Community Based Sustainable Tele-Chronic Disease Management: A Pilot Project Proposal on Hypertension

Summary

Introduction: Chronic diseases are major causes of morbidity and mortality across the globe including developing countries like Bangladesh. Digital tools have been used successfully to control blood pressure with higher patient satisfaction at Ochsner health system compared to office-based management in the United States. Principles of Community Based Participatory Development and Research, such as community ownership, social networks, and felt need, can be applied to adopt such digital blood pressure monitoring programs in developing country like Bangladesh. This is a pilot project proposal, which will attempt to do so.

Methodology: A Community's "lived reality" will be described including geographic boundaries, lifestyles, occupations, gender and age structures and roles, health issues, access to food and water, for example, by facilitating open-ended discussions at "hotspots" or "locations where people gather" in the community. Fifteen patients will be chosen based on documented record of hypertension or detection of high blood pressure (systolic >140 mm Hg or diastolic >90 mm Hg) during house to house screening. Special attention will be given to include marginalized members in the community. Patients' social networks will be described, and trusted leaders, defined as members in the community who are willing to work for the community and are trusted by the residents, will be identified. We will work with selected patients to identify goals of care. We will ask for their permission to interview members of their close-tie social networks so that, together, we can establish goals of care that are relevant to participants and supported by members of their close social networks. Similarly, we will identify patient's barriers to care, and facilitate solutions that primarily proposed, implemented, and maintained by the patients supported by their close social network. We will facilitate assignment of defined roles proposed and accepted by the patient and members of his/her close social networks to meet the goals and address the barriers to care. We will consult the leaders to establish a system of data collection and data entry in a secured system accessible to providers remotely. We will facilitate generating a process of collaborative action by the patient, members of close social network, and leaders that can be implemented by the participants to ensure blood pressure reading measurement, regular data entry, and addressing issues/barriers to care as they arise. Providers will work with the collaborative network to meet goals of care and remove barriers. The providers will be licensed physician from Bangladesh. They will require to agree to the project methodology and outcome.

Outcome: The primary outcome will be to collect blood pressure reading and make information remotely accessible consistently. Secondary outcomes will be to control blood pressure, overcome barriers, and increase ownership to care. The outcome of controlling blood pressure will be measured from the data entered in the computer system. The participants' accomplishment to overcome barriers and perceived ownership will be determined by open ended interviews which will be guided by previously established goals of care. Documented outcome of each patient will be used to determine feasibility, necessary modification and possible expansion of the project.

Diagram of proposal

Independent Variables:

Community-based Participatory Health Change (CBPHC) Concept: Felt needs → Ownership and Responsibility

- Determined through hotspot discussions, interviews with identified potential participants, and members of their social networks

CBPHC Concept: Social support to maintain patient's health status related to hypertension.

- Determined through interviews with identified potential participants, members of their social networks and leaders, and facilitating roles and collaborative action among them to meet patient's goals of care.

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Dependent Variables

Collection of health data to telemonitor hypertension of selected patients

- Moderated through identified potential participants, members of their social networks, and potential leaders (see definition of leader in methodology), who will coordinate data collection

Improved health outcomes (e.g. better management of hypertension)

- Determined by clinical data, and documentation of meeting patient's goals of care through collaborative action among each patient, patient's social network and leaders.

Introduction

Scale of the Problem

Chronic diseases, such as hypertension, diabetes, high cholesterol, and stroke, are major causes of mortality and morbidity. It is often thought that chronic diseases are predominantly prevalent in developed countries[1]. However, the world health organization (WHO) estimates that 80% of chronic disease occurs in low- and middle-income countries[1]. Each year 2.6 million people die from being overweight or obese; 4.4 million people die as a result of high cholesterol, and 7.1 million people die as a result of raised blood pressure[1] in developing countries. Within these countries, impoverished communities are much more likely to get affected because of substantial financial burden, limited access to care, and often complex socio-cultural mileu[1]. Many of these chronic diseases are unlikely to get cured. Therefore, prevention and controlling of the diseases has been the mainstay of treatment. If actions are not taken, WHO estimates that 88 million people will die from chronic diseases in the next 10 years often prematurely affecting families, communities, and countries[1].

Like many low-middle income countries in the world, Bangladesh is also experiencing a shift from a disease prevalence dominated by infectious disease, malnutrition, and maternal and childbirth related conditions to more non-communicable chronic diseases[2]. In Bangladesh, chronic diseases such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes account for half of the annual morbidity(47%) and mortality (54%)[2]. Cardiovascular diseases have become a major contributor to illness ranking among top 10 causes of death in Bangladesh. Similarly prevalence of diabetes is rising rapidly[2]. Per estimate, up to 4 million people will have diabetes by 2025 rising from 1.5 million in 2000[2].

Tele-chronic Disease Management: A Program and Study from Ochsner Health System, USA.

Considering the nature and magnitude of the problem, novel approaches have been taken to address the need. Milani and Levi et al. employed a home digital blood pressure monitoring program among patients at Ochsner Health System in the United States[3]. Their program used digital tools to maintain surveillance and initiate appropriate intervention in patients diagnosed with chronic hypertension[3]. It resulted in significant success in achieving patient's target blood pressure (described in detail below)[3]. Even though it was done in resource rich context, we will describe the study as we find that the principles of the intervention can be relevant to resource limited context as well.

The home blood pressure monitoring program at Ochsner considered multifactorial nature of chronic disease management. They recruited patients (n=156) who had high blood pressure (systolic >140 mm Hg or diastolic >90 mm Hg) at each of their 3 most recent visits within previous 18 months[3]. The recruited patients were administered questionnaires that assessed factors related to hypertension and chronic disease management, such as dietary sodium, alcohol consumption, depression, medication adherence, patient, activation, physical activity, health literacy, medication affordability, financial circumstances, and comorbid conditions[3]. Electronic medical record were consulted to obtain clinical data for serum sodium, potassium, creatinine, estimated glomerular filtration rate, thyroid function test, and body mass index (BMI)[3]. A home blood pressure monitor was given that was able to transmit blood pressure data directly to the android/i-phone device, which was synchronized with the patient's electronic medical records profile[3]. Patients were asked to take at least one blood pressure reading per week, but were encouraged to do more up to 3-4/ week[3]. Patients were notified if the electronic medical records, monitored by health care provider team, did not update blood pressure reading for more than 8 days[3].

If blood pressures were not controlled, patient received phone calls from pharmacists to discuss treatment options to improve blood pressure control[3]. If depression or obstructive sleep apnea was identified, patients were referred to a physician or to a specialist[3]. If they screened positive for excess dietary sodium, patients received focused education and were asked if other individuals purchase or prepare patient's food[3]. If such individuals were identified, following patients' consent these individuals were notified by giving automated messages and educational materials at the behest of the patient[3]. Patients with medication financial issues were prescribed low cost/generic drug, or were enrolled in financial assistance program[3]. Patients with compliance issues were given educational materials, apps and resources, and simplified medication regiment. Efforts were made to co-create plans endorsed by both patients and providers[3]. Pharmacist and health coaches were trained to provide relevant and appropriate intervention for patients using current practice guidelines[3]. Algorithms were used to analyze data to cater the interventions to each patient's needs and circumstances[3]. Patients were given monthly reports that detailed progress and gave direction to future care[3].

The primary outcome of the interventional study was the proportion of patients with controlled hypertension defined as systolic blood pressure < 140/90 mm Hg or < 130/80 if patients also had diabetes or chronic kidney disease, at 90 days[3]. The researchers also looked at changes in systolic blood pressure and diastolic blood pressure, patient engagement using patient activation measure at 90 days as secondary outcomes[3]. The control (n=400) of this intervention was patients with usual office based care[3]. Compared to the control group, 71% of digital-medicine achieved targeted blood pressure control versus 31% of usual-care patients[3]. Systolic/diastolic blood pressure was decreased 14/5 mm Hg on average versus 4/2 mm Hg in usual care (P < .001)[3]. Average blood pressure reading taken by digital medicine group was 4.2 readings per week. Patients reduced their salt consumption from 32% to 8% (P ¼ .004)[3]. Patient activation increased from 41.9 to 44.1 (P ¼ .008)[3]. Low patient activation percentage decreased from 15% to 6% (P ¼ .03) in the digital medicine group[3]. The authors concluded that their digital hypertension program, which takes an integrated approach, was associated with improvement in blood pressure control rates and lifestyle modification as well as was associated with greater patient activation and acceptance[3].

Challenges of Implementing Telehealth in Developing Countries Including Bangladesh

Telehealth or the use of information and communications technology for health has been implemented in both developed and developing countries to different extent[4]. Evidence suggests that telehealth is in use in all the countries, but the programs have struggled with sustainability, particularly in developing world[4]. The reasons suggested are lack of proven methodology to conduct large-scale operations, poor evidence for best practice, inadequate implementation, ignorance of community capacity and change management, limited resources, poor connectivity, unreliable power, and lack of awareness and education[4]. Many telehealth projects has been implemented across Latin America and the Caribbean, Asia, and Africa in the form of teleconsultation, telecardiology (transmission of ECGs), teleradiology, and teledermatology[4]. However, only isolated examples of sustainable programs exist[4].

An attempt was made by the author of this proposal to do a review of existing telehealth studies in Bangladesh. A search done in Pubmed, Embase, Cochrane Review, and Web of Science showed seven, two, two, one results respectively, which indicates limited data availability. Khatun et al. conducted multiple community-based studies on telehealth which looked at community readiness, determinants of readiness, and prospects of mobile health services in Chakaria subdistrict in Bangladesh[5,6]. In assessing community readiness, Khatun et al. showed, after studying 4915 households in the subdistrict of Chakaria, that only 45% owned mobile phones, 37% generally read mobile messages and only five percent had capability to use internet service[5,6]. Despite these capacity issues, qualitative interviews done by the same researcher revealed that the community members are generally attracted to rapid access to the providers, time savings and low costs[7]. Some participants did not see the value of mobile health compared to face to face consultation. Community members identified illiteracy, lack of trust, and technological incapability as barriers of implementing telehealth[7].

Khatun et al.'s study showed that the at least some members of the community she studied have interests in engaging in mobile health services, but lack of education, and technological resources are key barriers[5-7]. This can be attributed to the lack of economic development and educational access in the rural areas of Bangladesh. It seems that the community members understand the value of mobile health. They recognize the benefits of telehealth, such as rapid access to the providers, time savings, and low costs[7]. A major limitation of the Khatun et al. study is that it has been only in one sub-district making it difficult to generalize the results. Furthermore, a community's lack of technical resources as well as lack of education have been identified as key barriers, but how that problem can be solved remains unaddressed. Because community members in Bangladesh have interests in telehealth project, and since health has high value in the country, community-based telehealth may play a role in not only meeting health needs, but also help community members achieve some increased capability in improving health. However, these projects need to make addressing capacity issues a priority.

Principles and Practice of Community Based Participatory Development for Sustainable Change

In the recent past, the ideas of community based participatory research and development (CBPRD) has challenged traditional "top-down" approaches to development, projects driven predominantly by experts with little ownership from people, in favor of "bottom-up" approaches to development. CBPRD advocates approaches that build from local understanding of problems, clear understanding of local priorities, and appreciation of local resources, capability, and leadership. Bhatyacharya states that the goal of community development is to promote agency defined as the "capacity to control's one's meaningful world"[8]. The opposite of agency is dependency, a condition where people depend on others to solve problems with only passive participation of presumed beneficiaries[8]. In practice, the participatory approach requires understanding the "felt need" of a community, that is the shared understanding among residents of priorities, problems, and potential solutions. The goal is to promote ownership through consensus about shared problems and strategies for their solutions that involves defined roles and clear responsibilities for those who are expected to benefit from interventions and changes[8].

Moreover, Aday et al note that communities have structures, processes, relationships that function almost organically and evolve over time[9]. These need to be understood as part of efforts to identify felt needs and community owned solutions. When we understand community as collective, structural, and connected entity, we recognize that change requires integrated effort that promote both individual and collective benefits. Individuals influence the community, but they are also shaped, restrained and empowered by existing discourse, belief systems, tradition, and practices of the community. By understanding and galvanizing these structures, processes, and networks of relationships, community based participatory development approaches seek to promote collaboration and collective efficacy to meet community's felt need leading to development that is driven and sustained by the community[9]. Indeed, sustainability of a project independent of external organizations is the standard of success in the CBPRD approach.

The application of the above-mentioned participatory approach has resulted in inspiring success. Author's own experience with Munda community as a part of US based non-profit is an example. The non-profit works with Khulna University and Bangladeshi non government organization (NGO) named Initiative for Right View (IRV) in implementing CBPRD in climate change affected communities in Bangladesh. The Munda Community is an indigenous community in Khulna whose lands were confiscated when the shrimp culture became profitable in the 1980s. Due to the the loss of their land, the community members' access to necessities, such as food and water became problematic. Being indigenous and different from mainstream, the Munda community continue to face deep legal and societal discrimination including discrimination from regaining ownership of their lands.

As a part of CBPRD process, the Khulna University students conducted door-to-door interviews with a member each of the 32 households in the community to understand community felt needs, issues most pressing in the community, and solutions which were both wanted and achievable. After these household visits, multiple public forum meetings with representatives from each household were conducted to prioritize the community's felt needs and proposed solutions. Through these discussions, it emerged that the most urgent need in the community is water accessibility and that the most plausible solution that the community members almost unanimously endorsed was to have water tanks to capture rain water during the wet season (April - October) and provide drinking water throughout the dry season (November - March). Because the space in the community was limited, families in the community agreed to pair up to share water tanks. Furthermore, the community members elected a management committee of eight community members to implement and monitor this project. The committee was also responsible for coordinating among community members in taking care of the water tanks and ensuring equitable distribution of water based on family need. As the next step, 16 water tanks were distributed among 32 families. While objective data is still pending, phone call follow up conversations with the committee members and field visit indicated that community members are using the tank and can manage the tanks on their own.

Aday et al. described similar projects to promote sustainable change in Dominican Republic and Nicaragua[9]. Their project involved conducting ethnographic descriptions of the communities and their health and health care concerns and resources[9]. More specifically, they described housing, water resources, sanitation, flooding, and health resources and risks, and conducted house to house interviews to 1) learn community's health care concern 2) understand shared priorities . The goal was to use the understandings to encourage collective efforts through a sense of commonality and mutual relationship[9]. They collected data to describe social networks to understand patterns of interpersonal networks of communications, collaboration, and leadership[9]. Using the techniques of social network analysis, the team measured network density defined as the "proportion of interpersonal connections that respondents report as compared to the total of all possible dyadic relationships in a community"[9]. The network density measures were an indication of communication flow, collaboration, and possibility of organized action. They were also able to identify people who were more connected to multiple groups in the community. Using this foundational knowledge, they were able to enable increased collaboration to generate community-endorsed five year plan, and establish partnerships with local and international groups[9].

Applying Principles of Community Development in Chronic Disease Management

It may be difficult to imagine how the principles of agency, felt need, social network, and collective efficacy apply to health care delivery. The current model of health care delivery is pre-dominantly driven by experts. The experts are doctors and allied health care personnel who deliver health care products based on patient's complaint/s and expert assessment. However, Milani notes that this health care delivery historically grew in the context of acute care[10]. In this model, a doctor prescribes a medication or an intervention in an office or hospital based setting to a patient suffering from diseases generally lasting short term[10]. A classic example is infectious diarrhea, where a doctor prescribes medications and fluids until the patient recovers, which is usually within few days. However, in current times, the burden of disease has shifted from acute diseases to chronic diseases[10]. Chronic diseases, such as, diabetes and hypertension, generally lasts for life. Patients with chronic diseases usually have to take multiple medications, make changes in life style, and follow up with doctors regularly. Here, much beyond the doctor's prescribing medications and advising life style changes, a patient has to "own" his/her care by ensuring medication compliance, overcoming financial burdens, and making changes in dietary and activity habits. The care for many chronic diseases must be primarily driven by patients with doctors helping patients to find direction.

This necessity of "owning" care in chronic diseases makes principles of community based participatory development relevant. In order to "own" care, a patient needs to "feel the need" to address his/her chronic disease; she/he need to identify and address barriers to his/her care, and find solutions that she/he can sustain. Furthermore, diseases of an individual affect not only the individual, but also his/her family and people close to him. This close network of people, at the patient's behest, can also be facilitated to collaborative action to meet patient's individual goal of care. This collaborative action can be particularly important in the context where resources are limited, because people living in that context show much more interdependent behavior than that of resource rich settings.

Milani and Lavie et al. notes that social networks influence and often perpetuate chronic diseases and their care[11]. The decisions to start to make an activity change, quit smoking, start a medication, or make a life change are not made in isolation, but rather reflects choices of interconnect groups[11]. This influence on behavior by interconnected networks can often reach up to 3 degrees of separation[11]. Thus, depending on the situation, the networks can harness positive or negative behavior. If social networks are included in care, it can lead to positive and sustainable effects[11].

This pilot project aims to apply the principles of agency, feel need, community's structure and organization, interconnected networks, and ownership in chronic disease care of selected patients at Shohoragachi village, Godagari subdistrict in Rajshahi District in Bangladesh.

Methodology:

1. Initial ethnographic description of the community:

The initial description of the community will be done by conducting open-ended discussions at "Hotspot" locations in the community. Hotspots are locations in the community where residents gather for necessities such as marketplace and schools. First, we will explain the purpose of our project stating:

"We want to do a community-based pilot project to mitigate the risk of heart attack and stroke by controlling hypertension. We plan to do this starting with 15 families in the community. If the pilot shows good results, we hope to expand the coverage.

Then, questions will be asked to describe the "lived reality" of the community as much as possible. Questions will be about boundaries of the community, work and occupations of members of the community, cultural practices and beliefs of members,, taking into account gender and age roles in the community, We will ask also about food and water access in the community, housing, and beliefs about common diseases in the community with particular attention to stroke, heart attack, diabetes, and hypertension. We will ask questions to gather information about the groups and subgroups that exists within the community and will attempt to

describe the differences among them with regards to living patterns and health related preferences.
Further questions will be asked to identify and describe possible marginalized groups in the community. Questions will be, such as the following: Are there distinctive cultural, religious, or other groups of people in the community? Are there groups or individuals who you consider do not belong in the community? Are there groups and individuals who cannot access to food, water, or health care?

Then we will ask questions about existing knowledge of hypertension, stroke, heart attack, and diabetes in the community. We will assess the general understanding among members and groups of the community about the link between hypertension with stroke and heart attack.

2. Selection of Patients:

If our initial studies indicate grassroots interest and support for the proposed intervention, we will ask residents how we should select the 15 trial patients in the community. If they recommend 15 patients, we will ask for their reasons, and encourage them to include individuals from marginalized groups in the community.

If the residents do not have any preferences or ideas about selection, we will start from one end or a landmark in the community and serially screen households to select 15 patients for our pilot project. We will conduct the screening process by introducing the project as mentioned above and ask for consent. If the family members consent, we will ask who in the family they recommend will benefit from the project. Based on their recommendations, we will collect blood pressure readings with an electronic blood pressure reading machine. If blood pressure readings are high by the electronic machine, we will conduct manual blood pressure measurement. Final selection will be based on either documented record of chronic hypertension or who had high blood pressure (systolic >140 mm Hg or diastolic >90 mm Hg) at the time of screening, and patients' interest and willingness. If necessary, we will provide necessary information about the role of hypertension in prevention of stroke and heart attack as well as general principles of its management.

The recruited patients will be asked questions that assess and document factors related to hypertension and chronic disease management, such as dietary sodium, medication adherence, physical activity, understanding of the disease, use of complementary and alternative medicine, belief about allopathic medicine, medication affordability, financial circumstances, comorbid conditions, and health related behaviors. If available, we will gather their latest records for serum sodium, potassium, creatinine, estimated glomerular filtration rate, thyroid function test. We will calculate body mass index (BMI).

We will provide the selected patient with electronic blood pressure monitor. We will teach the patient how to use the electronic blood pressure machine. We will ask the patient to collect at least one blood pressure reading per week but encourage to take 3-4 times/week.

3. Identifying social networks that the patient is closely connected with:

After selection, we will ask who in the community/family patient feels close to and can relate with most to the extent that patient trusts in his or her care. We will also ask who in the family/ community plays a role in patient's lifestyle such as cooking and earning. Furthermore, we will ask who in the family/community does work for the patient; who in the community with a patient trusts in times of trouble; who in the community is capable to help meet patient's need and is willing to help him. We will select 3-4 community/family members based on individual patient's recommendation.

Then, we will ask who the patient trusts in the community in the sense that she/he is willing to work for the community and in the interest of the selected patients. We will seek evidence of altruism by asking examples of works that the trusted person did for the community. For our discussion, we will consider the person as "leader". We will also ask if the patient perceives the leader will be capable and willing to coordinate data collection among selected patients to enter into an electronic database accessible to providers. We will collect 3 to 4 names from each of the selected patients, and try to find common names who we can approach.

5. Identifying barriers to care and seeking community owned solutions:

Then we will discuss with the patient and close social networks of the patient at the patient's behest with regards to the barriers of the care. Examples of barriers include medical compliance, access to food and medications, low income. We will then ask what patient and members of his/her social network think they can do to overcome these barriers, and based on our capacity, what role we can play. We will document the proposed solutions and discuss with patients and close social network to determine clear roles and responsibilities of each of the selected members from the network to meet that solution. Furthermore, we will ask what they expect from the trusted leader help them to meet the solution.

Then if the patient consents, we will work with the trusted leader/s to see how the leader can help the selected patients to meet their blood pressure goal. We will document each of the roles and responsibilities of each select member as well as leaders, and give a copy to the patient, selected members of the network and the leader.

6. Blood Pressure Reading Collection:

We will work with the trusted leader in the community to discuss methods to collect weekly blood pressure data from the selected patients and insert it into web-based computer program. We will invite the leader to determine who in the community may be able to conduct the task. We will take the recommendation from the leader and discuss leader's recommendation with patients. Based on consensus, we will select one data collector who both leader and the patients agree. A confidentiality agreement will be signed between the data collector, the leader, and the patients. The data collector will collect data once a week and input in the computer program. We will provide appropriate compensation to the data collector for his/her task.

7. Collaborate with patient and social networks to meet patient goals:

If the weekly collected blood pressure data indicates that blood pressure is not controlled, we will first reach out to the patient; if the patient is not accessible, we will reach out to the close network, and if necessary work with a leader to access patient and promote collaborative action based on the initially defined roles and responsibilities to meet goals of care. If change in medication is necessary, we will provide them with prescriptions written by a Bangladeshi Doctor. We will give remote access to hypertension measurement data inserted into web-based computer program to selected licensed Bangladeshi medical provider for medical assessment and prescription writing purpose. The selected provider will need to agree with our approach and confidentiality of patients. We will work with a local pharmacy doing business in the community for prescribing medication. If new barriers to care are identified, we will work with patient, close network, and leaders to determine the solution they propose to promote collaborative action in the above described method. For our pilot project purpose, we aim to collect weekly data for a year.

Outcomes:

The primary outcome of this project will be to collect weekly blood pressure reading and make it accessible remotely consistently. Secondary outcomes will be able to meet patient's health goals by promoting collaborative action among patient, close social network, and leaders. Other measure we will look at are patients' satisfaction and subjective assessment of "ownership" of their care.

The outcomes through this project will enable us to gather initial data on the functionality, efficiency, efficacy and initial cost of a patient-centered, community-driven, telemedicine supported chronic disease care model in a medically remote and underserved population in Bangladesh. It will give us information on effective practices in establishing this model in additional populations and will enable us to ask new research and interventional questions to be assessed in modeling care for patients with hypertension in remote and underserved communities using patient's social networks and technology. We will document each of the outcome for individual patients, which will form the basis of necessary modification and expansion of the project.

Budget:

	Item	Quantity/Calculation	Amount (USD)
1.	Blood Pressure Monitor Cuffs	20 (5 Extra); 25 X 50 USD =	1250.00
2.	Computer System (Laptop)	2 (one back up)	650.00 X 2= 1300
3.	Internet setup and software maintenance	For one year	300 .00X 12= 3600
4	Technician Cost	5000 taka/month X 12 months= 60000 taka	750.00
5.	International Travel Cost		1600.00
6.	Internal Transportation		550 .00
7	Living in Rajshahi	500 USD / month X 4 months	2000.00
8	Misc.		500.00
Total			11,000 USD

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