Adding screening for “end organ damage” to the noncommunicable disease package in primary care

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There are several global and local initiatives aimed at screening for noncommunicable diseases (NCD). The fundamental health system strengthening to achieve this goal is by developing the primary care infrastructure. Most newly developed or improved primary care centers focus on maintaining an NCD register for onward reporting. However, the register is also the cornerstone for implementing systematic screening of all complications of NCDs. With epidemiologic transition, end organ damage due to NCDs is one of the most common causes of morbidity and mortality. Screening for end organ damage and early identification of treatable complications are far more impactful than waiting for self-reported symptomatic complications. Here, we show an example of how the Government of Kerala utilized the NCD register to implement a systematic diabetic retinopathy screening that allows for annual or biennial re-call in the primary care and refer treatable eye conditions to secondary care. The success of this program enabled the Government to initiate a holistic approach to screen for other complications of diabetes.

Key words: End organ damage, noncommunicable diseases, screening

The contribution of good quality primary care, defined as “that level of a health service system that provides entry into the system, provides person-focused care over time, provides care for all but very uncommon or unusual conditions, and coordinates or integrates care provided elsewhere or by others,” to improving health outcomes is well documented. The four key areas covered in this definition are: Functions as the first point of interface between a person and the formal health care system, has a relationship with the individual for a long period, caters to all but specialized health care needs, and coordinates or integrates services received elsewhere in the health system. The quality of primary care system may be assessed on how it performs on these four parameters.

In India, primary care has traditionally focused on mother and child health and communicable diseases but has not focused on noncommunicable diseases (NCDs) [2]. In countries which have passed through the epidemiologic transition, good quality primary care has contributed to reduction in morbidity and mortality from NCDs. Hansen et al. [3] analyzing data from twenty-seven countries in the European Union found that health outcomes for persons with chronic conditions were significantly better in countries with good primary care system. Macinko et al. [4] reported that, in US, increased primary care improved health outcomes including cancer and cardiac conditions especially in underserved areas and among the poor. A strong primary care system and practice characteristics were associated with improved population health in the Organization for Economic Cooperation and Development countries. [5] This was due to better primary prevention, early detection of disease, and overall improvement of efficiency of health systems, including reduced progression to serious conditions, lower hospitalization, and emergency room admission rates. A systematic review of 14 countries found that comprehensive primary health care reduced mortality from NCDs. [6] These studies show that, in mature health systems, primary health care is an effective strategy to address the challenge of NCDs.

A recent analysis of the health status of Indian states shows that an epidemiological transition with increased incidence of NCDs is evident in all states to varying degrees. [7] The most effective strategy to address the challenge of NCDs is to develop capacity in primary care centers to manage them. Good primary care centers maintain an updated NCD register, prepared after screening eligible populations, as the basis for NCD response. With NCD prevalence over extended periods, end organ damage is among the most common causes of morbidity, disability, and mortality. Screening for end-organ damage and early identification of treatable complications are far more impactful than waiting for self-reported symptomatic complications. Given the current state of health system in most states in India, the country does not have the resources, both technical and financial, to treat the conditions that will arise if the complications from NCDs are not detected and treated early.
Since India is attempting to revamp provision of primary care by setting up Health and Wellness Centers (HWCs), the country has an opportunity to introduce flexibility in the package of services that constitute primary care. One of the services proposed to be provided at HWCs is: “Screening, Prevention, Control, and Management of Noncommunicable diseases.” Controlling NCDs is a non-negotiable strategy to reduce NCDs and their complications. But for the states that are undergoing the epidemiological transition this may not be adequate. Policymakers have an opportunity to leverage the strength of the primary care system to reduce the burden that NCDs will impose on India’s health system. The impact of NCDs cannot be handled episodically through emergency room admissions or hospitalizations. Most of the downstream complications of diabetes, for instance, manifest themselves as symptoms only when they have reached levels of permanent damage, be it ophthalmic, neurological, or nephropathic and can often be irreversible, debilitating, and very expensive to manage. Given the shortage of secondary and tertiary facilities in India, especially in semiurban and rural settings, only a small percentage of the people who need treatment are likely to get it. Since these facilities are mostly in the private sector and the dominant mode of financing is out of pocket at the point of treatment, only the rich can afford them. The poor, if they access the system, will end up liquidating their meager assets or going into debt.

Primary care providers (PCPs), on the other hand, screen even asymptomatic persons who are eligible to be screened. If diabetes and hypertension are picked up early, which is possible if the eligible population is screened as per national guidelines, primary care providers stand the best chance of ensuring that the conditions are kept within safe limits. Good PCPs build up long-term relations with their patients, communicate regularly with them, understand their barriers to treatment, track their compliance to pharmacological management and lifestyle changes, monitor their status, and adapt the regimen to suit their needs.

However, this is not enough in communities that crossed the epidemiological curve years ago. At that time, no state in India had a good primary care program for the detection and management of NCDs. Thus, diabetes and hypertension (and other NCDs) were not treated, except in instances where they were picked up opportunistically. Even then they were detected in a hospital setting and managed for the proximate condition without any follow-up. Therefore, uncontrolled diabetes and hypertension is likely to have been prevalent for a long time and would have led to substantial end organ damage in the population. This would include proliferative retinopathy, peripheral neuropathy, and nephropathy for diabetes and stroke, retinopathy, coronary heart disease/myocardial infarction and heart failure, proteinuria and renal failure, and in the vasculature, atherosclerotic change including the development of stenoses and aneurysms in hypertension. To illustrate the role and feasibility of primary care to detect and manage end organ damage of NCDs, we describe how the government of Kerala utilized the NCD register to implement screening for diabetic retinopathy (DR) and refer treatable eye conditions to secondary hospitals. This became a template for a holistic approach to screen for other complications of diabetes.

In the National Health Service in the United Kingdom, diabetic retinopathy screening is a stand-alone service. Although it is logistically easier to deliver the service, it also has the disadvantage that it is removed from the holistic package provided in primary care for other complications.

**Diabetic Retinopathy Care Pathway: The Kerala Pilot Study**

In 2016 Kerala launched the Aardram Mission for health sector reform. An important component of the mission was to restructure services available in primary care centers in line with the current epidemiological situation, increasing emphasis on NCDs and mental health, and reducing the focus on family planning. There were concomitant changes including additional staff (three doctors in place of one, four nurses instead of one, an additional pharmacist and lab technician), additional infrastructure, increased working hours (9 am to 6 pm instead of 9 am to 2 pm), digitization of patient management and electronic health records.

Kerala is one of the states that has progressed further along epidemiological transition than most Indian states. A recent study found that one-third of the adult population had hypertension and one in five have diabetes. However, only 13% of persons diagnosed with diabetes achieved glycemic control and only 16% of those with hypertension achieved the targeted blood pressure. In response, the Government of Kerala had started a program to manage the NCD burden in the state. This included screening for diabetes, hypertension and Chronic obstructive pulmonary disease (COPD), their pharmacological management, and counseling on lifestyle modifications. Persons eligible for screening, based on age, were selected from the Family Health Register and invited, through community health workers, to be screened for hypertension and diabetes. Positive cases were entered in an NCD register, which formed the basis for monitoring treatment compliance and disease progression.

However, the program did not address screening for end organ damage as policymakers, while recognizing the need, did not have replicable models to guide them. To address the problem of DR, the Government of Kerala collaborated with Moorfields Eye Hospital, London and other institutions in UK within a UK Research and Innovation Global Challenge Research funded project to undertake research to test the feasibility of DR screening and care pathway using the government health system at the primary care center but involving secondary and tertiary institutions in one district in Kerala. This was a major shift in strategy as symptomatic DR patients would normally go to a tertiary care centers for treatment, stressing the already crowded facilities there. Detecting DR early at the primary care center, from where the positive cases are directed to secondary or tertiary care center as per their need, would improve quality and reduces stress points at tertiary care centers.

The project was implemented in 16 Family Health Centers (FHCs)--transformed primary health centers (PHCs) linked to four secondary and one tertiary hospital. Screening was offered to all the persons registered in the diabetes registry in the FHCs where they were mobilized by the community health workers. General nurses were trained to carry out mydriatic fundus photography using a fixed model...
of nonmydriatic camera. The retinal images were transmitted through the IT network at the FHCs and graded remotely by trained ophthalmologists. All those who were screen positive, had ungradable retinal images and other eye conditions that required attention were referred to ophthalmologists at secondary hospitals. They were equipped and trained to carry out laser treatment for sight-threatening DR (STDR). Severe cases were referred directly to the tertiary center.

The success of the project was assessed by the percentage of people eligible to be screened who were screened, proportion of ungradable retinal images, images positive for STDR, cataract cases, by a comparison of the visual acuity of persons who were referred from the project compared to self-referrals using the current mode of care, and the number of cases of visual impairment averted by timely screening and laser treatment for STDR. Since the FHCs are close to the residence of patients, they are normally visited for all minor illnesses and since DR screening takes place after an appointment, this adds to the comfort level of patients. For the government, a case managed at the FHC level is less expensive than at a secondary or tertiary hospital. STDR picked up early is less expensive and more efficient to manage.

The project has proved the feasibility and effectiveness of DR screening in a primary care setting and treatment in secondary care hospitals. This is a more efficient way of managing DR than using tertiary hospitals as is the practice today. The success of the project has given confidence to the Government of Kerala not only to scale up the DR care pathway to the entire state, but also to introduce screening for diabetic nephropathy and foot care in all the FHCs in the state. The three services together add a vital missing ingredient to the primary care strategy of a state that has a large number of persons with diabetes and its complications.

Some challenges have been identified in scaling up the pilot project. The addition of screening for DR added to the workload of the FHC, which had already seen increased patronage due to new services and improved quality. Persons detected with early-stage DR were reluctant to undergo treatment as they did not perceive any disability. The Community Health Workers, while they were incentivized to bring patients for screening, could not ensure that all positive cases accessed treatment. This calls for identifying and addressing knowledge and attitudinal barriers that dissuaded those testing positive for DR to access treatment.

The need to screen for DR has been recognized in other states too. Interventions done in Tamil Nadu and Telangana also demonstrate the feasibility of integrating DR screening into the primary care system. While the Tamil Nadu government has focused on screening using portable fundus photography in tertiary and secondary hospitals, a pilot project done in partnership with an NGO has commenced screening with portable fundus cameras at block level PHCs in 4 districts and is involved in the process of setting up 5 mobile ophthalmic units for screening in remote areas. In 2019, Telangana set up a pilot program in 10 centers in two districts to screen for DR using AI-enabled fundus camera where the images would be read remotely by ophthalmologists. Results from the first six months of implementation are promising. The experience of the two states also demonstrates that integration of DR screening and by extension, other end organ damage from diabetes is possible within primary care settings with appropriate policy and implementation measures.

Key operations for national implementation of a DR screening program in other states

1. Revision in policy and redesign of primary care: Most complications of diabetes can be managed in primary care settings, integrated with secondary or tertiary care where needed. However, to scale this up in other states, a revision in policy and a redesign of primary care is needed. The current guidelines of National Program for prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and stroke (NPCDCS), which is the national program for management of NCDs, does not explicitly recognize the problem of complications from NCDs. The health information system for NPCDCS also does not have a provision for reporting on common complications. Without data on the prevalence of complications from NCDs, it will not be possible to generate evidence to convince policymakers. But since states differ from each other on the level of epidemiological transition and health is a state subject, state health departments can examine whether end organ damage is already a problem in their state. If the assessment reveals that it is a problem, they should consider integrating screening and management of complications of NCDs, into the primary care package in their state.

2. Preparation and planning: The biggest hurdle is likely to be a change in the mindset of primary care providers, who are trained to focus on family planning, mother and child health, and management of communicable diseases. Expanding the scope of their work to include the complications of hypertension and diabetes is moving beyond the familiar and therefore unsettling. While explicit policy statement by the government including screening and management of end organ damage is a necessary condition, it is not adequate. Primary care providers need to understand the role of this service in ensuring population health in their catchment population. Epidemiological data and details of hospital admissions from conditions that could have been prevented by early detection and management are useful as advocacy tools. Pradhan Mantri Jan Arogya Yojana (PMJAY), the arm of Ayushman Bharat that pays for hospitalization coverage, lists at least 44 procedures related to complications from NCDs that are sensitive to early intervention. If baseline data is available, then screening and management of end organ damage in primary care setting could be run as intervention research to demonstrate its feasibility and impact.

3. Building capacity at PHCs: After convincing primary care providers and instilling confidence in them that they are capable of carrying out the interventions and making a difference, it is important to build capacity. The workload of the PHCs may make the team reluctant to take on new work. Re-arranging the work or hiring additional staff may be required at least for some of the functions. Skills for foot examination, with or without aids, ophthalmic examination, and interpreting values for albumin or microalbumin tests will have to be taught. If aids such as biothesiometer or fundus camera are used, they have to be procured and the assigned member of the team has to be trained on how to use them and interpret their results.

4. Ensure treatments can be provided at secondary or tertiary care: Screening has to be followed up with intervention if
needed. Some of the interventions are difficult to provide in primary care setting. Therefore, the primary care team has to be linked to a secondary or tertiary care center through a referral network. These institutions can also handle training and mentor the primary care providers. The hypertension and diabetes registries, which track positive cases, can function as the baseline document, for other interventions.

5. Health education and behavior change: The primary care team has to assume responsibility for ensuring that patients are offered health education on the necessity of glycemia and blood pressure control, screening and management of hypertension and diabetes, screening for end organ damage, referral to higher centers for management, helping patients navigate the levels of care, and continue to support them post procedures. Communication on the need for annual screening for end organ damage has to be given to persons with diabetes to ensure uptake of screening and follow-up treatment. It is important to stress that DR is symptomless in its early stages and early identification is vital to prevent vision loss.

Conclusion

The strengths of a good primary care system can be effectively leveraged for the management of NCDs in the population. Good primary care is people centered, is founded on long-term relationship between individuals and primary care provider teams, involves the community they care for, is capable of equipped to support them to navigate their way through the health system, and is integrated with secondary and tertiary levels of care. In communities that have a long-term prevalence of NCDs, there is bound to be a high incidence of disease complications. When the primary care team is skilled to diagnose these complications and is integrated with the rest of the health system, it can smoothly pass NCD patients on to higher levels should the need arise and receive them back for continued follow up, which can considerably cushion the impact of end organ damage from NCDs. Kerala has demonstrated that this can be successfully implemented in the Indian context, if the policy decision is taken to facilitate them, additional resources are invested, and provider teams are mentored and trained to provide these services. Given the rapidity of epidemiological transition that is happening in all Indian states, soon the question will no longer be whether the government can afford to integrate the management of end organ damage in primary care setting, but whether it can afford not to.

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