Primary care for chronic conditions in rural India

Impact

The objective of this research was to understand the delivery of chronic care in rural India and to test the implementation of a package of interventions aimed at improving the quality of care for chronic diseases at primary care. I first studied in depth the processes of care for diabetes and hypertension at public (government funded) and private primary health facilities. This understanding enabled me to identify gaps in the delivery of care. Further, I worked with three primary health centres, funded by the government to co design and implement an intervention package to overcome barriers to good quality of care. I found that the package of interventions that included; task distribution, was successful in improving the quality and outcomes of care, however, there were challenges in implementation. Changing practices at primary care is a complex endeavour. I found that local norms and organizational culture such as the prevalent hierarchies that place the doctor at the apex, have a large role to play in the adoption of interventions. I also found that the team is constrained for time and that involving the community health worker to strengthen support for patients in the community was difficult.

The study and its findings has implications for the design of chronic primary care delivery in rural India. Currently, in India, the design for chronic care through government primary health care facilities is guided by the National Program for Non- Communicable Diseases (NPCDCS). The NPCDCS program is vertically structured at primary, secondary and tertiary levels of care. The program guidelines identify a package of services at each level of care. The role for primary care is currently limited and includes health education programs, screening activities and continuation of medication after diagnosis. The diagnosis and initiation of treatment is planned at NCD cells, located at the sub district hospital. A sub district hospital is usually at a distance from most villages and many patients are unable to access the NCD cell for diagnosis and follow up visits. Community based care is not mentioned in the guideline document and apart from health promotion there is no specific role for the frontline health worker. These are some gaps in the structure of the program that I believe the findings of this study will help to fill.

This study enables me to make recommendations for the improvement of the quality of chronic care in rural India, especially with regard to the role of primary care in the NPCDCS program.

1. Primary care is ideally placed to coordinate screening, diagnosis and management of diabetes and other chronic conditions and should be strengthened.
2. Guidelines for tasks that need to be done at primary care facilities should include counselling and foot examination in addition to evidence based treatment. Medical records for continuity of care need to established. Nurse led models of care are

experiment worthy and training of primary care teams especially leaders of the team in relational leadership is important.
3. Person centred approach to health care should include strengthening of community support through a community based model of chronic care as proposed in this thesis.
4. A statement of values underlying the chronic care model, such as person centred, team based, should be made to enhance implementation of interventions to strengthen care.
5. External quality improvement teams should be considered for primary care quality improvement in India.

This study demonstrated the feasibility of an increased role for diagnosis and management of diabetes or hypertension at primary care centres. The focus on primary care is especially important as this is the point of care the closest to peoples' home and is ideal for continuity of care. Traditionally, at PHCs there has been no clinical record keeping for various reasons including constraint of space. A major limitation to chronic disease care at primary health centres is the lack of clinical records and information for follow up of patients. It is possible to treat acute conditions like an episode of diarrhoea or pneumonia without access to prior clinical information but not chronic diseases like diabetes. In my study, we experimented with the introduction of paper based records for patients enrolled for care and this was feasible at the PHC. Therefore, this study showed that primary care needs to be and can be enhanced for chronic conditions like diabetes and hypertension. The NPCDCS guideline could be revised to include a greater role for primary care with a person centred approach.

There were challenges in implementation and this gave insight in how the change towards person centred model of care can be made. Along with introduction of interventions and revisions in workflows or tasks, attention to the local organizational culture, norms and values is required. I found this to be very important. I found especially that the hierarchical arrangements with the doctor at the apex of the team hinders team based care. Thus, consideration of nurse led models as a way to overcome the doctor centred model of care currently prevalent is proposed. Another way in which this can be overcome is through appropriate training of primary care leaders to lead the primary care team with relational principles, taking everyone along and facilitating team based care. And lastly, a statement of values has the potential to influence individual action and create a culture of person centred thinking. We found values that underlie the health care delivery system to be important as they influence the behaviour of individuals in the health system. Values such as putting people and their families at the centre of the care processes and treating all patients with dignity are important. Equally important is understanding that disease is more than an elevated blood sugar reading but is

defined and shaped by the experience of the individual. These need to be stressed in guideline documents to bring about change.

I designed the interventions with primary care teams. This meant that local teams were empowered to plan and monitor the interventions. This involved local capacity building to improve skills at counselling and enable evidence-based treatments. The research team and I played the role of an external quality team to support the improvements in quality. A small but sure impact of the research was in drawing attention to quality, the need to improve quality of care for chronic conditions and the role of an external teams in supporting quality improvement.

These research results are relevant to policymakers that plan for chronic disease control in India and other similar contexts. In India, the officials of the health and welfare ministry concerned with the non- communicable disease program would be a target group for the findings of this study. The national health mission that guides primary health care and community based activities is also a program that could put into practice some of these recommendations. There is a large role for non-governmental organizations in India to demonstrate person centred care for chronic conditions. Civil society organisations like the people's health movement can also set the agenda for person centred care. The findings of this research would be useful to NGOs and civil society organisations in improving the demand for better quality of care.

I plan to disseminate the findings to these groups mentioned above through various channels. I have already presented the findings to the teams I worked with and the district level health officials. There is a general agreement that quality of care needs to be improved and primary care should be strengthened to deliver chronic care. In the course of this work and interactions with the district health officials I notice a greater priority to chronic disease care than before that may have been influenced by this research. The findings of the research have been published in leading high impact journals and contribute to the literature on quality improvement for chronic disease and implementation research in India. I have also had the opportunity to present findings of this work and person- centred chronic care ideas at two consultative meetings that were convened to plan for future directions of primary health care in Karnataka. I am writing a commentary on the findings that present the recommendations mentioned earlier and hope to publish this in a widely read journal as well as in a blog. I also am actively seeking funding to test the model of care I propose at the end of the thesis.

There are millions of people with a chronic condition in India and the numbers are steadily increasing. This research and more are needed to ensure that the health system does not fail people living and coping with chronic conditions.