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Integrated Non-Communicable Disease Management in Low-Income Settings: Exploring the synergies between Palliative Care, Primary Care and Community Health

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Keywords:	Chronic conditions, Cultural issues, Home care

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Integrated Non-Communicable Disease Management in Low-Income Settings: Exploring the synergies between Palliative Care, Primary Care and Community Health

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ABSTRACT

Palliative care is recognized as a fundamental component of Universal Health Coverage (UHC) which individual countries, led by the UN and WHO are committed to achieving worldwide by 2030 - Sustainable Development Goal (SDG) 3.8. As the incidence of non-communicable diseases (NCD) in low and middle-income countries (LMIC) increases, their prevention and control are central aspects of UHC in these areas. Whilst the main focus is on reducing premature mortality from NCDs (SDG 3.4), palliative care is becoming increasingly important in LMIC in which 80% of the need is found. This paper discusses the challenges of providing comprehensive NCD management in LMIC, the role of palliative care in addressing the huge and growing burden of serious health related suffering and also its scope for leveraging various aspects of primary care NCD management. Drawing on experiences in India and Nepal and particularly a project on the India-Nepal border in which palliative care, community health and primary care led NCD management are being integrated, we explore the synergies arising and describe a model where palliative care is integral to the whole spectrum of NCD management from promotion and prevention, through treatment, rehabilitation and palliation. We believe this model could provide a framework for integrated NCD management more generally in rural India and Nepal and also other LMIC as they work to make NCD management as part of UHC a reality.

Key Words: Universal Health Coverage, Non-communicable disease management, palliative care, community health, primary care, low and middle income countries, India, Nepal

INTRODUCTION

In 2015 the UN agreed a set of Sustainable Development Goals (SDG) to be achieved by 2030. SDG 3.8 commits to the achievement of Universal Health Coverage (UHC), which is defined as 'all people and communities [are able to] use the promotive, preventive, curative, rehabilitative and palliative health services they need, [which are] of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.'[1]

Palliative care is now recognized as a fundamental component of UHC[1] and a human right.[2] In 2014 the World Health Assembly agreed a declaration that signatory countries would ensure the availability of palliative care throughout a person's life course by incorporating palliative care into their health services.[3] However, in 2013 it was estimated that only 20 (8%) of countries had achieved high levels of integration of palliative care into their health systems and Uganda was the only low or middle income country (LMIC) to have done so.[4] Of the 25.5 million people in the world with serious health related suffering (SHRS) each year, 80% live in LMICs.[5] Poverty, lack of health care resources and frequently complex social and cultural issues make achieving palliative care integration in LMICs challenging.[6] Moreover each country needs to define how

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it will achieve the integration to which it has committed and to develop the evidence base for it.[7]

Achieving UHC including palliative care in LMIC by 2030 is a great challenge made all the greater by an emerging global non-communicable disease (NCD) pandemic.[8] Both India and Nepal have made serious efforts to ensure they are on target to provide UHC having launched recent health plans in which it is a primary aim.[9, 10] In 2017 Nepal also adopted a Strategic Plan for Palliative Care with an emphasis on nationwide provision through primary health care [11] and similarly India, in its Health Plan (2017), included palliative care in its vision for primary care led UHC.[10]

Both countries, along with other low and middle income countries are undergoing a dramatic demographic shift, with increasing numbers of people living with and dying from NCDs. WHO data modeling suggests that in India 53% and in Nepal 60% of all deaths are due to NCDs, making deaths from NCD significantly higher than in other low income countries such as those in sub-Saharan Africa.[12] In these South Asian countries the commonest NCD deaths are from cardiovascular and respiratory diseases, with cancer making up only around 6-8%.[12]

The recent Nepal STEP survey found that 26% of the adult population had raised blood pressure with 90% either being undiagnosed or not being adequately managed; 4% had raised blood sugar.[13] Hospital admissions are increasingly frequent for NCD related episodes.[14] In a recent needs assessment in two rural districts in Nepal we discovered that very few of the patients surveyed who were living with NCDs were receiving integrated NCD management.[15] In two studies from Nepal reported in 2017, 10% and 30% of patients admitted to hospital respectively had palliative care needs.[16, 17]

The main drivers of the increase in NCD prevalence in low-income settings are changes in lifestyle with increasing levels of obesity, type-2 diabetes, hypertension and smoking. Whilst the incidence of diabetes and hypertension are higher in urban than rural areas,[13, 18, 19] numbers here are also increasing. [20] In addition in rural areas there are fewer health workers and people are less likely to be able to access comprehensive health care.[20, 21]

Cancer incidence is also increasing with late presentations being the norm as there is lack of awareness and little screening available.[22, 23] In rural north India and southern Nepal, the common cancers in men are oral, secondary to smoking and chewing tobacco, often mixed with betel-quid [24] and lung cancer and for women, cervical (few women have regular pap smears and generally girls do not receive HPV vaccination)[25], and breast cancer.[26]

WHO advocates for primary care led systems of NCD management to be developed which are appropriate for LMICs.[27] This enables NCD management to be delivered close to the patient's home and at less cost to both the patient and health services than if management is secondary care based.[28] WHO has developed guidelines for primary care led NCD management which are adaptable

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within the local setting.[29] Containing health costs from NCD management is vital in low income settings as out of pocket expenditure on chronic disease management is rapidly increasing.[30] There is evidence that health costs from the management of cancer and complications of NCDs are the commonest way families fall into debt and poverty.[31]

However in Nepal and in 'low-income' northern states of India there is little or no provision of integrated NCD management.[20] As in other low income settings, health care provision is based on a model of acute care with little development of systems appropriate for chronic disease management.[32] New models are needed which establish a platform for integrated management which can include prevention, screening, treatment of NCDs and their complications along with rehabilitation and palliative care.

In this article we present a new model for palliative care *and* NCD prevention and control which is being established in a project in the north Indian state of Bihar, in a rural district bordering Nepal (see figure 1). We believe this project could provide insights for other LMICs which are looking to develop integrated programmes for NCD management as part of UHC. This model (see box 1) uses a community palliative care approach which has been developed in north India [33] and which is now being extended to include NCD prevention and treatment through collaboration with community health and primary care.

(place figure 1 here)

Figure 1 – Map of North India and Nepal showing project site

Box 1 – The CHETNA Palliative Care and NCD Management Programme
The CHETNA NCD programme was established in April 2017 in East Champaran District of Bihar State, which borders onto Nepal. The project's aim is to raise awareness of NCDs (particularly diabetes, hypertension and cancer) in the population and amongst other stakeholders, including primary health care providers working in government Primary Healthcare Centres and Sub-Health Centres. It also aims to provide screening for hypertension, diabetes and oral cancer, to facilitate the provision of appropriate and affordable NCD management and to provide holistic palliative care to those with advanced disease.

The project is delivered by the community health department of The Duncan Hospital, Raxaul, building on work previously undertaken in various aspects of health, nutrition and sanitation. Palliative care is central to the project and is delivered according to a model of community palliative care based on home visits, developed by Emmanuel Hospitals Association (EHA), which is appropriate for rural north India.

The community health team, made up of experienced community health professionals, is led by a community medicine specialist and includes a registered nurse who leads the palliative care service along with several

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community health workers who have received training in providing palliative care. Physicians and family practitioners from Duncan Hospital with palliative care experience support the palliative care team in undertaking home visits as necessary.

Community health staff have been taught how to take blood pressure readings and use a glucometer to measure blood sugar. Working to strict protocols they refer people found with raised blood pressure or blood sugar readings to Duncan Hospital for formal diagnosis and implementation of management. Oral surgeons have also taught the staff how to screen for oral cancer and precancerous lesions.

Non-clinical community health team members have produced health education material in Hindi and undertake awareness-building events in the community, including in secondary schools. They have also worked with local community groups (called 'Sewa Dal'), which were formed as part of a previous awareness-building programme for mental health.

Government health workers including Auxiliary Nurse Midwives (ANMs) who provide village level health care are being trained at Duncan Hospital to provide follow up and maintenance for patients who have been diagnosed with NCDs. The community team also visit people diagnosed with NCDs (not in need of palliative care) who are unable to easily travel for follow-up.

Patients, particularly those with complex problems e.g. suspected cancer, are asked to attend the hospital clinic on a Friday and Saturday when they can be accompanied by team members through the busy clinics and helped to understand the need for ongoing therapy, particularly if it includes referral to a higher centre for cancer treatment.

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BACKGROUND TO THE PROJECT

In 2010 the Emmanuel Hospitals Association (EHA), an Indian association of 22 mission hospitals, established a model of community based palliative care in rural north India. This innovative service model, designed following a needs assessment was initially piloted in five EHA hospitals and subsequently evaluated.[33] The initial needs assessment found that people requiring palliative care, particularly those with advanced cancer, do not frequently present to local hospitals or clinics but are sequestered in their homes, often receiving very little care or attention from their families. This results from large amounts of money having been spent on cancer therapies which have made the family impoverished. The person with advanced cancer and the family return home but the family have little or no insight in how to care for them. There is also considerable stigma attached to advanced cancer, particularly when it involves fungating wounds and a frequently held belief is that cancer is transmissible.[34] These issues compound the fears and sense of hopelessness for the person with cancer and their families.

In order to find people in need of care, the palliative care teams use various case finding strategies in the community. These include a health education approach

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in villages speaking to local groups, often of women, explaining about cancer and how the team are able to offer care for people at an advanced stage. The team are often told about friends or neighbours where there is someone with advanced disease and on visiting the family they offer to do a home assessment and provide care as needed. In other sites teams have found that awareness building in schools can be effective, often with teachers alerting the palliative care team about possible people needing their care. Other groups assisting in case finding include 'traditional health workers' and Ayurvedic practitioners.[33]

Distinctive features of the CHETNA NCD Programme

The CHETNA model has extended the EHA palliative care model by providing an integrated palliative care service as part of a NCD prevention and control strategy. The project is being led by an experienced community health team trained in palliative care. The team have combined their understanding of the stigma and hiddenness of end stage illness with awareness building for NCD prevention and control, screening for NCDs and enabling primary care led NCD management. They raise awareness of the effects of unhealthy practices such as smoking, chewing tobacco-betel quid, lack of exercise and obesity and the link between these and hypertension and diabetes in the etiology of serious NCDs such as CVA, ischaemic heart disease and cancer. In addition, through training at Duncan Hospital and working in rural health centres, the CHETNA team are equipping primary care providers in the locality to deliver integrated NCD management, so that people can receive care close to home, rather than repeatedly travelling potentially long distances to hospital. Results from the first 15 months of operation of the project are given in Table 1.

A remarkable synergy between palliative care, community health and primary care NCD management has been emerging (see figure 2) which we present in the next section.

(insert figure 2 here)

Figure 2: Chetna model of Palliative Care NCD management and Community Health and Development

SYNERGY EMERGING

Palliative Care and Community Health and Development

Rural Bihar has some of the highest poverty rates in India with poor health indicators and low levels of literacy.[35] There has been considerable investment in community health to try to improve the health status and health outcomes. However because of severe staff shortages, low educational rates among local communities and lack of investment in local infrastructure, most of the community health professionals working in such settings are not local. The consequence of this is that they are often looked upon with suspicion by the local population and do not necessarily understand local health beliefs.[33]

In established EHA palliative care projects, the service provided has been transformational to communities and has created new pathways to healthcare. Patients and families are given new hope and the providers, by touching and

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WORKFORCE	**Number (status)**
CHETNA community health Team	10(Employed by Duncan Hospital)
Sewa Dal – community groups	157 (Volunteers) (*16 groups)*
TRAINING/ AWARENESS/ ADVOCACY	
Training delivered by programme/ hospital	**Number (status)**
Government primary health care staff (ANM)	53 (Government employees)
Government community workers (ASHA)	135 (Volunteers)
Faith based organisations	137 (Organisation members) from 4 groups
Awareness building in the community	**Meetings and attendance**
NCD general awareness programmes	30 meetings in 20 villages. Estimated 1890 attended
	10 meetings in schools. Estimated 1680 attended
Advocacy meetings with government officials Outcomes included: primary care sites to join project; training to start in nursing school; screening to begin in urban area; screening equipment provided for primary care staff; cancer patients to receive financial assistance.	13 (Including: Civil Surgeon, Chief Medical Officer, District Programme Manager, District NCD Officer, Medical Officer in Charge)
CLINICAL SERVICE	**Number**
1) Screening for NCDs (Total screened)	547 (Village residents)
Referred for diagnostic assessment after screening	122 (20%) (Percentage referred of those screened)
Referred for further Blood Pressure assessment	65
" " " Blood Sugar assessment	55
" " " Cancer assessment	2
2) Identified for palliative care service (Total)	56 (Village residents)
Cancer	50 (Total) Breast 17, Oral 8, Bone 4, Synovial 4, GI 4, Lung 4, Cervix 3, Neck 1, Parotid 1, Prostate 1, Oesophagus 1, Haematological 1, Not specified 1.
Paralysis	3
Renal failure	1
COPD	1
Large benign leg ulcer needing home care	1

Table 1: Results of CHETNA NCD programme activities after first 15 months

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caring for patients (e.g. those with unpleasant wounds), challenge the beliefs and stigma attached to cancer. Families are taught to clean and dress wounds without fear and neighbours start to visit the patient again. The communities, some of which have been quite resistant to community health programmes, become more responsive as new trust emerges between the local community and the team.[33]

The community health team through establishing local community groups (see box 1) are seeing effective community led health education about life style, avoidance of behavior leading to NCDs and the need to be screened. One group visited villages talking about what they had learned about healthy lifestyles such as stopping smoking and chewing tobacco-betel and taking regular exercise. They claimed to be seeing many of their neighbours heeding their messages to avoid unhealthy practices. Another group had persuaded some shopkeepers to stop selling tobacco-betel and were arranging a campaign to persuade others to stop. These groups were unpaid and considered their activities to be a service to the community. So far a total of 16 groups are in formation (Table 1). Discussion is now ongoing about training some members of these groups as palliative care volunteers in the future. Members of faith-based organisations are starting to become involved as volunteers, visiting people in their homes to provide practical, emotional and spiritual support (Table 1).

Communities are becoming more responsive to messages about changing lifestyle and receiving screening for NCDs. This has emerged sequentially as people who witness the care provided for patients with advanced cancer become more open to accept screening for cancers, particularly mouth cancer, which is greatly feared. Discussing the project with Sewa Dal during a recent evaluation (DM) the volunteers reported that, the villagers are becoming more receptive to health related messages and are beginning to understand how disease can go unnoticed in its early stages – demonstrated dramatically by oral cancer starting from small lesions which are hardly noticed. People then begin to identify with messages about the need for screening for hypertension and diabetes also. Awareness building for these 'hidden illnesses' is becoming more successful as people begin to understand that there is a link between them and serious complications such as strokes, heart disease and diabetic gangrene; conditions which are becoming more commonly seen in these communities.

Palliative Care and Primary Care led NCD management

Delivery of effective NCD management by health care professionals requires excellent communications skills, attention to the importance of follow up and a patient-centred approach where the patient is a partner in management, engaging in self monitoring and life style change and not merely someone to follow instructions to take medication.[32] The health care services in north India and Nepal in keeping with other LMIC were configured to deal with acute illnesses, where the person who is unwell presents for a consultation, a diagnosis is made and treatment given. The patient is not followed up again partly because of the acute nature of the illness, but also because clinics are busy with long queues, people might have to travel significant distances and incur considerable expense – both in terms of direct and indirect costs with time away from

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work.[36] Institutions training health workers have not prioritized training in communication and patient focused skills, resulting in a 'mindset' amongst practitioners that tends to be hierarchical and authoritarian and which is not conducive to such a change.[37]

All of these essential skills are particularly well demonstrated in palliative care practice and healthcare professionals can learn them in this context. This is being demonstrated in a medical undergraduate programme in Nepal where students follow up patients with advanced illness, not just to learn the principles of palliative care but to learn a values-based approach – including communication, patient centeredness and healthcare ethics that can be applied to the breadth of their practice.[38] Similarly, it is envisaged that as rural health workers in the project area are exposed to palliative care and receive training in it, they too can learn these skills. So far over 50 Auxiliary Nurse Midwives (ANM) have received initial training (Table 1) and this training will continue to be developed. Palliative care thus does not just represent a core activity in NCD management, but provides skills fundamental to the whole range of clinical activity in prevention and control of NCDs.

Primary care teams observing palliative care delivery and receiving training in palliative care as part of an integrated NCD management approach are enabled to deliver primary palliative care to those with a variety of chronic illnesses including non-cancer conditions which are particularly prevalent in these low-income settings.[12] It is widely acknowledged that involving the whole healthcare workforce in delivering palliative care is necessary to deliver palliative care for all.[39] Use of simple tools such as the recently developed Supportive and Palliative Care Indicator Tool for Low Income Settings (SPICT-LIS) could be very effective in enabling this emerging model of community palliative care.[40]

Primary care led NCD management and Community Health and Development

Over the last 60 years, community health programmes have been remarkably successful in reducing deaths and disease burden from infectious diseases and maternal and child health causes.[41] Tuberculosis control and HIV management have also been community led through the Directly Observed Treatment System (DOTS).[42] The success of community health programmes can be illustrated in Nepal where provision of maternal and child health services has seen a reduction in maternal mortality from to 850 to 229/100,000 live births [43] and under 5 mortality from 118 to 39/1,000 over a 20 year period.[44] In total the Millennium Development Goals (MDG) focusing on these three areas, between 2000 and 2015 are estimated to have led to between 21 and 29.7 million lives saved worldwide.[45]

Whilst the MDGs saw multiple 'vertical' programmes for disease eradication and control, these can lead to fragmented health services which frustrate the achievement of UHC.[36] This has been recognized as a challenge and is being addressed by such groups as the Global Fund to Fight AIDS, Tuberculosis and Malaria which provide community professionals who can also treat patients with

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other disease.[46] However, UHC needs to be addressed more generally at the primary care level and focusing on primary care led NCD management within the context of community health and palliative care could provide a synergy to help make UHC a reality.

NCD management provided closer to home leads to healthier communities generally as out of pocket expenditure reduces and fewer people suffer from the complications of NCDs at younger ages. It has been recognized that providing UHC for NCDs has the potential to help achieve other SDGs in addition to reduction of early deaths (SDG 3.4): reducing poverty and hunger (SDG 1 and 2), increasing health and wellbeing (SDG 3), gender equality (SDG 5), decent work and economic growth (SDG 8) and reduced inequalities (SDG 10).[47] There is also evidence emerging that the EHA palliative care model itself is leading to poverty reduction in areas where it has been operating.[48]

DISCUSSION

Preliminary evaluation suggests that a programme based on the synergy between primary care led NCD management, palliative care and community health provides a promising model for integrated NCD prevention and control in a low income context. In this model palliative care is an integral part of the whole programme, being embedded into primary care and transforming communities, encouraging a greater openness to community health interventions. Communities are being mobilized to engage not just with individuals utilizing the services on offer, but by becoming partners in spreading the message about NCD prevention and control. Involving communities in this way has already been demonstrated in the EHA palliative care programme, where, as the service becomes more widely known and trusted, case finding becomes established in the community.[33] With some members of faith-based communities starting to volunteer in providing social and psychological support, it is envisaged that with time the community will become more involved in volunteering to provide care – an important aspect of a public health approach to palliative care [39] as being demonstrated in Kerala.[49]

In addition, palliative care is providing an example and a context to teach primary health care staff communication skills, taking a patient centred approach and arranging follow up and continuity of care. Primary care professionals with appropriate training and support have been shown capable of providing effective NCD management in north India.[50]

The project, under the leadership of a community health specialist, is undertaking a robust survey which will be able to establish a baseline for the prevalence of NCDs in the area, a very important aspect of its work as so few data are currently available. The use of mobile phones (which are widely owned in the community) to collect data, register people who have been screened and arrange follow up is being considered to aid in both data collection and providing the clinical service.[51] Research into local health beliefs and health seeking behavior is, so far, beyond the scope of the project, but is an important facet of achieving UHC in such rural areas and if funding is available could be built into the project.

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The project is not without its challenges. As is common in rural settings, primary care centres are not functioning particularly well in the project area, with poor buildings, lack of trained staff and those who are working there have little support.[21] Lack of essential medications is also a major problem with patients forced to purchase medication from private 'medicine shops' where the dispensers – who also function as diagnosticians - are often untrained. This has been exposed as an inherent weakness for the rural health provision as laid out in the Indian Health Plan (2017) and requires a significant amount of investment and training.[52] However, the Indian government is committed to working with NGO providers, such as the Duncan Hospital to fill gaps and utilize their local expertise.[10] Advocacy with local government health officials is beginning to bear fruit with permission to work with primary care professionals and provision of necessary equipment (see Table 1).

Currently the project is working in one area of 83,000 – a tiny space considering the 500 million who live in rural north India and Nepal. The project is at a 'proof of concept' stage, however the apparent synergy between palliative care, community health and primary led NCD management is emerging. We hope that as the feasibility of the approach is tested, more centres will be able to develop the model. A proposal to establish two similar projects in Nepal has now been submitted. The concept needs to be studied in depth and properly evaluated. Data which are collected as the intervention is developed in an iterative manner in Bihar and Nepal will enable initial evaluation to be undertaken and robust methods of measurement to be established. Developing the model in a number of low-income settings and the sharing the learning will allow local differences to be identified. Should the early promise of this approach continue to emerge the intervention should undergo more formal evaluation, for instance in a cluster randomized control trial or realist evaluation.[53] We believe this approach has great potential in providing remote communities that lack financial and clinical resources with a system of UHC which includes robust NCD prevention and control, into which palliative care is integrated and through which palliative care can add value as it strengthens the intervention at multiple points.

CONCLUSION

Palliative care has been recognized as integral to NCD management which should be provided as part of primary care led UHC in all settings, including remote and rural parts of LMIC. Achieving this is a significant challenge and requires novel approaches where synergies can be exploited and effective services can be delivered at affordable cost. We believe that the emerging synergy between palliative care, community health and development and primary care led NCD management is a promising concept which needs further exploration.

AUTHORSHIP

DM had the original concept for the article and discussing and developed it with all authors. VK and SK provided details of the Chetna programme and local knowledge about the community where the project is based and expertise regarding community health. LG provided expertise in Global Health and

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3 palliative care. DM drafted the article and all authors were involved in
4 contributing to it. All authors agreed with the submitted draft.
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VK and SK are employed by Duncan Hospital. DM undertook an evaluation of the Chetna programme at Duncan Hospital, for which he received expenses but was not paid and he evaluated the original EHA palliative care programme for which he received an honorarium. LG has no conflict of interest to declare.

EXCLUSIVE LICENCE
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Integrated Non-Communicable Disease Management in Low-Income Settings: Exploring the synergies between Palliative Care, Primary Care and Community Health

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ABSTRACT

Palliative care is recognized as a fundamental component of Universal Health Coverage (UHC) which individual countries, led by the UN and WHO are committed to achieving worldwide by 2030 - Sustainable Development Goal (SDG) 3.8. As the incidence of non-communicable diseases (NCD) in low and middle-income countries (LMIC) increases, their prevention and control are central aspects of UHC in these areas. Whilst the main focus is on reducing premature mortality from NCDs (SDG 3.4), palliative care is becoming increasingly important in LMIC in which 80% of the need is found. This paper discusses the challenges of providing comprehensive NCD management in LMIC, the role of palliative care in addressing the huge and growing burden of serious health related suffering and also its scope for leveraging various aspects of primary care NCD management. Drawing on experiences in India and Nepal and particularly a project on the India-Nepal border in which palliative care, community health and primary care led NCD management are being integrated, we explore the synergies arising and describe a model where palliative care is integral to the whole spectrum of NCD management from promotion and prevention, through treatment, rehabilitation and palliation. We believe this model could provide a framework for integrated NCD management more generally in rural India and Nepal and also other LMIC as they work to make NCD management as part of UHC a reality.

Key Words: Universal Health Coverage, Non-communicable disease management, palliative care, community health, primary care, low and middle income countries, India, Nepal

INTRODUCTION

In 2015 the UN agreed a set of Sustainable Development Goals (SDG) to be achieved by 2030. SDG 3.8 commits to the achievement of Universal Health Coverage (UHC), which is defined as 'all people and communities [are able to] use the promotive, preventive, curative, rehabilitative and palliative health services they need, [which are] of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.'[1]

Palliative care is now recognized as a fundamental component of UHC[1] and a human right.[2] In 2014 the World Health Assembly agreed a declaration that signatory countries would ensure the availability of palliative care throughout a person's life course by incorporating palliative care into their health services.[3] However, in 2013 it was estimated that only 20 (8%) of countries had achieved high levels of integration of palliative care into their health systems and Uganda was the only low or middle income country (LMIC) to have done so.[4] Of the 25.5 million people in the world with serious health related suffering (SHRS) each year, 80% live in LMICs.[5] Poverty, lack of health care resources and frequently complex social and cultural issues make achieving palliative care integration in LMICs challenging.[6] Moreover each country needs to define how

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6 it will achieve the integration to which it has committed and to develop the
7 evidence base for it.[7]
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9 Achieving UHC including palliative care in LMIC by 2030 is a great challenge
10 made all the greater by an emerging global non-communicable disease (NCD)
11 pandemic.[8] Both India and Nepal have made serious efforts to ensure they are
12 on target to provide UHC having launched recent health plans in which it is a
13 primary aim.[9, 10] In 2017 Nepal also adopted a Strategic Plan for Palliative
14 Care with an emphasis on nationwide provision through primary health care
15 [11] and similarly India, in its Health Plan (2017), included palliative care in its
16 vision for primary care led UHC.[10]
17
18 Both countries, along with other low and middle income countries are
19 undergoing a dramatic demographic shift, with increasing numbers of people
20 living with and dying from NCDs. WHO data modeling suggests that in India 53%
21 and in Nepal 60% of all deaths are due to NCDs, making deaths from NCD
22 significantly higher than in other low income countries such as those in sub-
23 Saharan Africa.[12] In these South Asian countries the commonest NCD deaths
24 are from cardiovascular and respiratory diseases, with cancer making up only
25 around 6-8%.[12]
26
27 The recent Nepal STEP survey found that 26% of the adult population had raised
28 blood pressure with 90% either being undiagnosed or not being adequately
29 managed; 4% had raised blood sugar.[13] Hospital admissions are increasingly
30 frequent for NCD related episodes.[14] In a recent needs assessment in two rural
31 districts in Nepal we discovered that very few of the patients surveyed who were
32 living with NCDs were receiving integrated NCD management.[15] In two studies
33 from Nepal reported in 2017, 10% and 30% of patients admitted to hospital
34 respectively had palliative care needs.[16, 17]
35
36 The main drivers of the increase in NCD prevalence in low-income settings are
37 changes in lifestyle with increasing levels of obesity, type-2 diabetes,
38 hypertension and smoking. Whilst the incidence of diabetes and hypertension
39 are higher in urban than rural areas,[13, 18, 19] numbers here are also
40 increasing. [20] In addition in rural areas there are fewer health workers and
41 people are less likely to be able to access comprehensive health care.[20, 21]
42
43 Cancer incidence is also increasing with late presentations being the norm as
44 there is lack of awareness and little screening available.[22, 23] In rural north
45 India and southern Nepal, the common cancers in men are oral, secondary to
46 smoking and chewing tobacco, often mixed with betel-quid [24] and lung cancer
47 and for women, cervical (few women have regular pap smears and generally
48 girls do not receive HPV vaccination)[25], and breast cancer.[26]
49
50 WHO advocates for primary care led systems of NCD management to be
51 developed which are appropriate for LMICs.[27] This enables NCD management
52 to be delivered close to the patient's home and at less cost to both the patient
53 and health services than if management is secondary care based.[28] WHO has
54 developed guidelines for primary care led NCD management which are adaptable
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within the local setting.[29] Containing health costs from NCD management is vital in low income settings as out of pocket expenditure on chronic disease management is rapidly increasing.[30] There is evidence that health costs from the management of cancer and complications of NCDs are the commonest way families fall into debt and poverty.[31]

However in Nepal and in 'low-income' northern states of India there is little or no provision of integrated NCD management.[20] As in other low income settings, health care provision is based on a model of acute care with little development of systems appropriate for chronic disease management.[32] New models are needed which establish a platform for integrated management which can include prevention, screening, treatment of NCDs and their complications along with rehabilitation and palliative care.

In this article we present a new model for palliative care *and* NCD prevention and control which is being established in a project in the north Indian state of Bihar, in a rural district bordering Nepal (see figure 1). We believe this project could provide insights for other LMICs which are looking to develop integrated programmes for NCD management as part of UHC. This model (see box 1) uses a community palliative care approach which has been developed in north India [33] and which is now being extended to include NCD prevention and treatment through collaboration with community health and primary care.

(place figure 1 here)

Figure 1 – Map of North India and Nepal showing project site

Box 1 – The CHETNA Palliative Care and NCD Management Programme
The CHETNA NCD programme was established in April 2017 in East Champaran District of Bihar State, which borders onto Nepal. The project's aim is to raise awareness of NCDs (particularly diabetes, hypertension and cancer) in the population and amongst other stakeholders, including primary health care providers working in government Primary Healthcare Centres and Sub-Health Centres. It also aims to provide screening for hypertension, diabetes and oral cancer, to facilitate the provision of appropriate and affordable NCD management and to provide holistic palliative care to those with advanced disease.

The project is delivered by the community health department of The Duncan Hospital, Raxaul, building on work previously undertaken in various aspects of health, nutrition and sanitation. Palliative care is central to the project and is delivered according to a model of community palliative care based on home visits, developed by Emmanuel Hospitals Association (EHA), which is appropriate for rural north India.

The community health team, made up of experienced community health professionals, is led by a community medicine specialist and includes a registered nurse who leads the palliative care service along with several

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community health workers who have received training in providing palliative care. Physicians and family practitioners from Duncan Hospital with palliative care experience support the palliative care team in undertaking home visits as necessary.

Community health staff have been taught how to take blood pressure readings and use a glucometer to measure blood sugar. Working to strict protocols they refer people found with raised blood pressure or blood sugar readings to Duncan Hospital for formal diagnosis and implementation of management. Oral surgeons have also taught the staff how to screen for oral cancer and precancerous lesions.

Non-clinical community health team members have produced health education material in Hindi and undertake awareness-building events in the community, including in secondary schools. They have also worked with local community groups (called 'Sewa Dal'), which were formed as part of a previous awareness-building programme for mental health.

Government health workers including Auxiliary Nurse Midwives (ANMs) who provide village level health care are being trained at Duncan Hospital to provide follow up and maintenance for patients who have been diagnosed with NCDs. The community team also visit people diagnosed with NCDs (not in need of palliative care) who are unable to easily travel for follow-up.

Patients, particularly those with complex problems e.g. suspected cancer, are asked to attend the hospital clinic on a Friday and Saturday when they can be accompanied by team members through the busy clinics and helped to understand the need for ongoing therapy, particularly if it includes referral to a higher centre for cancer treatment.

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BACKGROUND TO THE PROJECT

In 2010 the Emmanuel Hospitals Association (EHA), an Indian association of 22 mission hospitals, established a model of community based palliative care in rural north India. This innovative service model, designed following a needs assessment was initially piloted in five EHA hospitals and subsequently evaluated.[33] The initial needs assessment found that people requiring palliative care, particularly those with advanced cancer, do not frequently present to local hospitals or clinics but are sequestered in their homes, often receiving very little care or attention from their families. This results from large amounts of money having been spent on cancer therapies which have made the family impoverished. The person with advanced cancer and the family return home but the family have little or no insight in how to care for them. There is also considerable stigma attached to advanced cancer, particularly when it involves fungating wounds and a frequently held belief is that cancer is transmissible.[34] These issues compound the fears and sense of hopelessness for the person with cancer and their families.

In order to find people in need of care, the palliative care teams use various case finding strategies in the community. These include a health education approach

in villages speaking to local groups, often of women, explaining about cancer and how the team are able to offer care for people at an advanced stage. The team are often told about friends or neighbours where there is someone with advanced disease and on visiting the family they offer to do a home assessment and provide care as needed. In other sites teams have found that awareness building in schools can be effective, often with teachers alerting the palliative care team about possible people needing their care. Other groups assisting in case finding include 'traditional health workers' and Ayurvedic practitioners.[33]

Distinctive features of the CHETNA NCD Programme
The CHETNA model has extended the EHA palliative care model by providing an integrated palliative care service as part of a NCD prevention and control strategy. The project is being led by an experienced community health team trained in palliative care. The team have combined their understanding of the stigma and hiddenness of end stage illness with awareness building for NCD prevention and control, screening for NCDs and enabling primary care led NCD management. They raise awareness of the effects of unhealthy practices such as smoking, chewing tobacco-betel quid, lack of exercise and obesity and the link between these and hypertension and diabetes in the etiology of serious NCDs such as CVA, ischaemic heart disease and cancer. In addition, through training at Duncan Hospital and working in rural health centres, the CHETNA team are equipping primary care providers in the locality to deliver integrated NCD management, so that people can receive care close to home, rather than repeatedly travelling potentially long distances to hospital. Results from the first 15 months of operation of the project are given in Table 1.

A remarkable synergy between palliative care, community health and primary care NCD management has been emerging (see figure 2) which we present in the next section.

(insert figure 2 here)

Figure 2: Chetna model of Palliative Care NCD management and Community Health and Development

SYNERGY EMERGING
Palliative Care and Community Health and Development
Rural Bihar has some of the highest poverty rates in India with poor health indicators and low levels of literacy.[35] There has been considerable investment in community health to try to improve the health status and health outcomes. However because of severe staff shortages, low educational rates among local communities and lack of investment in local infrastructure, most of the community health professionals working in such settings are not local. The consequence of this is that they are often looked upon with suspicion by the local population and do not necessarily understand local health beliefs.[33]

In established EHA palliative care projects, the service provided has been transformational to communities and has created new pathways to healthcare. Patients and families are given new hope and the providers, by touching and

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WORKFORCE	**Number (status)**
CHETNA community health Team	10(Employed by Duncan Hospital)
Sewa Dal – community groups	157 (Volunteers) (*16 groups)*
TRAINING/ AWARENESS/ ADVOCACY	
Training delivered by programme/ hospital	**Number (status)**
Government primary health care staff (ANM)	53 (Government employees)
Government community workers (ASHA)	135 (Volunteers)
Faith based organisations	137 (Organisation members) from 4 groups
Awareness building in the community	**Meetings and attendance**
NCD general awareness programmes	30 meetings in 20 villages. Estimated 1890 attended
	10 meetings in schools. Estimated 1680 attended
Advocacy meetings with government officials Outcomes included: primary care sites to join project; training to start in nursing school; screening to begin in urban area; screening equipment provided for primary care staff; cancer patients to receive financial assistance.	13 (Including: Civil Surgeon, Chief Medical Officer, District Programme Manager, District NCD Officer, Medical Officer in Charge)
CLINICAL SERVICE	**Number**
1) Screening for NCDs (Total screened)	547 (Village residents)
Referred for diagnostic assessment after screening	122 (20%) (Percentage referred of those screened)
Referred for further Blood Pressure assessment	65
" " " Blood Sugar assessment	55
" " " Cancer assessment	2
2) Identified for palliative care service (Total)	56 (Village residents)
Cancer	50 (Total) Breast 17, Oral 8, Bone 4, Synovial 4, GI 4, Lung 4, Cervix 3, Neck 1, Parotid 1, Prostate 1, Oesophagus 1, Haematological 1, Not specified 1.
Paralysis	3
Renal failure	1
COPD	1
Large benign leg ulcer needing home care	1

Table 1: Results of CHETNA NCD programme activities after first 15 months

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caring for patients (e.g. those with unpleasant wounds), challenge the beliefs and stigma attached to cancer. Families are taught to clean and dress wounds without fear and neighbours start to visit the patient again. The communities, some of which have been quite resistant to community health programmes, become more responsive as new trust emerges between the local community and the team.[33]

The community health team through establishing local community groups (see box 1) are seeing effective community led health education about life style, avoidance of behavior leading to NCDs and the need to be screened. One group visited villages talking about what they had learned about healthy lifestyles such as stopping smoking and chewing tobacco-betel and taking regular exercise. They claimed to be seeing many of their neighbours heeding their messages to avoid unhealthy practices. Another group had persuaded some shopkeepers to stop selling tobacco-betel and were arranging a campaign to persuade others to stop. These groups were unpaid and considered their activities to be a service to the community. So far a total of 16 groups are in formation (Table 1). Discussion is now ongoing about training some members of these groups as palliative care volunteers in the future. Members of faith-based organisations are starting to become involved as volunteers, visiting people in their homes to provide practical, emotional and spiritual support (Table 1).

Communities are becoming more responsive to messages about changing lifestyle and receiving screening for NCDs. This has emerged sequentially as people who witness the care provided for patients with advanced cancer become more open to accept screening for cancers, particularly mouth cancer, which is greatly feared. Discussing the project with Sewa Dal during a recent evaluation (DM) the volunteers reported that, the villagers are becoming more receptive to health related messages and are beginning to understand how disease can go unnoticed in its early stages – demonstrated dramatically by oral cancer starting from small lesions which are hardly noticed. People then begin to identify with messages about the need for screening for hypertension and diabetes also. Awareness building for these 'hidden illnesses' is becoming more successful as people begin to understand that there is a link between them and serious complications such as strokes, heart disease and diabetic gangrene; conditions which are becoming more commonly seen in these communities.

Palliative Care and Primary Care led NCD management

Delivery of effective NCD management by health care professionals requires excellent communications skills, attention to the importance of follow up and a patient-centred approach where the patient is a partner in management, engaging in self monitoring and life style change and not merely someone to follow instructions to take medication.[32] The health care services in north India and Nepal in keeping with other LMIC were configured to deal with acute illnesses, where the person who is unwell presents for a consultation, a diagnosis is made and treatment given. The patient is not followed up again partly because of the acute nature of the illness, but also because clinics are busy with long queues, people might have to travel significant distances and incur considerable expense – both in terms of direct and indirect costs with time away from

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work.[36] Institutions training health workers have not prioritized training in communication and patient focused skills, resulting in a 'mindset' amongst practitioners that tends to be hierarchical and authoritarian and which is not conducive to such a change.[37]

All of these essential skills are particularly well demonstrated in palliative care practice and healthcare professionals can learn them in this context. This is being demonstrated in a medical undergraduate programme in Nepal where students follow up patients with advanced illness, not just to learn the principles of palliative care but to learn a values-based approach – including communication, patient centeredness and healthcare ethics that can be applied to the breadth of their practice.[38] Similarly, it is envisaged that as rural health workers in the project area are exposed to palliative care and receive training in it, they too can learn these skills. So far over 50 Auxiliary Nurse Midwives (ANM) have received initial training (Table 1) and this training will continue to be developed. Palliative care thus does not just represent a core activity in NCD management, but provides skills fundamental to the whole range of clinical activity in prevention and control of NCDs.

Primary care teams observing palliative care delivery and receiving training in palliative care as part of an integrated NCD management approach are enabled to deliver primary palliative care to those with a variety of chronic illnesses including non-cancer conditions which are particularly prevalent in these low-income settings.[12] It is widely acknowledged that involving the whole healthcare workforce in delivering palliative care is necessary to deliver palliative care for all.[39] Use of simple tools such as the recently developed Supportive and Palliative Care Indicator Tool for Low Income Settings (SPICT-LIS) could be very effective in enabling this emerging model of community palliative care.[40]

Primary care led NCD management and Community Health and Development

Over the last 60 years, community health programmes have been remarkably successful in reducing deaths and disease burden from infectious diseases and maternal and child health causes.[41] Tuberculosis control and HIV management have also been community led through the Directly Observed Treatment System (DOTS).[42] The success of community health programmes can be illustrated in Nepal where provision of maternal and child health services has seen a reduction in maternal mortality from to 850 to 229/100,000 live births [43] and under 5 mortality from 118 to 39/1,000 over a 20 year period.[44] In total the Millennium Development Goals (MDG) focusing on these three areas, between 2000 and 2015 are estimated to have led to between 21 and 29.7 million lives saved worldwide.[45]

Whilst the MDGs saw multiple 'vertical' programmes for disease eradication and control, these can lead to fragmented health services which frustrate the achievement of UHC.[36] This has been recognized as a challenge and is being addressed by such groups as the Global Fund to Fight AIDS, Tuberculosis and Malaria which provide community professionals who can also treat patients with

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other disease.[46] However, UHC needs to be addressed more generally at the primary care level and focusing on primary care led NCD management within the context of community health and palliative care could provide a synergy to help make UHC a reality.

NCD management provided closer to home leads to healthier communities generally as out of pocket expenditure reduces and fewer people suffer from the complications of NCDs at younger ages. It has been recognized that providing UHC for NCDs has the potential to help achieve other SDGs in addition to reduction of early deaths (SDG 3.4): reducing poverty and hunger (SDG 1 and 2), increasing health and wellbeing (SDG 3), gender equality (SDG 5), decent work and economic growth (SDG 8) and reduced inequalities (SDG 10).[47] There is also evidence emerging that the EHA palliative care model itself is leading to poverty reduction in areas where it has been operating.[48]

DISCUSSION

Preliminary evaluation suggests that a programme based on the synergy between primary care led NCD management, palliative care and community health provides a promising model for integrated NCD prevention and control in a low income context. In this model palliative care is an integral part of the whole programme, being embedded into primary care and transforming communities, encouraging a greater openness to community health interventions.

~~This community health led palliative care and NCD prevention and control project is beginning to demonstrate the synergy between the three elements of the project. Palliative care is an integral part of the whole project and is being embedded into primary care. Palliative care provision is transforming communities, encouraging a greater openness to community health interventions~~. Communities are being mobilized to engage not just with individuals utilizing the services on offer, but by becoming partners in spreading the message about NCD prevention and control. Involving communities in this way has already been demonstrated in the EHA palliative care programme, where, as the service becomes more widely known and trusted, case finding becomes established in the community.[33] With some members of faith-based communities starting to volunteer in providing social and psychological support, it is envisaged that with time the community will become more involved in volunteering to provide care – an important aspect of a public health approach to palliative care [39] as being demonstrated in Kerala.[49]

In addition, palliative care is providing an example and a context to teach primary health care staff communication skills, taking a patient centred approach and arranging follow up and continuity of care. Primary care professionals with appropriate training and support have been shown capable of providing effective NCD management in north India.[50]

The project, under the leadership of a community health specialist, is undertaking a robust survey which will be able to establish a baseline for the prevalence of NCDs in the area, a very important aspect of its work as so few data are currently available. The use of mobile phones (which are widely owned in the community) to collect data, register people who have been screened and

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arrange follow up is being considered to aid in both data collection and providing the clinical service.[51] Research into local health beliefs and health seeking behavior is, so far, beyond the scope of the project, but is an important facet of achieving UHC in such rural areas and if funding is available could be built into the project.

The project is not without its challenges. As is common in rural settings, primary care centres are not functioning particularly well in the project area, with poor buildings, lack of trained staff and those who are working there have little support.[21] Lack of essential medications is also a major problem with patients forced to purchase medication from private 'medicine shops' where the dispensers – who also function as diagnosticians - are often untrained. This has been exposed as an inherent weakness for the rural health provision as laid out in the Indian Health Plan (2017) and requires a significant amount of investment and training.[52] However, the Indian government is committed to working with NGO providers, such as the Duncan Hospital to fill gaps and utilize their local expertise.[10] Advocacy with local government health officials is beginning to bear fruit with permission to work with primary care professionals and provision of necessary equipment (see Table 1).

Currently the project is working in one area of 83,000 – a tiny space considering the 500 million who live in rural north India and Nepal. The project is at a 'proof of concept' stage, however the apparent synergy between palliative care, community health and primary led NCD management is emerging. We hope that as the feasibility of the approach is tested, more centres will be able to develop the model. A proposal to establish two similar projects in Nepal has now been submitted. The concept needs to be studied in depth and properly evaluated. Data which are collected as the intervention is developed in an iterative manner in Bihar and Nepal will enable initial evaluation to be undertaken and robust methods of measurement to be established. Developing the model in a number of low-income settings and the sharing the learning will allow local differences to be identified. Should the early promise of this approach continue to emerge the intervention should undergo more formal evaluation, for instance in a cluster randomized control trial or realist evaluation.[53] We believe this approach has great potential in providing remote communities that lack financial and clinical resources with a system of UHC which includes robust NCD prevention and control, into which palliative care is integrated and through which palliative care can add value as it strengthens the intervention at multiple points.

CONCLUSION

Palliative care has been recognized as integral to NCD management which should be provided as part of primary care led UHC in all settings, including remote and rural parts of LMIC. Achieving this is a significant challenge and requires novel approaches where synergies can be exploited and effective services can be delivered at affordable cost. We believe that the emerging synergy between palliative care, community health and development and primary care led NCD management is a promising concept which needs further exploration.

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AUTHORSHIP
DM had the original concept for the article and discussing and developed it with all authors. VK and SK provided details of the Chetna programme and local knowledge about the community where the project is based and expertise regarding community health. LG provided expertise in Global Health and palliative care. DM drafted the article and all authors were involved in contributing to it. All authors agreed with the submitted draft.

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CONFLICT OF INTEREST
VK and SK are employed by Duncan Hospital. DM undertook an evaluation of the Chetna programme at Duncan Hospital, for which he received expenses but was not paid and he evaluated the original EHA palliative care programme for which he received an honorarium. LG has no conflict of interest to declare.

EXCLUSIVE LICENCE
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Figure 1

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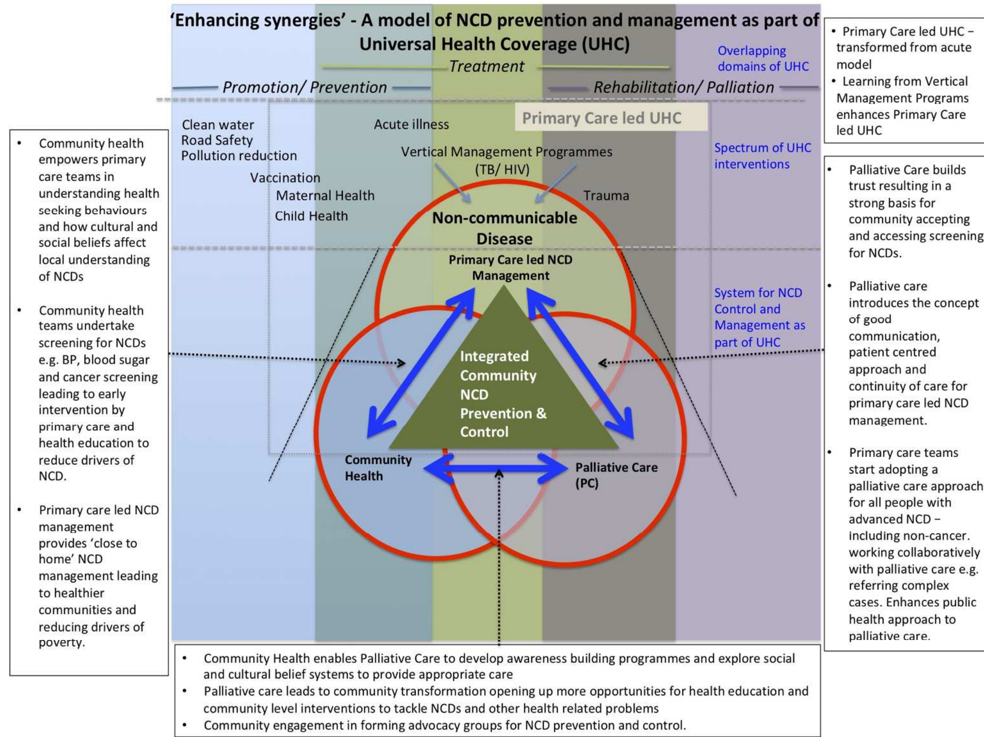

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