Consultative Workshop:

Formative Research on Engaging Frontline Workers in Non- Communicable Diseases and Palliative Care

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Background:

As costs of health care increase with the poor bearing a disproportionate burden of disease there is an increasing need to establish systems for combating Non Communicable Diseases becomes an imperative. Primary and secondary prevention for NCD will need innovative delivery models. Across the country there are examples from several non governmental agencies that have engaged frontline workers in a range of roles for prevention and health promotion related to NCD. A few states have begun actively involving ASHAs (female community health workers in most states of India at the level of about one per 1000 population) in NCD and in palliative care. The 12th Plan document also recommends that frontline worker such as the ASHA be involved in NCD. In order to understand the possible roles and areas for involving frontline workers in NCD and palliative care formative research in this area is a priority. It is also important to review national and global experiences and outcomes related to this issue and posit the findings against the existing capacity of the frontline workers, including the ASHA and support structures, to better enable support to the centre and states to design and implement context specific interventions. NHSRC organized a consultative workshop of practitioners and researchers to identify a set of issues on which formative research could be commissioned. The meeting was chaired by Ms. Sujaya Krishnan, JS, MOHFW, and also attended by Dr. D.C Jain, DDG, MOHFW. The list of participants is at Annexure 1. The workshop format combined presentations to enable an understanding of implementation issues, and open discussion to generate ideas for planning and research.

Dr T. Sundararaman in his inaugural session, welcomed participants and said that his vision for the workshop was that it serve as a platform that would enable participants to define questions that need to be researched, identify evidence gaps, and suggest topics for research to define roles of frontline workers for NCD in the near and medium term.. He talked about the need and levels of preparedness for a shift in public health policy focus from Reproductive and Child Health to also include non communicable disease related services, especially in states like Punjab, Himachal Pradesh, Kerala and Tamil Nadu. Currently government facilities such as medical colleges, the Regional Cancer Centres in a few states, offer tertiary level care for cancers, but care for other non communicable diseases at all levels is largely inadequate. Preventive services for NCDs have not yet been implemented in a systematic manner. He highlighted the need to make diagnostic and curative care for NCD affordable and easily accessible while also implementing the preventive measures for NCD in a focused manner. He asked that the group identify NCD interventions that can be delivered at community level, define the skill sets for the Community Level Workers like

ASHAs and specify measurable outcomes (demonstrated reductions in mortality/morbidity and reduced out of pocket expenditure). Considering the fact that ASHAs at present are devoting 15 to 18 hours/week and the recommendation of the HLEG report that about 12 person hours per day of a CHW would be required to address existing activities and adding on NCD interventions, we need to understand the implications of increasing the ASHAs tasks and to move towards two full tiem community level nurses.

Ms. Sujaya Krishan, Joint Secretary, MOHFW said that the community health worker should fundamentally ensure the access to public health facilities. She also added that disability, blindness control programme, deafness, geriatric care, mental health and palliative care should be covered under the scope of the existing NCD program and should be integrated with other vertical national programmes. She expressed the view that the community health workers could play a vital role in making NCD services accessible to the community, but that it was important for the group to consider the fact that the ASHA already works between three to five hours a day. Their recommendations should be rational in task allocation and should also specify the skills that the ASHA or other frontline workers would require.

Dr. Dinesh Jain, DDG, MOHFW pointed out that presently there is a project underway to address NCDs in about 100 districts, but that the scheme was being reworked, since the pace of the programme was slow.

After the opening addresses, there were five presentations on community based models to address non communicable diseases. The power point presentations are at Annexure 2. A brief summary of the presentations is as follows:

Dr Manjula Dutta, Senior Scientist from ASPIRE and Kidney Help Trust, Chennai, presented the experiences from the project which focused on community based management of diabetes and hypertension to prevent/delay the onset of renal disease in 26 villages in Tamil Nadu, covering a population of 24,600. Key elements of the model include: a) Recruiting and training Class XII passed girls (local residents) to a) Conduct a household survey once a year, b) test for urine protein and glucose, measure blood pressure and identify symptoms of chronic diseases, c) management with low cost drugs and d) surveillance for complications. After initial screening, people with abnormal findings are referred to a doctor for diagnosis and initiation of treatment. The programme was expanded after eight years to cover additional population of 23,000 which was also used as control area to assess the impact of the programme. The evaluation demonstrated that community based management and low cost drugs were effective in preventing renal disease onset. The interventions also had an effect on cardiac, neural, vascular and retinal complications. Dr. Dutta emphasized that the success of program was largely due to the presence of a trained community health workers who by virtue of being a local resident, was able to establish community rapport to enable early screening and monthly home based follow up and ensure compliance with treatment as well as life style modifications. Dr. Dutta shared that the average cost of the

programme was only Rs. 24.76 per capita per year and stressed that such cost effective community based models can prove very beneficial in improving access for health care services.

Dr. Anand Krishnan, faculty member at the All India Institute of Medical Sciences, (AIIMS) and lead for the WHO Coordinating Committee for Capacity Development and Research in Community based NCDPC**.** presented findings from a research study titled the "Role of Community Workers in NCD Prevention and Control- Experiences from Urban and Rural NCR'. Here ASHAs and community volunteers were trained to conduct risk assessment, provide counselling, follow up for compliance to treatment, scan community resources for NCD issues and hold community meetings. Various tools were developed for community health workers such as training modules, risk assessment questionnaires, family score card and log book. The ASHAs were supervised by the research staff. Overall findings were that frontline workers could undertake the defined tasks under the programme. Some of the challenges faced were lacunae in establishing referral linkage with doctors / health facilities and reservations faced by female health workers while interacting with men. Most of the workers on an average earned Rs. 800-1500 per month. Although the incentive amount was low, workers expressed that the community recognition for these activities was high.

Dr Elizabeth Vallikad, Professor and Head Department of Gynaecologic Oncology at St. John's Medical College presented the strategies adopted for 'Down-staging Cancer Cervix through Government Health Infrastructure'. The programme was based on utilizing the existing government health facilities (starting with the ANM) by using simple inexpensive methods like visual inspection with appropriate referral. The programme was launched in four phases and used different strategies to understand what works under in each context. Phase IV (2001-04) was a collaborative effort between Departments of Health and Family welfare, Women and Child Development, Rural Development and Department of Gynaecologic Oncology (SJMCH). Following the success of the model, Government issued a circular to introduce Visual Inspection to Downstage Cancer Cervix on a statewide basis in a Phased Manner – starting with Shimoga District in June 2005. Despite this, the model was not scaled up. She also stated that one third of known cancers are preventable, one third require curative and the remaining one third need palliative care, and that primary health care should focus on the first third, and facilitate early detection for the second third. Frontline workers also have an important role to play in palliative care. .

Dr Matthews, Medical Officer, NRHM Palliative Care Project shared the experience of Community Based Palliative Care Program in Kerala, which included Local Self governments, Government hospitals, Kudumbashree system, Community Based Organizations and community level health workers / volunteers. The programme encompasses primary, secondary and tertiary palliative care units. He highlighted the significant role of ASHAs / community level health volunteers in identifying patients in need, linking the patients with the health system, providing psychosocial Support and being an essential member of the home care team.

Dr Rahul Shidaye, Deputy Director Centre for Mental Health, Public Health Foundation of India, made his presentation on Role of Frontline Workers in bridging the gap for Mental Disorders and shared the details on PRIME, an ongoing research programme funded by UKAID in countries like Ethiopia, India, Nepal, Uganda and South Africa. He highlighted the critical role of community health workers in the programme specifically in the Community based mental health programme in Vidharba region of Maharashtra – "Vishram".

Highlights of Discussion: The group felt that all the models presented above had used frontline workers in various ways, and built their competencies to address several of the NCDs. It would now be important to study the models in depth and analyze how they could possibly be scaled up in their contexts or adapted for scaling up in other contexts. The group then discussed key areas for formative research across four NCD clusters: Cardiovascular diseases, Cancers, Mental Health and Palliative Care. Issues for discussion included:

1. What are the activities/tasks and outcomes expected of frontline worker (ASHA, ANM, Male Health Worker), assuming that the referral back up is at the level of a PHC Medical officer, and a specialist in the district hospital, ensuring a continuum of care between these three levels.
2. What are the competencies required of each category of frontline worker, and mid level providers? (such as a Community Health Officer, if this cadre was to materialize)
3. What are the underlying principles to design and plan allocation of tasks to each frontline worker amongst the varying types of workers available in the following areas:
    a. Training needs
    b. Technology needs (equipment/drugs)
    c. Information system needs
    d. Support and Supervision
    e. Referral pathways

While not all the areas could be covered for want of time, the following topics for formative research, possible areas for involvement of frontline workers, and competencies were generated:

1. Cardio vascular disease, Diabetes, Stroke : Led by Dr. Manjula Dutta

a) Assessment of Health seeking behaviour, Out of the pocket expense-and disease burden
b) Possible roles of frontline workers in behaviour change for substance abuse/ addiction
c) Explore new technology options for job aids for monitoring and supervision
d) Compare the results of opportunistic screening versus mass screening
e) National level survey related to CVD/ diabetes for identifying whether the new cases that have been detected actually got any preliminary care prior to detection (coverage evaluation of NPCDCS program).
f) Understand care seeking behaviour of populations, to enable planning for behaviour change, enable cooperation for screening, and referral linkages

g) Reliability and Sensitivity assessment of Risk score assessment approaches for use by frontline workers.
h) Development and field testing of appropriate indicators for field testing.

The group also suggested the following Activities/tasks and outcomes expected of frontline worker (ASHA, ANM, And Male Health Worker):

- Primary Prevention through raising community awareness and health education on the importance of balanced diet and physical activity
- Training for screening and early detection.
- Reinforcing compliance with treatment through home visits and counsleign of patient and family members.
- Providing support for appropriate referral to the system – escort and navigation
- Monitoring and supportive supervision through onsite surprise visits, data validation and work reports
- Outcomes could include: New cases detected and referred for treatment, Hypertension patients whose BP remained controlled, (could be incentivized), New cases of IHD detected and those that have come down, Complications who had a specialist referral for a complication (for most CVDs, Diabetes and strokes, and for epilepsy this would mean cases who were seen by a specialist and remained controlled, Patients who adhered to treatment more than 90% of time).
- Primary care centre should have a follow up regime for cases detected and referred by the frontline worker.
- Innovations in diagnostics for primary care providers are needed

2. Cancers: Led by Dr. Elizabeth Vallikad

a) Assess competencies of frontline workers required for early detection of cancers
b) Skills required for frontline workers to support patients and their families
c) Study the experience of existing models using frontline workers to assess in situ Ca Cx (VIA in Tamil Nadu)
d) Develop approaches for screening of Polycystic Ovarian diseases in working women and students and for colonic cancer that appear to have a rising incidence

Activities/tasks and outcomes expected of frontline worker (ASHA, ANM, And Male Health Worker):
The frontline worker has a role at each level that includes-

- Health education for prevention- in case of preventable cancers like oral and liver cancer, and vigilance for symptoms,
- Teaching self palpation (breast Ca) and visual inspection (oral Ca)
- Follow up and support to patients in case of referral for tertiary care,
- Ensuring continuity of treatment; intermediate treatment and the follow-up

- Residual disease detection and follow up at PHC level.
- Management of terminal care- palliative care
- Counseling on life style.
- The training period for ANMs for visual inspection for Ca Cx was about three months. It was pointed that training on visual inspection is relatively easier for ANM who has prior experience of inserting cervical speculum, but other frontline workers may need more training.

3. Palliative care : Led by Dr. Sakeena

a) Evaluation of existing palliative care models (include components of palliative care package, referrals, coverage, quality of care, out of pocket expenditure).
b) Calculations of the number of worker and / or the number of hours for providing palliative care and number of beds/nursing staff/any other support to provide palliative care.

Activities/tasks and outcomes expected of frontline worker (ASHA, ANM, And Male Health Worker):

- Palliative care needs team work. The Frontline worker can provide preventive (awareness building), diagnostic, and curative service. Apart from this he/she is also helpful in referral and rehabilitation activities. The existing technology must be used in execution of these services by FLW.
- Early domiciliary detection and Identification of bed ridden patient through HH surveys.
- Demonstrate and carry out activities for home based care of bed ridden and terminally ill patients
- Mobilization of community resources for patients in need.
- Mobile Health Units and a nurse led team at the PHC could play a useful role in supporting the frontline worker.
- Involving family in counselling and supportive care.
- Convergence with NGOs / other Departments – Panchayat, Women and child department.
- Maintaining records and ensuring compliance with treatment if any.
- A training of at least one month that includes both theory as well as practical in proportion of 20 and 10 days respectively is necessary, followed by refresher training through monthly visits with home care team.
- The FLW must be able to maintain confidentiality, and her skills developed in identifying and preventing stigma and discrimination, and in empathy and non judgemental attitude

The Indian Association of Palliative Care provides online course and the state could support particaption and completion of the course by existing frontline workers.

4. Mental Health: Led by Dr. Rahul Shidaye

a) Algorithms that can be used by frontline workers to identify conditions like - stress, anxiety, suicidal tendencies, alcoholism and depression

b) Feasibility of an incremental approach to building competencies of frontline workers: i.e, skills to identify obvious symptoms first, followed by higher level of skills to identify sub clinical conditions.

Activities / tasks and outcomes expected of frontline worker (ASHA, ANM, And Male Health Worker):

- Mental health requires team work and therefore the frontlien worker should be adeualtely supported and backed up by a sotrng primary health care system.
- Drug abuse and domestic violence should be considered under mental health.
- Incremental approach is required for a program for mental health.
- Mental Health Program can use a Layering approach with any other public health program.
- Mass level awareness and propagating of Mental Health Literacy should take place through small group meetings.
- Follow up and active management of patient is necessary.
- Psycho social interventions need to be an integral component of the intervention plan.
- Rehabilitation and Follow-up of Pharmacological Treatments is also equally crucial component.
- Existing training institution (i.e. SIHFW), counseling institutions and counselors can be used to train frontline workers. However selection of appropriate trainers is necessary given that the issue requires empathy, understanding of stigma and ability to take action against discrimination, and psychosocial counseling.

Other issues discussed:

Mr. V.R. Raman, PHFI, also indicated that primary ophthalmic and dental care should be included in the service package for frontline workers in the NCD program..

Dr Kapoor, St. Stephen's Hospital suggested that a new cadre of worker be created instead of overburdening the ASHA.

Dr D C Jain: empathised that the Government was considering a holistic approach to the issue of NCDs. His view was that the current training at NIMHANS be reduced from 3 months to 3 weeks. He added that the in the 12th five year plan, it has been planned to develop a data base of all non communicable disease and risk factors therof. He also pointed that the infrastructure is available for a program for non communicable diseases, but there is significant dearth of human resource for providing the necessary care and health education. Although the government has increased seats for UG/PG in medical college by nearly 25%, it would still take another 8 years for this additional human resource to be available. Thus the role of frontline workers was critical.

Dr Balasubramanya, advocated testing the use of technology for dissemination of information and monitoring of NCD program.

The meeting closed with a vote of thanks by Dr. T. Sundararaman, who said that NHSRC would develop a plan for formative research using the workshop inputs. He said that this would need partnerships for funding and research, and that workshop participants would serve as key partners.

Annexure 1: List of Participants:

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