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Viewpoint

Research needs for an improved primary care response to chronic non-communicable diseases in Africa

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Summary With non-communicable diseases (NCDs) projected to become leading causes of morbidity and mortality in developing countries, research is needed to improve the primary care response, especially in sub-Saharan Africa. This region has a particularly high double burden of communicable diseases and NCDs and the least resources for an effective response. There is a lack of good quality epidemiological data from diverse settings on chronic NCD burden in sub-Saharan Africa, and the approach to primary care of people with chronic NCDs is currently often unstructured. The main primary care research needs are therefore firstly, epidemiological research to document the burden of chronic NCDs, and secondly, health system research to deliver the structured, programmatic, public health approach that has been proposed for the primary care of people with chronic NCDs. Documentation of the burden and trends of chronic NCDs and associated risk factors in different settings and different population groups is needed to enable health system planning for an improved primary care response. Key research issues in implementing the programmatic framework for an improved primary care response are how to (i) integrate screening and prevention within health delivery; (ii) validate the use of standard diagnostic protocols for NCD case-finding among patients presenting to the local health facilities; (iii) improve the procurement and provision of standardised treatment and (iv) develop and implement a data collection system for standardised monitoring and evaluation of patient outcomes. Important research considerations include the following: selection of research sites and the particular NCDs targeted; research methodology; local research capacity; research collaborations; ethical issues; translating research findings into policy and practice and funding. Meeting the research needs for an improved health system response is crucial to deliver effective, affordable and equitable care for the millions of people with chronic NCDs in developing countries in Africa.

keywords health services research, epidemiology, non-communicable diseases

Introduction

Primary care is receiving more global attention, as indicated by the Director-General of WHO recently highlighting the importance of strengthened health systems based on primary care as 'the route to greater efficiency and fairness in health care and greater security in the health sector and beyond' (Chan 2009). In the light of greater attention also paid recently to chronic non-communicable diseases (NCDs), it is opportune to propose key research needs for an improved primary care response to chronic NCDs. The focus of this paper is on Africa, the region facing the greatest challenges in improving primary care, and now undergoing epidemiological transition. The proposed research needs are informed by our international health experience in general and in two countries (Uganda and Malawi) in particular.

In the wake of globalisation, changes are occurring in disease patterns around the world, including in developing countries (WHO 2004). The effects of globalisation are likely to have a particular impact on chronic NCDs, including obesity, diabetes, hypertension, smoking-related conditions, respiratory diseases and psychiatric disorders. Although the focus of international health in the past two decades has been on the problem of communicable diseases (Beaglehole & Bonita 2008), there is now increasing recognition of the double burden in developing countries of chronic communicable diseases (e.g. tuberculosis and HIV)

and chronic NCDs (WHO 2004). Chronic NCDs have a huge negative economic impact (Suhrcke *et al.* 2006) and represent a significant impediment to human development (Adeyi *et al.* 2002). The World Health Organization predicts that globally, NCD deaths will increase by 17% over the next decade, with the greatest increase in the African region (27%) (WHO 2008). In 2007, it was estimated that there were 246 million people living with diabetes mellitus, 6 million new cases and 3.5 million deaths, with 70% of these patients living in the developing world (World Diabetes Foundation 2008). In 2000, there were an estimated 972 million people with hypertension, 65% of whom lived in the developing world, with the number predicted to grow to 1.5 billion by 2025 (Anonymous 2007). The burden of chronic NCDs is also likely to increase as scaled-up programmes of antiretroviral treatment (ART) of HIV-infected people lead to reduced mortality from HIV/AIDS and possible metabolic side effects resulting from life-long ART medications (WHO *et al.* 2008).

With NCDs projected to become leading causes of morbidity and mortality in developing countries, research is needed to improve the health system response, especially in sub-Saharan Africa, which faces the greatest predicted increase in NCD deaths (WHO 2008) and has the least resources for an effective response to the double burden of communicable diseases and NCDs. The effects of globalisation are extending to developing countries in Africa, mostly to urban but also to rural areas, which may often be geographically remote but are increasingly exposed to globalised culture through modern communications. Growing recognition of the emerging importance of chronic NCDs in Africa raises the need for epidemiological research on NCD burden for purposes of planning an improved primary care response. The lack of a structured, programmatic, public health approach to chronic NCDs brings into question of the state of preparedness of primary care to respond to epidemiological transition (the dual burden of communicable diseases and NCDs). Health system research is needed with a focus on delivering a structured, programmatic, public health approach through primary care services (the main providers of care for people with chronic NCDs).

Because the burden of chronic NCDs in sub-Saharan Africa is inadequately measured and the primary care response is unstructured, we propose two main areas of primary care research needs. Firstly, epidemiological research to document the population burden of chronic NCDs (and associated risk factors) to inform primary care planning; and secondly, health systems research to assess how a structured, programmatic, public health approach can be implemented to improve the primary care response to this burden. We also outline some important considerations in addressing these needs.

Key research needs for an improved primary care response to chronic NCDs

Epidemiological research

The burden of chronic NCDs is generally much less well documented than that of communicable diseases in developing countries in Africa, with some data on chronic NCDs from middle-income countries, e.g. South Africa (Tollman *et al.* 2008), but few data from other low-income countries. The few available data tend to be from urban rather than rural areas. Few data are available on the likely impact of globalisation on the double burden of communicable diseases and NCDs in Africa. There is, therefore, a need to document the current burden and future trends of communicable diseases and NCDs, which may be exacerbated by the effects of globalisation. This information is needed to improve current estimates for purposes of planning local, national and international responses to changing patterns of disease burden, and monitoring the impact of these responses on disease burden. Epidemiological research is needed to establish the prevalence and demographic distribution of risk factors associated with chronic NCDs, e.g. occupational exposures, nutritional habits, smoking, and alcohol and drug use.

Epidemiological and clinical research are also needed to identify possible associations between communicable diseases and NCDs. Concurrent chronic infections may modify both the risk of developing NCDs and the clinical course of NCDs (Bach 2002). These interactions have potentially important implications for NCD prevention and care, but current data are very limited. Interest in identifying the genetic factors associated with NCD risk is rising, which may involve systematic genome-wide screening among people with and without particular NCDs. Established population-based epidemiological surveys provide a potential platform for research to assess the associations between genetic variation in populations in Africa and relevant infectious and metabolic diseases and traits. Exploring differences in NCD epidemiology between Africa and other parts of the world would be useful, including for example differences in response to various classes of hypertension drugs.

Health system research to improve primary care delivery for people with NCDs

Increasing recognition of the burden of chronic NCDs in developing countries has uncovered problems with the current approach to health care delivery: the burden of

long-term care on health systems and budgets, the costs that push households into further poverty, and the need for prevention in a situation in which risk factors often lie outside the direct control of the health sector (Abegunde *et al.* 2007). The burden of chronic NCDs in developing countries necessitates changes in health delivery systems that are often less well oriented towards dealing with chronic NCDs than with acute and chronic communicable diseases. The current approach is often unstructured, lacks systematic follow-up and monitoring of chronic clinical care, and provides little information about morbidity or mortality. This situation is common in developing countries in sub-Saharan Africa (Wilkinson & Wilkinson 2004). Detailing the needs in each country involves assessment of health system components such as human resources, logistics, case management guidelines and policies.

The research focus should be on improving the response of primary care services, which are the main providers of care for people with chronic NCDs. Suggested features of an improved response include establishing combined chronic care clinics for managing patients with various NCDs, integrating management of chronic NCDs with that of chronic infectious diseases (Coovadia & Bland 2008), developing chronic care services that cut across conventional categories of communicable diseases and NCDs (Setel *et al.* 2004) and adapting the international tuberculosis control strategy for NCD management (Harries *et al.* 2008). Health system research is needed to establish the feasibility and cost-effectiveness of these suggestions.

The experience gained in scaling up interventions for chronic communicable diseases, namely tuberculosis (Maher *et al.* 2007) and HIV infection (WHO *et al.* 2008), has informed the development of a framework representing a structured, programmatic, public health approach for improved primary care for people with NCDs that reflects the above suggested features (Maher *et al.* 2009). The framework comprises a goal, targets, defined package of interventions for quality care, key operations for national implementation of the interventions, e.g. staff training on guidelines and logistical back-up, and indicators to measure progress towards reducing the impact of chronic NCDs (Maher *et al.* 2009). The main objectives are to (i) identify and address risk factors, (ii) screen for common NCDs and (iii) diagnose, treat and follow-up patients with common NCDs using standard protocols, among all those accessing primary care (Maher *et al.* 2009). The framework entails a systematic programmatic approach to monitoring and evaluation, incorporating indicators of programme performance and access to services, and enabling assessment of progress of patients and measurement of the NCD burden on the health system and its response to health system interventions (Harries *et al.* 2009).

In evaluating this framework, key research issues are how to (i) integrate screening and prevention within health delivery (not only primary but also secondary prevention in patients with established NCDs, e.g. smoking cessation in patients with diabetes or hypertension); (ii) validate standard diagnostic protocols for NCD case-finding, in terms both of determining their performance characteristics (sensitivity, specificity and predictive values) in different epidemiological situations and assessing staff performance in use of protocols; (iii) improve the procurement and provision of standardised treatment and (iv) develop and implement a data collection system (using paper or electronic health records) for standardised monitoring, evaluation and reporting of patient outcomes (Harries *et al.* 2008).

The experience of Uganda and Malawi provides an illustrative example of research needs and responses at country level (see the Box 1).

Box 1 NCD research needs and responses – the example of Uganda and Malawi

Uganda

In Uganda's Health Sector Strategic Plan (HSSP) for 2005/2006–2009/2010, the core health interventions are grouped in four clusters, of which Cluster 4 is 'Prevention and Control of Non-Communicable Diseases' (Uganda Ministry of Health 2005). The Mid-term Review Report on implementation of the plan indicates the lack of data on key indicators of NCD programme performance at baseline before the start of implementation (2004/2005) and at the time of review of performance (2006/2007) (Uganda Ministry of Health 2008). This highlights the need for better information on the burden of NCDs in Uganda and the current provision of services for people with NCDs, and for steps to be taken to improve these services. Achieving the NCD programme's goal to reduce NCD morbidity and mortality through appropriate health interventions targeting the entire population of Uganda requires the development and validation of an approach to deliver these interventions at primary care level.

Recognising NCDs as a priority, the Ministry of Health has formed a department on NCDs to address research, delivery of interventions and policies. Planned activities include the following: a national NCD survey; collection of NCD epidemiological data using established survey platforms in collaboration with other departments (e.g. the national HIV sero-survey) and local research institutions (e.g. MRC/UVRI) and the

Box 1 (*continued*)

development and testing of standard guidelines for NCD prevention and care. These activities will prepare the ground for the stepwise nationwide implementation of a programme of NCD interventions, involving staff training, supervision, monitoring and evaluation.

Malawi

Problems of hypertension and diabetes mellitus tend to predominate in the urban cities of Malawi, such as Lilongwe and Blantyre; and in these central hospitals, there are clinics dedicated to the management of both conditions that have been in operation for 20 years or more. Despite these clinics, which are run by medical specialist staff, the management of diabetes and hypertension has often been substandard with hypertension and diabetes poorly controlled as a result of many factors that include inadequate drug stocks, poor education about the need for adhering to chronic, lifelong therapy and no regular system of cohort analysis of new cases starting on therapy or treatment outcomes (Kumwenda *et al.* 1992; Maher & Harries 1996). This is set to change. In both central hospitals, there has been agreement that patients with diabetes mellitus and hypertension must be regularly followed in a similar way to that carried out for tuberculosis patients and HIV-infected patients on antiretroviral therapy. Standardised treatment cards and registers will capture the socio-demographic and clinical details of new patients starting on therapy; and every 3 months, a quarterly and cumulative cohort analysis will be performed on numbers of new cases registered, cumulative cases ever registered and cumulative treatment outcomes. For conditions like hypertension and diabetes, paper-based systems may eventually become cumbersome to use, and operational research will be conducted to see whether robust, touch-screen computer systems can be used in the routine hospital settings to monitor and record numbers and outcomes. If successful in the central hospitals, there are plans to roll out these systems to district hospitals as well.

Important considerations in addressing key research needs for an improved primary care response to chronic NCDs

Selection of research sites

Population-based surveys are needed to provide data on NCD burden for planning purposes. Selection of epidemiological research sites should aim at ensuring representative data on the burden of NCDs from urban and rural areas, different regions of a country and the main socio-demographic strata. In sites selected for health systems research to improve primary care delivery for people with NCDs, evaluation should include different providers, e.g. government and private (non-profit and for profit) providers, and the different health facilities that provide primary care, e.g. hospitals and peripheral units, in both rural and urban environments.

Building on existing epidemiological and health delivery projects, and networks, e.g. INDEPTH (http://www.indepth-network.org/), has advantages. Sites with ongoing demographic and disease surveillance activities are well placed to participate in the proposed research because their activities can provide a platform on which to build NCD surveillance and evaluation of the framework for improved care at primary level. HIV surveillance projects have an advantage as a platform for investigation of NCDs on account of the increased risk of NCDs among people receiving ART and also on account of the availability of data relevant to both HIV and NCDs, including on demographics, mobility, alcohol and substance abuse.

Selection of chronic NCDs for study

In epidemiological and health system research, the common chronic NCDs initially targeted may include diabetes, cardiovascular disease, respiratory disease, epilepsy and chronic psychiatric disorders. Factors for consideration in targeting particular chronic NCDs include (i) information already available about the local common disorders, whether this is based on epidemiological assessment or on clinical experience; (ii) the result of a local needs assessment and (iii) the feasibility of applying the relevant standard measures for diagnostic evaluation and treatment in a low-resource setting.

Research methodology

Relevant types of epidemiological research include descriptive cross-sectional and cohort studies. Whatever the choice of research design appropriate to the setting and study question, health services research is likely to involve initial needs assessment, training, intervention delivery and evaluation (Craig *et al.* 2008). Because research is urgently needed to address the problem of NCDs in resource-limited settings, considerations in choosing the appropriate research methodology include feasibility, cost and the time taken to generate results. Operational research can be performed fairly easily and quickly in resource-constrained settings and is relatively inexpensive. Randomised

controlled trials tend to be expensive, often yield results after several years, and may be less relevant in health systems research on interventions of known efficacy than in research establishing their efficacy.

Developing local research capacity

In line with building research capacity as an essential feature of research in low-income and middle-income countries (Sewankambo & Ijsselmuiden 2008), research to improve the health system response to chronic NCDs provides an opportunity to support the development of local research capacity in health system research and related areas, e.g. epidemiology. International and national organisations with experience in training and capacity development play a key role.

Forming research collaborations

Identifying best practices in delivering affordable and equitable health care is likely to require research collaborations between different institutions (reflecting the relevant strengths of the particular institutions) and different disciplines (including epidemiology, clinical medicine, health systems, social science and health economics).

Ethical issues

Current ethical guidelines require that studies in developing countries should be responsive to local health needs (Council for International Organisations of Medical Sciences 2002). Indications of the emerging importance of chronic NCDs in developing countries in Africa suggest the relevance of this research in populations in this region. In undertaking epidemiological research on NCDs, it will be necessary to ensure the local referral of people identified with NCDs who need care.

Translating research findings into policy and practice

Successful evaluation of the proposed framework in a pilot area and when scaled up to district level should be a prelude to evaluation on a wider scale, e.g. at national level, and then if successful, used to inform international policy (Sanders & Haines 2006). Translation of research findings into policy and practice may involve a phased and iterative process of piloting, stepwise scaling-up and evaluation, combined with the critical discussion of findings among key stakeholders at local and national levels, e.g. researchers, service providers, public health managers, representatives of study populations and policy-makers. The development of an improved health system approach to NCDs must be driven by the key national stakeholders, who should be involved at each main step (including research planning and implementation, piloting of the improved response and scaling-up).

Local stakeholder meetings can contribute to the process of developing evidence-based policies and ensuring sustainability and acceptability of the new policies. A stakeholder meeting at project inception can serve to develop support for the research among policy-makers, with awareness of the project aims and methods, and of the implications of the results when they become available. A stakeholder meeting at the conclusion of the project enables dissemination of research findings and consideration among national policy-makers of the implications of these findings for policy and implementation.

Funding

As with all health programmes, funding of programmes on NCDs should include dedicated funding for research and for implementation activities. The need to fund research on NCDs is recognised by some bilateral donors, e.g. the UK Department for International Development (UK DFID 2008) and there may be prospects for funding from other donors. Established in 2001, the Global Fund to fight AIDS, tuberculosis and malaria has approved over USD$15 billion in funding for HIV/AIDS, TB and malaria programmes. There is growing discussion about how these funds can be used to drive broad improvements in general health systems, and this should include a focus on NCDs (Ooms *et al.* 2008).

Conclusion

In developing countries in Africa, there is an urgent need for epidemiological research on the burden of chronic NCDs and for health system research on evaluation of implementation of a structured, programmatic, public health framework for improved delivery of primary care for people with chronic NCDs (Maher *et al.* 2009). The generation of better data on the epidemiology of chronic NCDs in sub-Saharan Africa will help in planning responses to changing patterns of disease burden and in monitoring the impact of these responses on disease burden. An enabling environment for downstream research to evaluate implementation of the framework is provided by the upstream policy interventions in WHO's Action Plan for the Global Strategy for the Prevention and Control of NCDs (WHO 2008). Research in Africa on the framework is in line with that proposed globally by the representatives of health policy and research agencies who developed the 'Grand challenges in chronic NCDs'

(Daar *et al.* 2007). If evaluation of the framework confirms its feasibility, acceptability, effectiveness and cost-effectiveness, international and national support should be mobilised to extend the benefit to millions of people with chronic NCDs in developing countries in Africa.

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