poverty.

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My first introduction to the abject conditions in which some aged individuals live came through a woman whom, interestingly enough, I did not and could not interview.

This particular individual lived in a dilapidated straw-roofed house that hid in the outskirts of Mahadevapatnam village. Mud had swallowed what had once been a path to the main dirt road. The stench of absolute poverty—a combination of cow manure, unwashed clothes and despondence—was particularly pungent here. She sat amidst this squalor, with her back resting against a stained wall. Though we made considerable noise as we approached her, she made no acknowledgement of our presence.

"She is deaf," the CARE Byrraju coordinator responded upon seeing my confused expression. "And blind," he added. "You cannot interview her—she is alone." It always surprised me how the health center coordinators knew nearly everyone in each village, even those who were not CARE Byrraju patients. According to her neighbors, the approximately 65-year-old widow (her exact age was unknown) was uneducated and unemployed. She spent the majority of her time in the solitary confinement prescribed by her age and socioeconomic status. Every day, she leaned against the same cracked wall, waiting for her son to return from his agricultural labor. She lived with no other family members and had no friends. Given her inability to communicate, she was, as my guide said, completely and utterly alone – at least until nightfall, when her son returned from work.

Background

Many governmental and non-governmental bodies are aware of stories similar to this one and have attempted to mitigate the struggles of the rural elderly. The state of Andhra Pradesh has launched several initiatives aiming to supplement the National Rural Health Mission of India, which has established basic rural public health infrastructure throughout the country. For example, the state government established and effectively implemented Aarogyasri Health Insurance, for which any family with a "Below Poverty Line" (BPL) card may qualify (Aarogyasri, 2011). The scheme provides coverage of up to Rs. 2.0 lakhs (USD 4,000) for any heart, kidney, cancer, brain or accident-related ailment (FAQ, 2011). This program is particularly important because a primary barrier to health care access in rural regions is affordability. In fact, as of 2004, roughly 26.5% of rural households throughout India were designated "BPL" (Public Distribution, 2007).

Despite these recent improvements, the services offered remain insufficient to provide for the welfare of the entire rural community. The Indian Council of Medical Research (ICMR) reports that a large portion of the rural aged still do not have access to adequate healthcare due to insufficient medical supplies at government-funded Primary Health Centres (PHCs), lack of transportation or understaffing of medical personnel (Rao, 1990a). Several private agencies have established programs in an attempt to address these issues. The Health Management Research Institute (HMRI), for example, has pioneered many initiatives: 104 Advice, a helpline that provides medical information and counseling in English, Telugu and Hindi, 104 Mobile, a monthly fixed date health service for rural populations who reside more than three kilometers away from public health care providers that distributes free medicines every month (HMRI, 2010), Fixed Date Health Service, a monthly fixed date health service that complements existing public health systems and Telemedicine services. In order to facilitate transportation to health centers, GVK Emergency Management and Research Institute (EMRI) has established a free emergency ambulance service (Emergency, 2010).

CARE Byrraju, the host organization for this project, similarly aims to facilitate rural development. In 2001, the Satyam group, a prominent Indian information technology company, established this NPO as the Byrraju Foundation in order "to create a world-class platform for sustainable rural transformation." The foundation pursued a multipronged approach, creating programs that address women's empowerment, economic growth, healthcare and education, among other issues. Throughout the years, the organization has provided services for nearly three million people within several districts of Andhra Pradesh: East Godavari, West Godavari, Krishna, Guntur, Ranga Reddy and Visakhapatnam (About Us, 2009). The foundation established five to ten health centers per village in 80 villages. In 2009, the Care Rural Health Mission absorbed these health centers and now aims to sustain and improve the efficiency with which they function. Under this new leadership, the initiative has been renamed CARE Byrraju.

Despite all of these efforts to extend care to rural populations, many individuals still do not access these services. It was only when I engaged with the elderly population of AP that I began to understand the challenges of providing care to this constituency and the complexity of the psychosocial and physical health problems they face.

The Inadequacy of Health Systems in Rural India

Sanjana was approximately 60 years old when I met her. She lived with her husband in a roofless house constructed primarily from mud-bricks. They had attached giant blue plastic bags to the tops of the walls to create a pseudo-roof, but it was clear that this contraption would barely shelter them from the heavy rainfall of monsoon season. When we arrived at her doorstep, Sanjana cheerfully greeted us, set out three plastic chairs for us in her bedroom and offered us tea and biscuits. Only after we finally accepted the snacks did she launch into her story. Years ago, Sanjana's husband had suffered a stroke that left him with severe aphasia. He struggled to communicate his thoughts and, as a result, often expressed his anger by beating his wife. As she described her situation, I detected not despondence, but rather, acceptance. She could not blame her husband for his frustration. If she were in his place, would she not also feel overwhelming rage? But if Sanjana was taking care of her husband while enduring domestic violence, who was taking care of her? Despite her relentless joint pains, evidenced by her difficulties walking, Sanjana had no caregiver of her own. It became clear through my interactions with other families that this arrangement was fairly typical. Gender norms mandated that women provide care for their spouses, regardless of the state of their own health. Although both husband and wife suffered from hypertension, neither regularly purchased the necessary medications. They used to visit the Byrraju Foundation health centers until they were unable to afford the monthly fee of 25 rupees. To put this in perspective, 25 rupees are equal to approximately fifty cents.

Unfortunately, Sanjana was unaware of the services put in place to help people in exactly her situation. Certainly, as the ICMR reported, a large portion of the rural elderly cannot access the public health system due to insufficient medical supplies at PHCs, lack of transportation or understaffing of medical personnel (Rao, 1990b). My own surveys were consistent with these trends. Yet the faults of the existing public health system may be worsened by the target population's unfamiliarity with the services available to them. Many of the subjects I interviewed, including Sanjana, were completely unaware of the Aarogyasri Insurance program to which they were entitled and were ignorant of the HMRI and EMRI programs, only seeking medical attention when severe physical illness necessitated it.

While these issues theoretically may be mitigated through educational campaigns, several other deterrents may be more difficult to address. The aged in particular experience a substantial increase in physical, emotional and social vulnerabilities that inhibit health care access. Among the most prevalent physical ailments are chronic disease and immobility. Chronic diseases include visual handicaps, neurological illnesses, cardiovascular diseases, respiratory illnesses, dermatological ailments, gastrointestinal issues and diabetes (Rao, 1990c). These conditions may lead to further disability. Some symptoms, such as poor hearing, indigestion and insomnia, may not be indicative of ill health but rather of the general physical aging of the body (Eapen, 2004). Yet, as I learned through my interviews, many elderly individuals do not distinguish between symptoms of aging and symptoms of disease. Thus, they may either seek excessive care for natural signs of aging or may not recognize the need for medical attention when they fall ill. Existing health care systems often do not provide the counseling or treatment necessary to address these specific issues. This actual or perceived lack of services may discourage the aged from starting or continuing to utilize the medical care available to them.

The emotional and social repercussions of aging, particularly in the context of rural to urban migration and rapid demographic shift, may severely diminish overall quality of life. General weakness of the body, for example, may increase the risk of severe falls (Eapen, 2004). The aged often experience a decline in functional competence or tasks associated with daily living, such as eating, dressing and bathing. The resulting physical dependence on others can induce great psychological stress (Dasgupta, n.d.). This distress is exacerbated by common experiences of chronic verbal, financial and physical abuse and neglect from household members (Ingle & Nath, 2008). Furthermore, the disintegration of the joint family unit, in part caused by the recent increase in migratory labor and female employment, has increasingly isolated elderly individuals in the home (Pandey, 2009). This trend is supported by the Phase I outcomes of the ICMR report, which concluded from coded survey responses of aged subjects that a lack of family integration was widely observed among the rural aged (Venkoba, 1990a). This is particularly important, as regular social interactions may counteract the depressive effects of poverty and poor health (Rajkumar et al., 2009).

Unfortunately, as I quickly discovered, mental health is not considered a legitimate component of holistic health in India. In fact, psychiatric disorders remain so taboo that the local coordinators and nurses cautioned me against asking any questions relating to psychosocial behavior. When asked directly whether they frequently feel sad or depressed, many aged individuals claimed that they are satisfied and comfortable at home and, furthermore, that they are never lonely. However, although the majority of the subjects stated that they prefer spending time with others, many spend more than six hours per day alone. Of those who admitted that their physical or mental ailments prevent them from adequately socializing, one cited old age as the prime reason, one cited fatigue, two cited limited mobility, and one cited severe body pains. Furthermore, in conversation, several in-

dividuals claimed that their domestic disputes, financial troubles and limited socialization with others regularly upset them. In fact, the nurse in the village of Chinchinada told me that while she notices mental and psychological stress among patients, she is unable to provide care for these ailments. This information suggests that mental health is, indeed, a serious issue in these regions that should be addressed.

Conclusions and Recommendations

At the conclusion of my research project, I met with one of the leaders of the Byrraju Foundation to talk about the findings of my study. After I described the neglect of the elderly, their deteriorating physical and mental conditions, the gender-based roles that exacerbate the poor health of aged women and the absolute poverty in which many elderly individuals live, I was surprised to find him unmoved. "This is all very relevant and interesting," he said, "but at a certain point, I wonder if we really need to care about the elderly. They have already reached old age; why should we prolong their lives any further? In a country with high infant mortality rates, shouldn't we focus on ensuring the health of children rather than individuals who are close to the ends of their lives anyway?" I cannot deny that when I first was assigned this topic, I posed the same questions. But as I conducted the interviews, I realized that the fundamental view of health as a right prohibits the neglect of such a vulnerable population. Until my internship, I had been exposed to an India dramatically different from the one in which my interviewees lived—that of the urban upper class. From inside my grandfather's Fiat, I could observe the underprivileged, hand them pocket change to mitigate my pity and guilt and quickly roll up the window to return to my sheltered existence. My grandfather, unlike most of the villagers I met, could afford medical care and maintain an independent, prosperous life. He certainly experienced many health ailments and shared many of the psychosocial problems that the rural poor also face. However, in the context of poverty, the economic hardships facing the aging population are too crippling to ignore.

> The stench of absolute poverty—a combination of cow manure, unwashed clothes and despondence—was particularly pungent here.

As I proceeded to look for potential solutions to the problems I saw, I was drawn to the idea of home care nursing. This mode of delivery requires a nurse, which in this case would be a CARE Byrraju nurse (also known as the Village Coordinator, or VCO), to visit certain households and provide appropriate care. This program could be partially funded by the national government, given its increasing focus on the health care of the aged ("25%", 2012). As suggested by Rice (2006), objectives should include providing rehabilitative and palliative therapies, educating the patient and primary caregiver, increasing the patient's independence and reintegrating the patient into society. Old age homes may not be a feasible option, as cultural norms emphasize familial relations and the children's responsibility to care for their parents or elders even if, as my interviews showed, this attention is often inadequate.

Such a model has already been implemented in several populations. In the Republic of Korea, HelpAge, an NGO that supports elderly care, established a volunteer-based home care nursing program (Hyunse, 2007). This model was replicated in a series of pilot projects in other parts of Asia, including Indonesia, and has proven to be successful and cost-effective due to reduced infrastructural and training costs (Do-Le & Raharjo, 2002). The results of the impact study suggested the following general recommendations for development of similar projects: volunteers should be 21-55 years of age, must have experience with the aged and be trained in health care, home care and psychosocial issues. Such expertise would enable the nurses to simultaneously provide physical and emotional care. Additional volunteers may simply provide social support for the elderly, visiting them weekly to combat psychosocial issues and teaching them about the different health services available (Sabdono and Lansia, 2006).

Based on these interviews, I developed the following objectives and recommendations tailored to the villages I visited and the NPO with which I worked. The CARE Byrraju nurse should develop the skills necessary to address the general health issues experienced by the rural aged population. Specifically, the nurse should be equipped to administer general check-ups that address the health issues of the majority of the aged populations, such as common disabilities, hypertension and diabetes. In order to complete these tasks, the nurse should carry basic instruments (thermometers, stethoscopes, low-cost glucose meters, etc.) with them during the home visits.

Skills training should include:

- Provision of general check-ups, including routine measurement of blood pressure and blood glucose level.
- Full understanding of and ability to communicate the symptoms of specific diseases, including hypertension, diabetes, etc.
- Full understanding of and ability to communicate the function and side effects of drugs prescribed and administered.
- Communication of medication schedule, and the importance of adherence to treatment, to the patients and their caregivers.
- Recognition of symptoms of common mental illnesses (such as depression) and verbal/physical abuse.
- Basic ability to treat minor cases of mental illness or refer patient to a mental health specialist.

The frequency of the home visits should depend on the specific requests and ailments of the patients. In most cases, the nurse should visit the home of the patient twice a month to ensure the regular and proper administration of medicine. The frequency of home visits should be greater, up to once a week, for subjects who reside in hard-to-access homes or have extreme difficulty with mobility. The nurse should gather this data through identification of households to which a 60+ year old individual belongs. This information is available, in most cases, in the Panchayat population charts.

The nurse should obtain any relevant and available medical information for each individual in the program. Furthermore, if the nurse cannot diagnose or treat a health issue, she should present the case to a Byrraju Foundation doctor or an affiliated hospital (if the patient does not visit a regular doctor).

HelpAge India, a branch of HelpAge present in every state in India including Andhra Pradesh, may be contacted as a partner to establish a volunteer-based home care nursing program similar to the Korean model. This program may alleviate the health care issues that do not require medical expertise. The designated volunteer's repeated visits may decrease the social isolation that the aged often experience. This model addresses the concerns of the CARE Byrraju patients I had interviewed that the nurse will be unable to manage additional responsibilities. By delegating these tasks to non-medical volunteers, the nurse may focus on medically related issues. The volunteers should ideally reside in the same village as their designated patient and should visit the assigned home at least once a week.

Skills training for these non-medical volunteers should include:

- Assistance with household chores and personal care.
- Communication of the various health care options available (PHC, 104, 108, Byrraju Foundation, RMP Doctor, etc.) and the specific services offered by each provider.
- Full understanding of and ability to communicate the guidelines of Arogyasree Insurance and the benefits of health insurance.
- Communication of behavior through which particular symptoms may be alleviated and risk of ill-health may be decreased. Suggestions include:
  - o Reduction of potentially harmful physical activity (including household chores) and increase of beneficial physical activity (moderate exercise for those physically able to walk relatively easily or regular usage of a walking stick for those not able) to reduce joint pains.
  - o Fulfillment of nutritional needs through change in diet (if possible) or consumption of vitamins.

• Recognition of symptoms of mental illness (such as depression) and verbal/physical abuse.

CARE Byrraju nurses and employees should recruit these non-medical volunteers. A meeting should be held at the Byrraju Health Centre during which the volunteer's responsibilities are fully explained to those interested. Although the elderly are often neglected, respect for the aged remains a widely accepted value, and community engagement and solidarity seem to be foundational tenets in these villages. Because of these local values, it is likely that volunteers will be found; these workers will probably be young women because the gender dynamics in the region generally assign females household chores and males labor outside the home. The number of volunteers required will dramatically vary based on the size of each village. Based on the population charts provided by CARE Byrraju, the populations of the villages in West Godavari range from approximately 1,000 persons to 13,000 persons. Additionally, the required quantity of volunteers depends on the time commitments of each volunteer and the number of households that he or she is able to visit. In the worst case scenario, in which no volunteers are enlisted, compensation may be provided in the form of free CARE Byrraju health services or medicines in order to attract volunteers.

After volunteers commit to the program, the VCOs should invite the residents of the village to an information session. The presentation would include an explanation of the program and an outline of the services provided through this home care nurse model. The VCOs should also discuss basic preventative care measures, such as water treatment, nutrition and sanitation, and emphasize the importance of regular doctor or health care facility visits. Furthermore, normal symptoms of aging should be explained and contrasted with irregular symptoms that may be indicative of serious health problems. These ideas should be conveyed orally and visually through pictures, as the majority of the individuals I interviewed were illiterate or barely literate.

The volunteers should organize visits to the households of individuals aged 60 years and over within each village. They should specifically target districts that are far removed from health centers and individuals who may not have attended the nurse's information sessions. The nurse and volunteers should focus on reaching the female population, as women are often responsible for such household chores as cooking and cleaning, as well as care for the spouse. The volunteers should explain that they may provide assistance with these tasks and reduce the burden that such physically taxing activities may place on both the elderly individual and his or her caregiver, if one exists.

The majority of the subjects I interviewed stated that they would not be willing to pay any costs associated with a home care nurse program. The volunteer-based model is particularly appropriate because it allows for the establishment of the home care nursing program without the patient incurring costs. The costs associated with the extra tasks the nurse would perform and the training she and the volunteers must receive should also be evaluated. At the time of my project, I assumed that CARE Byrraju or another partnering NGO would absorb these costs. However, the recent shift in national health priorities suggests that the government may provide funding for such projects. The Ministry of Health and Family Welfare has revised the National Programme for the Healthcare of the Elderly in order to expand support to the rural aged. This program entails the training of post-graduates in geriatric medicine, the addition of weekly geriatric clinics to community and primary health centers and the availability of home care nurses for severely disabled individuals ("25%", 2012). A home care nurse program implemented through CARE Byrraju can supplement the ministry's initiatives, as the NPO's health centers reach populations that are isolated from or otherwise unable to access community and primary health centers. The nurses and volunteers may be trained through the programs developed by the government.

It is clear from my interactions with the patients and health care workers that designing interventions is difficult in resource-poor settings such as Andhra Pradesh, India. Nonetheless, I believe that such a model will be worth the costs. As shown by my interactions with the rural aged and the literature available on the subject, the needs of the elderly are often neglected. This is particularly worrisome given the rapidly increasing population of aged individuals in India and their increasing healthcare needs. Thus, I return to the elderly man's question, "What will you do to help?" I plan eventually to return to India to facilitate the strengthening of health systems and integration of services. In the meantime, I hope that CARE Byrraju will work with the ministry to effectively implement the recommendations provided in this paper.

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