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Cancer Registration Needs Assessment at a Tertiary Medical Center in Kilimanjaro, Tanzania

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From the Editor-in-Chief

This issue of World Health & Population presents three research papers that should be of great interest to our readers. The original papers have all been published online by WHP during the last quarter and are selected here as representative of recent outstanding contributions to the journal. Interestingly, these three, quite different, papers share a common theme around information needs.

The first paper, "Measuring Progress toward the Millennium Development Goals and the Missing Millions," by Roy Carr-Hill, calls attention to measurement issues around the Millennium Development Goals (MDGs). We are rapidly approaching the target date of 2015 for achieving the MDGs, and commentaries are proliferating about progress, lack of progress, needs for better progress, etc. Carr-Hill takes us back to the foundation for making any assessments: the data behind them. In particular he is critical of using household surveys as the basis for data collection, noting the numerous ways the "poorest of the poor" can be missed in such an approach. It is likely the case, as Carr-Hill contends, that policy makers at the country and international level are underestimating those at risk in the MDGs, and there are likely "missing millions," in particular among the poorest of the poor. Improved data systems in lower- and middle-income countries (LMICs) are, of course, necessary, but may unfortunately remain a lower-ranked priority competing with other pressing needs.

Leah Zullig, Charles Muiruri and colleagues are the authors of the second article in this issue, "Cancer Registration Needs Assessment at a Tertiary Medical Centre in Kilimanjaro, Tanzania." Picking up on the theme in this issue of data needs in LMICs, Zullig et al. did a survey to assess the readiness at a large academic medical centre in Tanzania to institute a cancer registry system. Although infectious disease remains the primary health threat in LMICs, chronic diseases such as cancer, heart disease and diabetes have also been increasing at alarming rates. Data systems across the board in these countries are generally inadequate and underfunded. Disease registries, which are known to improve diagnosis, care and outcomes, are virtually unknown. Before implementation of such a system, however, Zullig et al. have wisely assessed the organizational "readiness for change" to identify possible barriers, facilitators and needs at the institution.

Finally, "The Role of Developing Countries in Generating Cochrane Meta-analyses in the Field of Pediatrics (Neonatology and Neuropediatrics): A Systematic Analysis," by Sascha Meyer, Christiane Willhelm et al., documents the paucity of evidence originating from LMICs in an area of medicine of critical importance to the health and development of these countries, and the target of the MDGs as well. Recognizing the fact that birthrates and perinatal, infant and child mortality are vastly higher in LMICs than in the less resource-constrained countries in Western Europe and North America, it is distressing that more research and possible approaches and solutions are not originating from the places most affected. Imported approaches may not be the most relevant or feasible; increased evidence around effective local approaches would be of great value.

In conclusion, we hope that you find the papers in this issue interesting and worthwhile, and that you will also consult others recently released online at www.worldhealthandpopulation.com. WHP remains committed to its mission to provide a forum for researchers and policy makers worldwide to publish and disseminate health- and population-related research, and to encourage applied research and policy analysis from diverse global and resource-constrained settings. WHP is indexed on MEDLINE and is accessible through PubMed.

We look forward to continued enthusiastic submission of manuscripts for consideration, peer review and publication. Finally, the editors and publishers of WHP are always interested in any comments or suggestions you might have on the papers or about the journal and our mission. Please feel free to write or e-mail us.

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Measuring Progress toward the Millennium Development Goals and the Missing Millions

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Abstract

The 2015 target date for achieving the Millennium Development Goals (MDGs) is fast approaching, but there is very little discussion of the validity of the indicators used to measure progress.

In particular, there has been little attention given to the problems that arise when assessments of progress are based on household surveys. These are inappropriate for obtaining information about the poorest of the poor. Typically, they omit by design those not in households because they are homeless; those who are in institutions; and mobile, nomadic or pastoralist populations; and, in practice, household surveys will typically under-represent those in fragile, disjointed or multiple occupancy households; and those in urban slums and insecure areas of a country.

Those six subgroups constitute a pretty comprehensive ostensive definition of the "poorest of the poor." Between 300 and 500 million people – mainly in developing countries – will be missed worldwide from the sampling frames of household surveys.

Introduction

Millennium Development Goals

The 2015 target date for achieving the Millennium Development Goals (MDGs) is fast approaching. Moreover, the most recent report on progress (United Nations Development [UNDP] 2012) claims that three important targets have already been reached, including reducing poverty by half from the 1990 level, and significantly improving the lives of 200 million slum dwellers, well ahead of the 2020 deadline. Already civil society, academics, governments and the UN system are thinking about what the next era of development should look like, but there is very little discussion of the validity of the indicators used to measure progress. In particular, there has been little attention to the problems that arise when, as is increasingly common in developing countries, population estimates and assessments of progress toward more than half (29 of the 54) of the indicators used for monitoring progress toward the Millennium Development Goals are based on household surveys (see Appendix 1).

Population Counts

For several decades and in some countries for centuries, populations have been counted through national, usually decennial, censuses in which enumerators go to households. Inter-censal population estimates have usually depended on reliable birth and death registration systems. In most middle- and low-income countries, however, vital registration systems have never been fully functioning (Powell 1981), and there has been a similar decline in donor interest in censuses and vital registration systems (Setel et al. 2007). Instead, there is an increasing reliance on large-scale standardized household surveys for the basic data.

Many countries run national economic and social surveys to provide detailed information on consumer prices, income and employment, and other relevant data for planning. This move away from censuses to relying on surveys raises the obvious problem that drawing a sample for a survey depends on having a sampling frame in the first place which is frequently based on the census. Clearly, any problem with the census, if used as the sampling frame for a national survey, will lead to that sampling frame being biased. But there is –strangely – little recognition of these problems.

Censuses

Population censuses have always faced problems of complete enumeration. Groups of adults have been excluded from censuses in some countries for political and/or practical reasons. Non-citizens, cultural minorities or marginalized groups, and specific categories of prisoners or rebels who object to government oversight have often been excluded for political reasons (Buettner and Garland 2008), and although less frequent and certainly more transparent, this still continues (Indigenous Portal 2011; Abbasi-Shavazi and Sadeghi 2011).

Therefore, the general problem that censuses are not necessarily complete is well understood (Carr-Hill 2009). At the same time, there is an emerging consensus as to what constitutes good census practice (United Nations 2008); and censuses that follow those UN guidelines will usually overcome many of the deficiencies in earlier censuses. The guidelines are clear but there can still be problems in practice, as described below.

Housekeeping concept: While Cinderella is a fairy tale, the exclusion of poor servants from the census count in rich households (even though they usually share some of the household food), especially in Asia, is a reality, and their personal poverty is therefore missed.

Mobile populations: In developed countries, the young, highly mobile – usually male – population is also difficult to count, especially when they live in collective households, but they are relatively well-off; in developing countries, they may well be among the poorest.

Homelessness and counting de facto rather than de jure populations: These are difficult to count, especially where there are disputes over nationality (Refugees International 2007); equally, there are several millions internally displaced in many countries, either as a result of civil war or because environmental change (e.g., floods, nuclear accidents) makes their homes uninhabitable; and, although there are periodic counts, there is no regular database anywhere.

Institutional populations: There are a number of different types of institutions (care homes, [some] factory barracks, hospitals, the military, prisons, refugee camps, religious orders and school dormitories), and there is considerable variation in opinion on whether or how they should be included in the population count. They are often simply counted as special census blocks.

Careful census reporting documents how well these groups have been enumerated, and most categories are included in estimated census population counts of developed countries but not in those of many developing countries. Moreover, in many developing countries the census enumerators are often police or other government officials, who tend to use security-based national identity cards or family registration cards to validate the citizenship status of those they are enumerating (Di 2010; Dwinosumono 2006).

Assessing Poverty

In assessing the absolute level of poverty or the absolute levels of illness, household surveys are an inappropriate instrument for obtaining information about the poorest of the poor, especially in developing countries. This is because household surveys, with rare exceptions, typically omit, by design,

1. those not in households because they are homeless,
2. those in institutions, including refugee camps, and
3. mobile, nomadic or pastoralist populations.

In addition, in practice, because these individuals are difficult to reach, household surveys will typically under-represent

1. those in fragile, disjointed or multiple occupancy households (because of the difficulty of identifying them),
2. those in urban slums (because of the difficulty of interviewing), and
3. certain areas of a country deemed to pose a security risk.

If one wanted a practical – as distinct from theoretical – definition of the "poorest of the poor," the above collection of six population subgroups could hardly be bettered.

Census officials, because of the difficulty of enumeration, even in developed countries, often only estimate those groups' size and location, so their members are not included in the available sampling frames for household surveys. In developing countries, these marginalized groups may not be included at all, even in the estimated population counts. The lack of recognition of these problems with the design and implementation of household sample surveys, particularly in developing countries, has meant that there has been no systematic attempt to estimate the size and distribution of the population groups "missing" from the sampling frames of national household surveys.

How Many Are Potentially "Missing" from Population Counts and from Sampling Frames of Household Surveys?

The focus here is on groups for which there are credible sources, and that are normally among the poorest. Other groups, such as economic and environmental migrants (Myers 1997), are not considered below.

The Homeless

Rather obviously, household surveys omit the homeless and street children. Estimating numbers is very difficult. Over 20 years ago, the United Nations Children's Fund (UNICEF) estimated that there were about 100 million street children (UNICEF 1989) worldwide. The figure is still commonly cited but has no evidence base (Green 1998; Hecht 1998). But, however many there are, they will not be covered by household surveys.

Institutionalized Populations

Household surveys, by definition, omit from their sampling frame those in institutions: care homes, (some) factory barracks, hospitals, the military, prisons, refugee camps, religious orders and school dormitories.

Care Homes and Hospitals: Those in hospitals and care homes will on average be poorer because morbidity is associated with poverty (Lopez 2002), although that is less true for older people. There are an estimated 20 million hospital beds worldwide (World Health Organization [WHO] 2011).

Military: The Central Intelligence Agency's (CIA) World Factbook (CIA 2011) documents 92 million military personnel worldwide (including reservists).

Prison: Those in prisons will usually be poorer, and estimates of the world's total prison population are around 9.8 million (Walmsley 2003). None of these 9.8 million will be included in the sampling frame of household surveys.

Refugees: Refugees are not considered part of any nation's population so they cannot be included in survey sampling frames nor make any contribution to survey-based estimates. However, the United Nations High Commissioner for Refugees (UNHCR 2010) publishes figures annually on numbers of officially registered refugees, internally displaced persons and stateless persons. The worldwide total is 36.5 million, but these figures do not include the large number of illegal immigrants, most of whom will not be counted in a national population and, of course, not in the sampling frames of household surveys.

Nomadic and Pastoralist Groups by World Region

The permanently mobile are usually excluded from household surveys. In particular, censuses and surveys in developing countries have difficulty enumerating nomadic/pastoralist populations, who have much less access to services (UNICEF 2007); and, while it is difficult to assess their income and wealth, and there clearly are some who are rich-in-kind (or asset rich), the majority are usually poor in all senses.

There is no reliable information available on the number of nomadic pastoralists, including sea-faring mobile communities, worldwide. The only internationally comparable source is that compiled by the International Livestock Research Institute (Thornton et al. 2003), based partly on livestock numbers, although they will include agro-pastoralists who are semi-sedentarized. These estimates suggest there are 217.5 million in pastoralist households.

The Difficult to Reach

A) Fragile and Disjointed Households

The task of the census enumerator or survey interviewer is made much more difficult when the household structure is ambiguous or undefined so that either identifying the household head and/or counting the numbers in the household is almost impossible.

B) Urban Slums

The most recent estimates from UN-Habitat (2011) are that more than a billion people are living in urban slums in developing countries, but information is rarely disaggregated according to intra-urban location, and the poorest urban populations are often simply not included in data gathering.

The few surveys conducted in those slums show sharp gradients according to income quintiles within urban populations (UN-Habitat 2003). But, given the very high levels of mobility, it would seem reasonable to assume that a substantial minority of those households in the slum areas of cities in developing country are uncounted in any census. Moreover, even where they are counted in censuses, many would (because of interviewer reluctance) in practice, be excluded from sampling frames.

C) Insecure or Isolated Areas

This will obviously vary according to context and so will be a much larger problem in specific countries. Given the security situation – or simply difficulty of transport – in many countries, it can often be difficult for the implementing institutions to carry out a fully representative survey or census.

Overall Estimates, Discussion and Conclusions

Overall Estimates

The numbers vulnerable to undercounting are summarized in columns 3 and 4 of Table 1. Not all those missing populations are poor. Estimates of the poor are assumed to include all those in prison and all refugees (and there are assumed to be at least as many unofficial refugees as official refugees); all those hospitalized in low- or low-middle-income countries (about half), but only those in the military in low-income countries (about 20%); and between 20% and 40% of nomadic populations. In addition, based on informal conversations with census officials in several countries and on the difficulties of using satellite imagery in slum areas (Schurman 2009) (because of the need to rely on key informants and the visual obscurity of some structures), the number of slum dwellers missing is estimated at between 10% and 20%.

Table 1. Estimates of population groups missing from sampling frames of household surveys worldwide

		Vulnerable to undercounting		Estimated percentage poor	Missing poor (millions)	
		Minimum	Maximum		Minimum	Maximum
Pastoralists		217.5	–	20–40%	43.5	87.0
Institutionalized	Refugees	36.5	73.0	100%	36.5	73.0
	Hospitals	20.0	–	40–60%	8.0	12.0
	Military	92.0	–	15–25%	13.8	23.0
	Prisons	9.8	9.8		9.8	9.8
Urban populations		2535	–			
Slum populations		827.7	–	10–20%	82.8	165.6
Total					**194.4**	**370.4**

Source: Hospital beds – WHO (2011); Prisoners – Walmsley (2003); Military – CIA (2011); Refugees – UNHCR (2010); Nomads – Thornton et al. (2002); Urban population proportions – CIA (2011); Slum proportions in urban areas – estimated by author from UN-Habitat (2003/2011).

Worldwide, the totals in the subsections above add up to between 194 and 370 million (Table 1). Moreover, the estimates do not include the homeless, those in fragile or disjointed households, or those in areas where there are security risks. Most of the homeless are probably from urban slums, so there would be double counting, but the other two categories (large, but of unknown size) are definitely additional. Estimates of between 300 and 500 million worldwide would be reasonable.

Censuses and Sampling Frames

Counting Displaced and Illegal Groups

Census organizations in developed countries use several procedures for estimating the numbers of illegal immigrants. But those procedures would not work for South–South illegal migration. Moreover, there are other omitted subgroups, often quite large: for example, scheduled castes and tribes in India (Government of India, Ministry of Social Justice and Empowerment 2012) and illegal servants in rich households.

Counting and Sampling Nomads and Pastoralists

These are difficult to count simply because they are moving. Reasonable samples have been obtained through combining local-level surveys with remote sensing of livestock (Galvin et al. 2001), but documenting change in their human population remains, on the whole, elusive.

Counting Urban Slum Populations

Any face-to-face interviewing approach will be unreliable both because of the lack of a sampling frame and because respondents will be suspicious of the reason for the questions because they are illegally resident. But even if the census organization were to make available a listing of "houseless" people, given the high levels of intra-slum mobility, this would be an unreliable sampling frame for surveys.

Solutions and Conclusions

Accurate Censuses?

International organizations should support national census organizations in developing and testing procedures for counting pastoralists and other nomads (gypsies, highly mobile workers, long-distance truck drivers, travellers, etc.) and those in urban slums (Angeles et al. 2009; Schurman 2009); and in adopting best practice from UN guidelines. But the same procedures do not solve the sampling frame problem of household surveys, because of the delays between census and survey. In the absence of any simple solution, this author (Carr-Hill 2012) has shown that it may be possible to make estimates of the missing populations. It is crucial to develop similar methods more systematically, with an agreed theoretical basis.

Measuring Progress toward the Millennium Development Goals

These problems are urgent because these data are input for more than half the indicators used for assessing progress toward the Millennium Development Goals (Appendix 1) in developing countries. In particular, the UNDP (2012) claim that the goal of halving the poverty rate has been reached cannot be taken at face value. Even if there has been no growth in the number of uncounted – which seems unlikely given the collapse of vital and registration systems – the missing population means that the reported reduction of 50% from 2 billion to 1 billion in fact reflects a reduction of 43% from 2.3 billion to 1.3 billion (and the latter figure is probably a substantial underestimate).

Population undercounting means that any social program risks ignoring the poorest of the poor. This blindness is a public scandal affecting between 300 and 500 million of the poorest people in developing countries (between 4.5% and 7.0% of the total world population). It should be addressed immediately by international and national organizations, in terms of developing and testing appropriate procedures for counting.

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Appendix I. Indicators for Monitoring Millennium Development Goals that are dependent on population data

	Indicator Name
1	Proportion of population below $1 purchasing power parity (PPP) per day
1A	Poverty headcount ratio (percentage of population below the national poverty line)
2	Poverty gap ratio (incidence multiplied by depth of poverty)
3	Share of poorest quintile in national consumption
4	Prevalence of underweight children under 5 years of age
5	Proportion of population below minimum level of dietary energy consumption
6	Net enrolment ratio in primary education
8	Literacy rate of 15–24 year-olds
10	Ratio of literate women to men, 15–24 years old
13	Under-five mortality rate
14	Infant mortality rate
15	Proportion of 1-year-old children immunized against measles
16	Maternal mortality ratio
17	Proportion of births attended by skilled health personnel
18	HIV prevalence among pregnant women aged 15–24 years
19	Condom use rate of the contraceptive prevalence rate
19A	Condom use at last high-risk sex
19B	Percentage of population aged 15–24 years with comprehensive correct knowledge of HIV/AIDS
19C	Contraceptive prevalence rate
20	Ratio of school attendance of orphans to school attendance of non-orphans aged 10–14 years
21	Prevalence and death rates associated with malaria
22	Proportion of population in malaria-risk areas using effective malaria prevention and treatment measures
29	Proportion of the population using solid fuels
30	Proportion of population with sustainable access to an improved water source, urban and rural
31	Proportion of population with access to improved sanitation, urban and rural
32	Proportion of households with access to secure tenure
44	Debt service as a percentage of exports of goods and services
45	Unemployment rate of young people aged 15–24 years, each sex and total
46	Proportion of population with access to affordable essential drugs on a sustainable basis
47	Telephone lines and cellular subscribers per 100 population
48	Personal computers in use per 100 population
	Internet users per 100 population

Note: 48 indicators were defined but there were an additional 6 sub-indicators, making 54 indicators.

Cancer Registration Needs Assessment at a Tertiary Medical Centre in Kilimanjaro, Tanzania

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Abstract

Cancer burden is increasing in Africa more than in any other continent, but population-based tracking of cancer incidence is incomplete. Cancer registries can improve understanding of cancer incidence.

To assess organizational readiness to sustain registry development, we conducted a survey assessing change efficacy, resource availability and change commitment at the Kilimanjaro Christian Medical Centre (KCMC), an academic hospital in Moshi, Tanzania. Fifty-two surveys were returned (80% response rate). There was strong reliability among change efficacy and commitment survey items, with Cronbach's alphas of 0.93 and 0.77, respectively.

Clinicians, nurses and administrators conveyed similar responses regarding change efficacy. Clinicians had similar responses for change commitment. Echoing opinion in many low- and middle-income countries, approximately one-third of respondents indicated there were no funds to maintain the registry, and funds were not obtainable. For most resources, respondents felt that resources were sufficient or attainable. Respondents were generally confident and committed to registry implementation. Lessons learned at KCMC may be more broadly relevant.

Introduction

Cancer and Cancer Registration in Africa

The burden of cancer in sub-Saharan Africa is growing. Over the next ten years, the burden of cancer and chronic disease will increase in Africa more than in than any other continent (de-Graft Aikins et al. 2010). By best estimates, the cumulative incidence of cancer (excluding Kaposi's sarcoma and non-melanoma skin cancer) in Zimbabwe, for example, is only about 30% less than that of France, but cancer mortality is almost double (Parkin et al. 2008). These data suggest that in Africa both the incidence of cancer and mortality due to cancer are severely underestimated. An important first step in improving these estimates involves the establishment of reliable, population-based cancer registries. Unfortunately, in most of Africa the population-based tracking of cancer incidence has been incomplete; resources are limited, knowledge of cancer trends in this area is inadequate, and trends are based mostly on case series (Orem and Wabinga 2009; Parkin et al. 2008).

Models of capacity-building to support cancer registry development are a chief issue for low- and middle-income countries. In fact, the International Agency for Research on Cancer (IARC) has a Global Initiative for Cancer Registry Development in low- and middle- income countries that aims to create capacity to produce reliable and high-quality information on the burden of cancer to inform effective cancer control policies. The US-based National Cancer Institute (NCI) recently issued a report seeking to facilitate lessons learned from IARC and other groups to provide technical assistance and training to foster development of cancer registries in low- and middle-income countries (National Cancer Institute 2012). Our approach for the assessment of organizational readiness to change in preparation for cancer registry development supports this aim.

Assessing the perceptions of key stakeholders presents a critical foundation for establishing a sustainable, population-based cancer registry. In fact, experts in organizational change have found that readiness to change is an important predictor of successful implementation (Kotter 1996; Weiner et al. 2008). Without a clear understanding of organizational perceptions and readiness to change, the development of a cancer registry might not be aligned with the organization's values and needs. Organizational readiness to change is a multifaceted issue comprising two chief constructs – organization members' change commitment and change efficacy to implement organizational change. Change comprises intertwining levels, including both individual and organizational levels. When an individual believes that he or she can successfully make a change and that change is personally beneficial, the individual may be more likely to support an organizational change (Holt et al. 2010). Moreover, assessing individuals' readiness to change and perceived needs is critical for a sustainable foundation for population-based cancer registry development. Our objective was to assess shared beliefs among stakeholders in the organizational ability to initiate and maintain cancer registration activities at a tertiary referral medical centre in Moshi, Tanzania. In doing so, we present a model for ensuring sustainable cancer registry development in low- and middle-income countries (LMICs).

Methods

Kilimanjaro Christian Medical Centre

Located in northeastern Tanzania, the Kilimanjaro Christian Medical Centre (KCMC) was founded in 1971 by the Good Samaritan Foundation and has operated continuously for over four decades. KCMC has approximately 560 beds and serves a patient population of over 11 million people living in the Kilimanjaro region (Kilimanjaro Christian Medical Centre 2012). In addition to providing patient care, in 1996 KCMC was expanded to include medical training, with the establishment of Tumaini University Kilimanjaro Christian Medical College (Kilimanjaro Christian Medical Centre 2012).

KCMC has a history of cancer registration, although data collection has not been systematic and the quality and completeness of registry data have not been documented. At the time of manuscript preparation, KCMC cancer registration activities were inactive. However, because of the increasing cancer burden in eastern Africa and the need for high-quality, comprehensive data to inform resource planning, there has been renewed interest in expanding KCMC cancer registration activities.

Survey Design

We conducted a self-administered needs assessment survey at KCMC over a two-week period in June 2012. The survey contained 41 items assessing change commitment, change efficacy (Gist and Mitchell 1992; Weiner 2009) and determinants of change efficacy such as resource availability. Survey items assessing change commitment included, "How committed is your facility to implementing this change?" and "How willing is your facility to work hard to implement this change?" among others. Response options included "not at all," "a little," "fairly," "very" and "don't know."

The survey also assessed change efficacy. Change efficacy refers to organization members' shared organizational confidence in the communal ability to implement a change effectively – in this case further development of a cancer registration program. Examples of change efficacy items are, "Can the organization assign the right tasks to the right people in implementing this change?" and "Can the organization effectively use the resources that are currently available to implement the program?" Change efficacy items used in the survey were rated on a five-point Likert scale: "not at all confident," "a little confident," "fairly confident," "very confident" and "don't know."

The survey addressed two determinants of change efficacy – resource availability and situational factors (Weiner 2009). Resource availability refers to organizational members' perceptions about the availability and obtainability of resources. This includes an assessment of material, financial and human resources needed to advance the cancer registry. Respondents were asked about resources including pathologists, clinical staff to collect patient data, computers and software, among others. Response options for resource availability items included, "have none and resource is not available," "have insufficient, but resource is attainable," "already have sufficient resource," "not necessary" and "don't know." In addition to these discrete items, respondents were given the opportunity to answer open-ended questions with free responses. Regarding situational factors, respondents were asked whether hospital staff have sufficient time and political support to make needed changes.

Sampling and Recruitment

Because our goal was to obtain a comprehensive, organizational perspective, we conducted non-probability, purposive sampling (Trochim and Donnelly 2006). To maximize organization leaders' support, we initially met with the hospital's executive director and subsequently contacted the department chairs of obstetrics and gynecology, pediatrics, urology, surgery, internal medicine, medical records and nursing. Department chairs provided additional contacts and facilitated obtaining responses from their unit. We attended clinical meetings such as morning report to increase survey awareness and participation. In accordance with respondents' preference, surveys were administered on paper as well as electronically via e-mail.

Statistical Analysis

Frequencies were tabulated and, where appropriate, inconsistencies were checked against the original surveys for manual correction if required. Missing variables and incomplete questions were coded "missing." Missing values were examined for patterns in reporting and correlations with professional roles. Data were first analyzed for descriptive outcomes, including proportions, means, medians and ranges. Chronbach's alphas were examined as a measure of reliability among the change efficacy and change commitment survey items. Bivariate associations among clinical role, resource availability and change efficacy survey items were reported using chi-squared and

Fisher's exact tests as appropriate.

After we had examined raw change efficacy survey responses, survey responses were collapsed (e.g., "not at all confident" and "a little confident" were merged) and re-examined descriptively. Survey items were then classified into two categories – organizational management versus motivation. Within each category, survey items were ordered from highest percentage of confidence to lowest.

All analyses were conducted using Stata (StataCorp. 2011. Stata Statistical Software: Release 12. College Station, TX: StataCorp LP). Duke University Health System's Institutional Review Board reviewed and exempted this study. The Research Ethics Committee at Kilimanjaro Christian Medical Centre and Tumaini University Kilimanjaro Christian Medical College approved this study.

Results

Response Rate and Respondent Characteristics

A total of 64 surveys were administered (57 paper-based surveys delivered to possible participants; 7 electronic surveys e-mailed). Fifty-two surveys were returned, for a response rate of approximately 80%. Respondent characteristics are presented in Table 1.

Table 1. Respondent characteristics (*n* = 52)

	Percent/mean	SD	Minimum, maximum
Male	61.5%	–	–
Age	38.3	9.9	24, 66
Professional Role			
Physician	57.7%	–	–
Nurse	17.3%	–	–
Resident	9.6%	–	–
Administrator	7.7%	–	–
Medical student	7.7%	–	–
Medical Department			
Internal medicine	32.7	–	–
Surgery	13.5	–	–
Pediatrics	11.5	–	–
Urology	7.7	–	–
Medical records	7.7	–	–
Gynecology	5.8	–	–
Dermatology	3.9	–	–
Pathology	1.9	–	–
Not reported[a]	15.4	–	–

[a] Many respondents interpreted the medical department/specialty question as though it applied to physicians only. Therefore, the medical department was not reported by many nurse-respondents.

Missing Values

Data were examined for systematic patterns of missing values. No patterns were detected. No association was found between professional role and missing value. We examined associations between year of birth, a proxy measure for years of professional experience and missing values; no association was found.

Change Commitment

In addition to examining individuals' confidence in the organization's readiness to change, respondents were asked about the organization's commitment, motivation and willingness to work hard to implement the cancer registration program (Table 2). Cronbach's alpha for the change commitment items was 0.77, indicating acceptable reliability. Regarding both commitment to the cancer registry and willingness to work hard to implement the registry, approximately half of respondents reported that the organization was very committed/willing. However, only 37% (n = 19) reported that the organization was very motivated to implement the cancer registry.

Table 2. Change commitment (*n* = 52)

	Not at all committed % (n)	**A little committed % (n)**	**Fairly committed % (n)**	**Very committed % (n)**	**Don't know % (n)**	**Missing % (n)**
How committed is your facility to implementing this change?	3.9% (2)	5.8% (3)	28.9% (15)	51.9% (27)	9.6% (5)	0% (0)
	Not at all motivated % (n)	**A little motivated % (n)**	**Fairly motivated % (n)**	**Very motivated % (n)**	**Don't know % (n)**	**Missing % (n)**
How motivated is your facility to implementing this change?	1.9% (1)	9.6% (5)	44.2% (23)	36.5% (19)	7.7% (4)	0% (0)
	Not at all willing % (n)	**A little willing % (n)**	**Fairly willing % (n)**	**Very willing % (n)**	**Don't know % (n)**	**Missing % (n)**
How willing is your facility to work hard to implement this change?	0.0% (0)	5.8% (3)	36.5% (19)	50.0% (26)	7.7% (4)	0% (0)
	Not at all % (n)	**A little % (n)**	**Somewhat % (n)**	**Very much % (n)**	**Don't know % (n)**	**Missing % (n)**
How much does your facility want to implement this change?	1.9% (1)	3.9% (2)	30.8% (16)	55.8% (29)	7.7% (4)	0% (0)

Notes:

1. Respondents were instructed that when an organization makes a change, like expanding the cancer registry program, there is a core group of people who implement the change and use the program. This group probably includes administrators, managers, physicians, nurses or other staff. Respondents were advised that the survey items assessed their perception and opinion, not factual knowledge. They were then asked to indicate which response best reflected their understanding and confidence in their facility and its leadership regarding expanding the cancer registry.
2. Cronbach's alpha for the change commitment items was 0.77.

Change Efficacy

Cronbach's alpha for the change efficacy items was 0.93, indicating strong reliability. A comprehensive list of the survey items assessing change efficacy are described in Table 3. Forty percent (n = 21) of respondents indicated they were very confident that their organization could effectively use the resources currently available in order to implement the cancer registry. Over half of respondents (56%, n = 29) indicated they were very confident that clinicians could be encouraged to use the cancer registry. Similarly, 34.6% (n = 18) reported that they were very confident their organization could effectively coordinate the efforts of those involved in implementing the cancer registry. Respondents were divided regarding their perceptions of the organization's ability to communicate clearly regarding implementation of a cancer registry. Slightly less than one-third (29%, n = 15) believed very confidently that the organization could maintain the momentum going in order to implement the cancer registry. Approximately one-third of respondents were very confident and fairly confident (35%, n = 18; 37%, n = 19, respectively) that the organization could keep track of progress in implementing the registry.

Table 3. Change efficacy (*n* = 52)

	Not at all confident % (n)	A Little confident % (n)	Fairly confident % (n)	Very confident % (n)	Don't know % (n)	Missing % (n)
Effectively use the resources that are currently available to implement the program?	9.6% (5)	7.7% (4)	36.5% (19)	40.4% (21)	5.8% (3)	0% (0)
Encourage clinicians to try using this program (e.g., refer patients)?	0% (0)	9.6% (5)	32.7% (17)	55.9% (29)	1.9% (1)	0% (0)
Effectively coordinate the efforts of those involved in implementing this program?	5.8% (3)	13.5% (7)	42.3% (22)	34.6% (18)	3.9% (2)	0% (0)
Support clinicians as they adjust their clinical practice in response to this program?	1.9% (1)	11.5% (6)	36.5% (19)	44.2% (23)	3.9% (2)	1.9% (1)
Effectively solve problems that might arise in implementing this program?	7.7% (4)	17.3% (9)	42.3% (22)	26.9% (14)	3.9% (2)	1.9% (1)
Communicate clearly why the facility is implementing this change?	1.9% (1)	15.4% (8)	38.5% (20)	38.5% (20)	5.8% (3)	0% (0)
Keep the momentum going in implementing this change?	1.9% (1)	21.2% (11)	44.2% (23)	28.9% (15)	1.9% (1)	1.9% (1)
Keep track of how things are going in implementing this change?	1.9% (1)	19.2% (10)	36.5% (19)	34.6% (18)	3.9% (2)	3.9% (2)
Assign the right tasks to the right people in implementing this change?	5.8% (3)	15.4% (8)	32.7% (17)	44.2% (23)	1.9% (1)	0% (0)
Coordinate tasks so that implementation goes smoothly?	3.9% (2)	21.2% (11)	28.9% (15)	44.2% (23)	1.9% (1)	0% (0)
Support people as they adjust to this change?	1.9% (1)	17.3% (9)	50.0% (26)	23.1% (12)	5.8% (3)	1.9% (1)
Get people involved and interested in implementing this change?	9.6% (5)	9.6% (5)	42.3% (22)	34.6% (18)	1.9% (1)	1.9% (1)
Manage the politics of implementing this change?	7.7% (4)	17.3% (9)	32.7% (17)	30.8% (16)	7.7% (4)	3.9% (2)

Notes:

1. Respondents were instructed that when an organization makes a change, like expanding the cancer registry program, there is a core group of people who implement the change and use the program. This group probably includes administrators, managers, physicians, nurses, or other staff. Respondents were advised that the survey items assessed their perception and opinion, not factual knowledge. They were then asked to indicate which response best reflected their understanding and confidence in their facility and its leadership regarding expanding the cancer registry.
2. Cronbach's alpha for the change efficacy items was 0.93.

Perceptions of Organizational Motivation versus Management

The change efficacy survey items were collapsed and categorized (e.g., "fairly confident" and "very confident" were merged; survey items were classified into motivation versus management domains). There was a clear threshold of confidence and agreement between the organizational motivation versus management domains (Table 4). For example, being fairly or very confident within the management domain survey items ranged from 64% to 77%. The mean percentage response of fairly or very confident across these survey items was 73%. In contrast, respondents reported being fairly or very confident (or similar) for between 81% and 89% of motivational survey items.

Table 4. Collapsed change efficacy and change commitment responses (n = 52)[a]

	Not at all or a little confident % (n)	Fairly or very confident % (n)	Don't know or missing % (n)
Management tasks			
Communicate clearly why the facility is implementing this change?	17.3% (9)	76.9% (40)	5.8% (3)
Effectively use the resources that are currently available to implement the program?	17.3% (9)	76.9% (40)	5.8% (3)
Effectively coordinate the efforts of those involved in implementing this program?	19.3% (10)	76.9% (40)	3.9% (2)
Get people involved and interested in implementing this change?	19.3% (10)	76.9% (40)	3.9% (2)
Assign the right tasks to the right people in implementing this change?	21.2% (11)	76.9% (40)	1.9% (1)
Support people as they adjust to this change?	19.2% (10)	73.1% (38)	7.7% (4)
Keep the momentum going in implementing this change?	22.2% (12)	73.1% (38)	3.8% (2)
Coordinate tasks so that implementation goes smoothly?	25.1% (13)	73.1% (38)	1.9% (1)
Keep track of how things are going in implementing this change?	21.1% (11)	71.1% (37)	7.8% (4)
Effectively solve problems that might arise in implementing this program?	25% (13)	69.2% (36)	3.9% (2)
Manage the politics of implementing this change?	25.0% (13)	63.5% (33)	11.6% (6)
Organizational Motivation			
Encourage clinicians to try using this program (e.g., refer patients)?	9.6% (5)	88.6% (46)	1.9% (1)
Support clinicians as they adjust their clinical practice in response to this program?	13.4% (7)	80.7% (42)	5.8% (3)
	Not at all or a little % (n)	**Somewhat or very much % (n)**	**Don't know or missing % (n)**
How much does your facility want to implement this change?	5.8% (3)	86.6% (45)	7.7% (4)
	Not at all or a little willing % (n)	**Fairly or Very willing % (n)**	**Don't know or Missing % (n)**
How willing is your facility to work hard to implement this change?	5.8% (3)	86.5% (45)	7.7% (4)
	Not at all or a little committed % (n)	**Fairly or very committed % (n)**	**Don't know or missing % (n)**
How committed is your facility to implementing this change?	9.7% (5)	80.8% (42)	9.6% (5)
	Not at all or a little motivated % (n)	**Fairly or very motivated % (n)**	**Don't know or missing % (n)**
How motivated is your facility to implementing this change?	11.5% (6)	80.7% (42)	7.7% (4)

[a] Survey responses presented in Table 4 were collapsed (e.g., "not at all confident" and "a little confident" were merged). Survey items were reorganized into two categories – organizational motivation and management tasks. Within each category, survey items were then ordered from highest percentage of confidence to lowest percentage of confidence.

Resource Availability

Respondents were asked to report on perceived availability of resources needed for development of the cancer registry (Table 5). When asked about the availability of pathologists, approximately half of respondents indicated they "have none and resource is not attainable." Respondents were asked about the availability of staff to collect, enter, follow up on and audit cancer registry patient data. For each of these items, most respondents reported that the organization had insufficient staff, but the resource was attainable; specifically, staff to collect patient data (44%, n = 23), staff to enter patient data (46%, n = 24), staff to follow up on registered patients (35%, n = 18) and staff to audit the registry (44%, n = 23). The resource assessment also inquired about the availability of computers, software, and staff with computing expertise. In each of these categories, the most common response category was that the resource was insufficient but attainable. Respondents were also asked about the availability of funds to maintain the registry. Interestingly, answers were more evenly distributed across response categories for this survey item than for any other.

Table 5. Resource availability (n = 52)

	Have none and resource is not attainable % (*n*)	Have insufficient, but resource is attainable % (*n*)	Already have sufficient resource % (*n*)	Not necessary % (*n*)	Don't know % (*n*)	Missing % (*n*)
	48.1% (25)	38.5% (20)	5.8% (3)	0.0% (0)	1.9% (1)	5.8% (3)
Pathology technicians	9.6% (5)	63.5% (33)	13.5% (7)	1.9% (1)	3.9% (2)	7.7% (4)
Staff to collect patient data	11.5% (6)	44.2% (23)	28.9% (15)	0.0% (0)	5.8% (3)	9.6% (5)
Staff to enter patient data	13.5% (7)	46.2% (24)	26.9% (14)	0.0% (0)	5.8% (3)	7.7% (4)
Staff to follow up on registered patients	17.3% (9)	34.6% (18)	25.0% (13)	1.9% (1)	13.5% (7)	7.7% (4)
Staff to audit the registry	19.2% (10)	44.2% (23)	15.4% (8)	0.0% (0)	13.5% (7)	7.7% (4)
Computers	9.6% (5)	57.7% (30)	17.3% (9)	0.0% (0)	7.7% (4)	7.7% (4)
Software	17.3% (9)	48.1% (25)	11.5% (6)	0.0% (0)	15.4% (8)	7.7% (4)
Staff with computing expertise	17.3% (9)	44.2% (23)	17.3% (9)	0.0% (0)	13.5% (7)	7.7% (4)
Funds to maintain the registry	34.6% (18)	19.2% (10)	5.8% (3)	0.0% (0)	32.7% (17)	7.7% (4)

Bivariate Analysis

Due to the small sample size, we utilized Fisher's exact test to examine whether professional role (e.g., physician, administrator) was associated with differences in perception regarding availability of resources. For the majority of resources, there was no association between professional role and perception of resource availability. However, there was an association between professional role and availability of pathology technicians (p=.04). Further, we assessed differences in reported change efficacy and professional role. For each of the 13 change efficacy questions, there was no association between reported confidence in an organization's ability to implement the registry and professional role.

We then examined whether specialty (e.g., internal medicine, surgery) was associated with reported change efficacy. Of 13 items, differences between specialties were found for only four measures. Significant differences were found for the following items: support clinicians as they adjust clinical practice in response to the program (p=.01), keep the momentum going in implementing this change (p=.00), assign the right tasks to the right people (p=.04), and coordinate tasks so that implementation goes smoothly (p=.02).

Discussion

Overall, respondents reported a high degree of change commitment and change efficacy, suggesting that KCMC clinicians and administrators expressed confidence in their shared ability to organize and implement the process needed to develop and implement the cancer registry. Furthermore, responses were consistent among people of varied professional roles; clinicians, nurses, trainees and administrators all conveyed similar responses regarding their organization's readiness and ability to implement systematic cancer registration. In general there was also agreement between professionals of different medical specialties. Readiness to change and organizational endorsement are strong predictors of success in making a change (Kotter 1996; Sweeney and Whitaker 1994; Weiner 2009). This consensus among a multidisciplinary team suggests that KCMC is an organization with a drive to change. While each institution in low- and middle-income countries is unique, identifying strengths and concerns at KCMC may inform other, future cancer registration projects in similar environments.

The two measures with the highest reported levels of confidence were, first, to encourage clinicians to try using the registry (e.g., refer patients to the registry) and, second, to support clinicians as they adjust their clinical practice in response to the registry. Comparatively lower levels of confidence were reported for three measures: (1) effectively solve problems that might arise, (2) keep track of how things are going, and (3) manage the politics of implementing this program. This suggested that there was perceived support for clinicians, but respondents were not as confident about the organization's ability to manage change throughout implementation. When we collapsed and classified the change efficacy items into two categories – organizational motivation versus management – a clear threshold presented itself. Over 80% responded positively (e.g., "fairly confident" or "very confident") for each of the motivational survey items; respondents indicated that KCMC was very committed to registry implementation, very willing to work hard to implement it, and wanted very much to implement the registry. However, when asked about issues of management such as task coordination and problem solving, respondents responded positively far less frequently.

This distinction between organizational motivation and task management is important to understand, particularly in the context of cancer registry development in low- and middle-income countries. In learning healthcare organizations, managers must extend beyond traditional management roles and must serve as designers and teachers (Hernandez et al. 2000). This may be particularly true in the resource-limited settings where managers must be innovative. Organizations must communicate goals and values to their employees in an effort to build a sense of organizational belonging. To that end, it is essential that those internal and external stakeholders are involved early in the implementation process and that there is organizational endorsement. Relevant stakeholders within low- and middle-income countries must be identified, and their attitudes toward the change, such as cancer registry implementation, must be assessed (Hernandez et al. 2000). Moreover, it is critical that the political climate both internal and external to the organization is aligned well to support cancer registration activities. There must be clear delineation of responsibilities, an understanding of decision-making patterns, and a balance of tasks between employees (Charns and Gittell 2000; Hernandez et al. 2000).

Despite the high level of change efficacy, limited resources were available for all human resources except pathologists (e.g., staff to collect and enter patient data); the largest percentage of respondents indicated that currently the resource was insufficient but that it was obtainable. We surveyed a wide variety of professionals ranging from medical records technicians to hospital administrators. Respondents' professional role may limit their knowledge of certain resources. For example, a medical records technician may not be as knowledgeable about the availability of funds to maintain the registry, compared to the hospital administrator. Interestingly, we found similar responses across professional roles for most items. From a change-management perspective, the assessment of perception of resource availability may be particularly important. If resources are truly unavailable, change efficacy may be undermined. Nearly half of respondents reported that they had no pathologists and none were obtainable. However, pathology residents from KCMC are currently undergoing training to return as staff pathologists; clearly, a communication gap exists between perception and actual availability of resources. Despite this communication gap, the assumption of KCMC staff is likely based on the known shortage of trained pathologists in sub-Saharan Africa (Awadelkarim et al. 2012). For example, the entire country of Tanzania has only 15 pathologists; this equates to one pathologist per 2.5 million people (Okesina 2009; Rambau 2011). This shortage needs to be addressed on a broader scale. A potential solution to shortage of trained pathologists involves telepathology, where pathologic slides are prepared and images are transmitted to pathologists located off-site (Hazin and Qaddoumi 2010), and working partnerships with high-income countries (Knaul et al. 2012).

Slightly more than one-third of respondents indicated that there were no funds to maintain the registry and funds were not obtainable. This sentiment is echoed in many LMICs, so lessons learned at KCMC may be more broadly relevant. Allocating scarce resources to a cancer registry can create additional strain in a system already stretching funds to provide appropriate health care. However, an initial investment in cancer registration is critical to understanding the disease burden, and unless disease burden is understood, appropriate resources cannot be allocated to cancer control. In order to ensure sustainable funding for population-based cancer registries, those leading cancer registration should involve health ministry officials in their respective countries early on (Anderson et al. 2011). Furthermore, long-term partnerships between high- and low-income countries have led to successful implementation of cancer control and treatment programs (Carlson et al. 2010). In order to bridge the resource gap, smaller-scale, hospital-based cancer registries can be initially developed and later scaled up for more comprehensive population coverage. Information obtained in our survey supports the aims of the NCI and other organizations aimed at facilitating lessons learned in low- and middle-income settings for broader dissemination in the implementation of cancer registry development (National Cancer Institute 2012). To that end, we posit that conducting a needs assessment is a critical early-stage component when beginning or expanding a cancer registry program, particularly in LMICs where resources are scarce. Perspectives gained from a survey like ours may be useful in conducting intra-institutional educational programs and/or prioritizing resource acquisition. While each country and institution is unique, our survey design and methodology may be suitable for other contexts.

There are a number of successful cancer registries in LMICs that serve as an exemplar for aspiring cancer registration program like KCMC's. An example of one such registry is the Gharbiah regional cancer registry in Egypt. For well over a decade, the Gharbiah registry has achieved over 90% population coverage. Data from the Gharbiah registry have informed several publications describing patterns of cancer in the region, including a monograph describing cancer incidence in several Middle Eastern countries and comparing that information with the US-based Surveillance Epidemiology and End Results (SEER) cancer registry (Freedman et al. 2006). There are two unique attributes of the Gharbiah registry that may have facilitated its success. First, in 1996 ministers of health in Egypt, Israel, Jordan, Cyprus and the Palestinian Authority established the Middle East Cancer Consortium (Middle East Cancer Consortium 2010). These registries use common software called CANREG, which was developed by IARC. Second, the registry is affiliated with Cairo University. These strategic alliances bolster resources and provide collaborative partnerships that will help developing cancer registry programs in low- and middle-incomes countries succeed. KCMC is uniquely positioned in its affiliations with Tumaini University and Kilimanjaro Christian Medical College. Despite this, respondents reported a perception that their organization is generally supportive of change regarding the cancer registry program but lacks many tools needed to expand it. This information shapes our approach in terms of interaction with KCMC staff and registry expansion. Though not geographically proximal to KCMC, Dar es Salaam in Tanzania is also home to a referral cancer centre. KCMC may partner with local institutions and those in higher income countries to increase its capacity for cancer registration.

This study has several limitations. KCMC is a single institution, and survey results from KCMC may not be generalizable to other organizations. Surveys were self-administered. While no identifying information was collected, it is possible that respondents were hesitant to disclose responses that might reflect negatively on their organization. Given the consistency of responses across surveys, however, this is not a significant concern. We utilized a cross-sectional survey technique. Change efficacy and readiness to change will evolve longitudinally. It is possible that, even within a single institution, results would differ if measured over time. Because of the two-week survey administration time period and the sampling strategy, it is possible that important potential survey participants were not contacted. Effort was made to mitigate this limitation by sending electronic, e-mailed surveys.

In conclusion, administrators and medical staff at a large referral centre in sub-Saharan Africa believed strongly in the utility of cancer registration. However, they expressed concerns regarding registry management and sustainability. These are valid concerns that likely translate across borders to other institutions or regions in LMICs looking to develop cancer registries. Identifying such strengths and concerns prior to initiating cancer registration will help focus resources and improve chances of long-term success.

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The Role of Developing Countries in Generating Cochrane Meta-analyses in the Field of Pediatrics (Neonatology and Neuropediatrics): A Systematic Analysis

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Abstract

Background: There is a lack of up-to-date, systematic reviews that critically assess the role and potential limitations of evidence-based medicine and systematic Cochrane reviews originating in developing countries.

Methods: We performed a systematic literature review of all Cochrane reviews published between 1997 and 2010 by the Cochrane Neonatal Review Group (CNRG) in the field of neuropediatrics. The main outcome parameter of our review was the assessment of the percentage of reviews that originated in developing countries and the number of reviews that provided conclusive/inconclusive data.

Results: In total, 262 reviews were performed in the field of neonatology and 112 in the field of neuropediatrics. Only a small fraction (15/262 in neonatology [7/15 conclusive] and 16/112 in neuropediatrics [9/16 conclusive]) originated in developing countries.

Conclusions: There is an ongoing need for high-quality research that addresses specific issues that are most relevant to the medical care of children in developing countries. Funding and research agencies will play a pivotal role in selecting the most appropriate research programs for the developing world.

Introduction

Undoubtedly, evidence-based medicine (EBM) has contributed substantially to improving the quality of medicine in general, and in neonatology and pediatrics in particular (Davis 2006). Cochrane reviews are systematic reviews/meta-analyses of primary research in the medical and health policy fields. They are considered the highest standard in EBM. Systematic Cochrane reviews analyze the effects of interventions for prevention, treatment and rehabilitation on populations. In addition, they assess the accuracy of a diagnostic test for a given condition in a specific cohort and setting. They are published and regularly updated online in The Cochrane Library, ensuring that treatment decisions can be based on the most up-to-date and reliable evidence. Each systematic review addresses a specific medical problem of relevance in the treatment or diagnosis of specific patient cohorts.

The Cochrane Neonatal Review Group (CNRG) is one of 50 review groups within The Cochrane Collaboration, and one of the most active (Sinclair 2004). A number of examples illustrate the importance of systematic reviews in improving the delivery of medical care, for example, administration of antenatal steroids, surfactant replacement therapy, hypothermia for hypoxic ischemic encephalopathy, and probiotics to prevent necrotizing enterocolitis. Moreover, and of importance, Cochrane reviews have also contributed to identifying interventions that are ineffective or harmful, for example, administration of antenatal thyrotrophin-releasing hormone and early postnatal administration of dexamethasone (Crowther et al. 2004; McGuire et al. 2010).

Thus, the Cochrane database may prove particularly beneficial for low-income countries with limited resources. However, most published clinical research has been conducted in highly industrialized Western countries, and it remains unclear how the results gained from these randomized controlled trials (RCTs) will translate into changes in medical care in the developing world. Thus, it is important that developing countries themselves get involved in the process of generating Cochrane reviews, based on their specific medical problems and needs.

Therefore, the main purpose of this study was to assess the number of Cochrane reviews that originated in low-income countries, and whether these meta-analyses provide useful data for the clinician caring for children in these countries. The aim of this study was not to systematically assess the role and potential implications of RCTs performed in Western countries for the developing world.

Methods and Clinical Questions

Based on two previous systematic literature reviews (Girisch et al. 2012; Willhelm et al. 2012), including all reviews from the CNRG (http://neonatal.cochrane.org/) and on neuropediatrics from 1997 to 2010, we conducted a subgroup analysis. The following data were retrieved from the Cochrane review database: time and origin of publication by country. The main outcome parameters were:

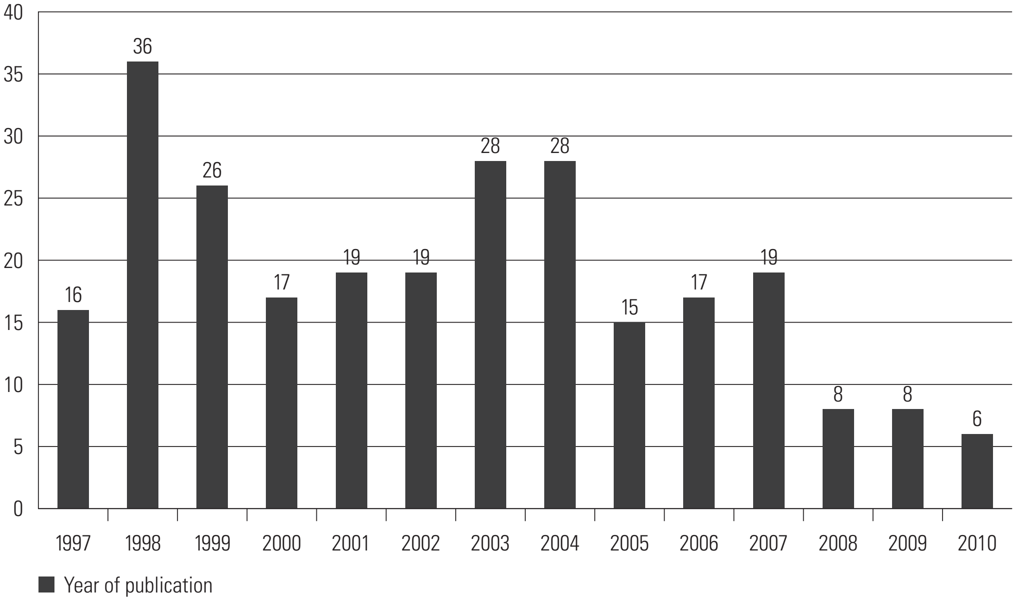
- Number (percentage) of reviews that originated in developing countries
- Number (percentage) of reviews that provided conclusive/inconclusive data.

All data were retrieved from the CNRG and Cochrane database and stored in electronic form, using SPSS 19.0 (SPSS, Chicago, IL., USA).

Results

In the field of neonatology, a total of 262 reviews were included in this study (Figure 1); five were excluded because they dealt exclusively with maternal or parental issues.

Figure 1. Number of reviews published between 1997 and 2010 (neonatology)

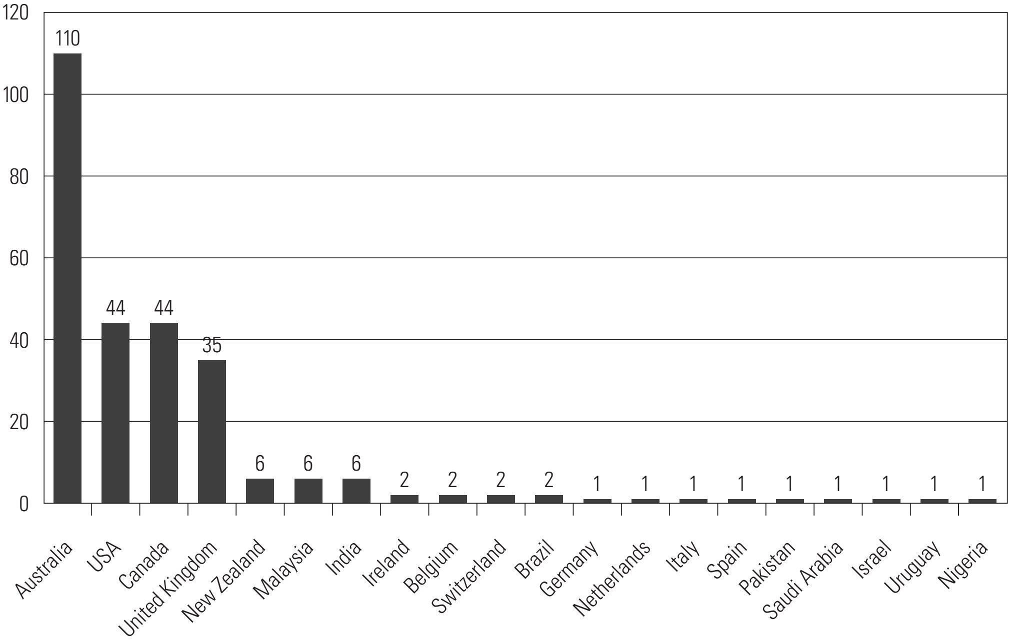


As depicted in Figure 2, the vast majority of Cochrane reviews were performed in Western, industrialized countries (Australia, North America and Europe: 247/262), while only a minority of papers originated in developing countries (15/262). Table 1 provides specific data with regard to included studies. Only seven of those 15 reviews provided conclusive recommendations (six negative, one positive). In industrialized countries, 36/247 issued a positive recommendation, 97/247 issued a negative recommendation and 114/247 were inconclusive.

Table 1. Included Cochrane reviews in the field of neonatology (1997–2010)

Country	Year	First author	Title	Therapeutic recommendation
Malaysia	2006	Nai Ming Lai	Increased energy intake for preterm infants with (or developing) bronchopulmonary dysplasia/chronic lung disease	No studies available
India	2003	Sachin S. Shah	Inhaled versus systemic corticosteroids for preventing chronic lung disease in ventilated very low birth weight preterm neonates	Not recommended
India	2005	Nandkishor S. Kabra	Multiple versus single lumen umbilical venous catheters for newborn infants	Not recommended
Pakistan	2006	Shahirose S. Premji	Higher versus lower protein intake in formula-fed low birth weight infants	Insufficient data – inconclusive
Brazil	2009	Marcela Bottino	Interventions for prevention of neonatal hyperglycemia in very low birth weight infants	Not recommended
Brazil	2009	Marcela Bottino	Interventions for treatment of neonatal hyperglycemia in very low birth weight infants	Insufficient data – inconclusive
Uruguay	2000	Agustin Conde-Agudelo	Kangaroo mother care to reduce morbidity and mortality in low birthweight infants	Not recommended
Malaysia	2000	Jacqueline J. Ho	Continuous distending pressure for respiratory distress in preterm infants	Insufficient data – inconclusive
Malaysia	2002	Jacqueline J. Ho	Early versus delayed initiation of continuous distending pressure for respiratory distress syndrome in preterm infants	Insufficient data – inconclusive
Saudi Arabia	2008	Khalid M. AlFaleh	Probiotics for prevention of necrotizing enterocolitis in preterm infants	Recommended
Israel	2004	Karla Soares-Weiser	Rotavirus vaccine for preventing diarrhoea	Not recommended
Nigeria	2004	Christy A.N. Okoromah	Diazepam for treating tetanus	Insufficient data – inconclusive
India	2007	Prakash Vemgal	Interventions for non-oliguric hyperkalaemia in preterm neonates	Insufficient data – inconclusive
Malaysia	2007	Jacqueline J. Ho	Magnesium sulfate for persistent pulmonary hypertension of the newborn	No studies available
India	2004	Sachin S. Shah	Intraventricular antibiotics for bacterial meningitis in neonates	Not recommended

Figure 2. Country of origin (neonatology)



In the field of neuropediatrics, a total of 112 reviews were included, with only 16/112 originating from developing countries (detailed information is provided in Figures 3 and 4 and Table 2). Nine reviews provided conclusive recommendations (five negative and four positive), while six were inconclusive. One report provided conditional recommendations. Of reviews performed in the Western world, 33/94 provided a positive recommendation, 11/94 a conditional recommendation, and 32/94 a negative recommendation, while some 30/94 remained inconclusive.

Figure 3. Number of reviews published between 1997 and 2010 (neuropediatrics)

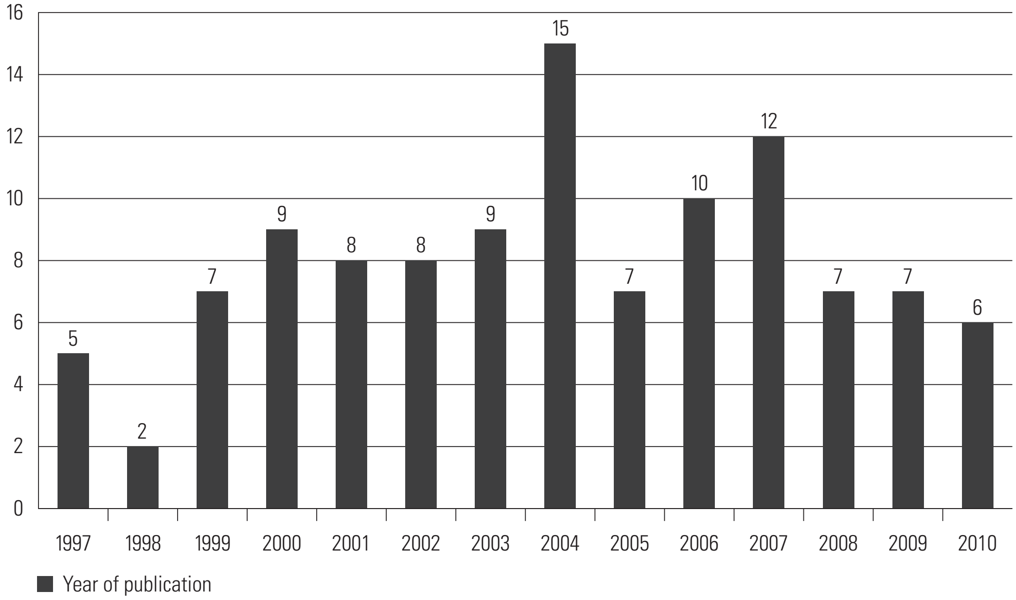


Figure 4. Country of origin (neuropediatrics)

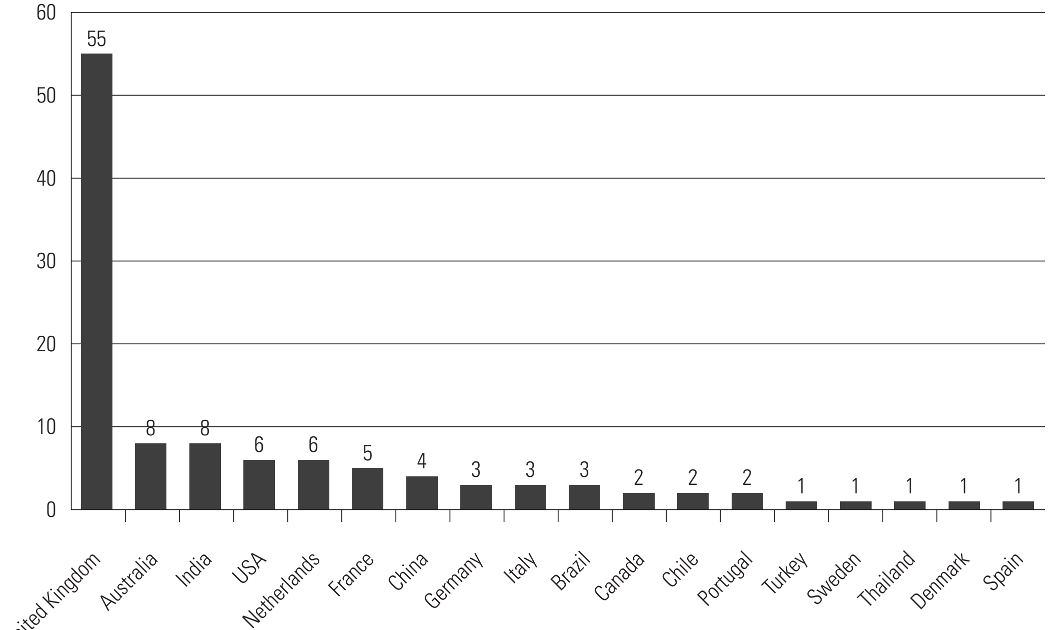


Table 2. Included Cochrane reviews in the field of neuropediatrics (1997–2010)

Country	Year	First author	Title	Therapeutic recommendation
India	2006	Lakshmi Narasimhan Ranganathan	Rapid versus slow withdrawal of antiepileptic drugs	Insufficient data
India	2005	Lakshmi Narasimhan Ranganathan	Vitamins for epilepsy	Not recommended
India	2005	Kameshwar Prasad	Anticonvulsant therapy for status epilepticus	Recommended
India	2001	Sridharan Ramaratnam	Psychological treatments for epilepsy	Not recommended
India	2004	Man Mohan Mehndiratta	Plasma exchange for chronic inflammatory demyelinating polyradiculoneuropathy	Recommended
India	1999	Sridharan Ramaratnam	Yoga for epilepsy	Insufficient data
India	1997	Kameshwar Prasad	Surgery for primary supratentorial intracerebral haemorrhage	Conditionally recommended
China	2009	Qifu Li	Traditional Chinese medicine for epilepsy	Not recommended
China	2006	Daniel K.L. Cheuk	Accupuncture for epilepsy	Not recommended
China	2005	Ming Liu	Acupuncture for acute stroke	Insufficient data
China	2004	Li He	Acupuncture for Bell's palsy	Insufficient data
Brasil	2009	Marcio M. Oliveira	Pharmacological treatment for Kleine–Levin syndrome	Insufficient data
Brasil	2007	Adriana S. Ramacciotti	Dipyrone for acute primary headaches	Insufficient data
Chile	2002	Rodrigo A. Salinas	Corticosteroids for Bell's palsy (idiopathic facial paralysis)	Recommended
Chile	2000	Sergio M. Castillo	Oxcarbazepine add-on for drug-resistant partial epilepsy	Recommended
Thailand	2001	Rungsan Chaisewikul	Calcium antagonists as an add-on therapy for drug-resistant epilepsy	Not recommended

Discussion

In this review, we demonstrated that only a small minority of these Cochrane reviews – both in the fields of neonatology (5.7%) and neuropediatrics (14.3%) – originated in developing countries. This is of concern, for worldwide the vast majority of neonates and children are born and raised in these countries. Moreover, the recommendations issued in Cochrane reviews performed in highly industrialized countries are largely applicable to the fields of neonatology and neuropediatrics as practised in industrialized countries and will potentially exclude the majority of neonates, infants, and children being born and cared for in the developing world. However, recently, efforts (through initiatives such as the Effective Health Care Alliance and the SEA-orchid consortium) have been undertaken to disseminate knowledge from the CNRG to low- and middle-income countries to ensure that care practices are evidence-based and that scarce resources will be used and allocated appropriately (Garner et al. 2004; Henderson-Smart et al. 2007). These programs target generators as well as users and teachers of evidence in order to ultimately ensure the implementation of effective interventions (Garner et al. 2004; Henderson-Smart et al. 2007).

It is also interesting to note that a disproportionately high number of systematic Cochrane analyses originate in Australia and the United Kingdom. Although speculative, this may at least in part be attributed to the fact that these countries have played important roles in the generation and promotion of EBM. Moreover, one of the most influential centres of EBM is located in Oxford, England.

The use of systematic reviews as provided by the CNRG and Cochrane database plays an important role in disseminating the best available evidence, thus contributing to the provision of good medical care at the bedside. A substantial proportion of systematic reviews provided data with regard to the question of whether a certain intervention should or should not be performed (Tables 1 and 2). This will provide the physician at the bedside with invaluable information with regard to both optimal and unnecessary treatment modalities. However, interpretation and possibly implementation of these data should be done only in conjunction with "local modifiers," for example, the decision to use intramuscular vitamin A to prevent bronchopulmonary dysplasia (BPD) may depend on local BPD incidence rates. Moreover, vitamin A may prove a valuable tool in reducing threshold retinopathy of prematurity (ROP), seen endemically in developing countries (Darlow and Graham 2007).

However, and of note, our study also demonstrated that a substantial percentage of systematic Cochrane reviews from developing countries were inconclusive and failed to provide any recommendation with regard to a specific intervention. This is in line with previous reports on this subject (Girisch et al. 2012; Mandel et al. 2006; Sinclair et al. 2003; Willhelm et al. 2012) that have also demonstrated that a substantial number of systematic reviews from highly industrialized Western countries provide only inconclusive recommendations. These reviews usually conclude that, following an extensive literature search and appraisal, insufficient trial evidence was found to guide clinical practice. Often only a trend can be seen, or statistically significant changes can be seen for short-term outcome parameters (e.g., ventilated days) (Mariani et al. 1999) but not for long-term outcome parameters (e.g., the incidence of death or chronic lung disease at 36 weeks, intraventricular hemorrhage grade 3 or 4, or periventricular leucomalacia) (Woodgate and Davies 2001). Moreover, it is noteworthy that a recent analysis demonstrated that many apparently conclusive Cochrane neonatal meta-analyses may become inconclusive when the statistical analyses take into account the risk of random error due to repetitive testing (Brok et al. 2009).

The most common reasons for failure to generate specific recommendations in our analysis were usually given as a small number of patients, poor and insufficient methodology, and heterogeneous study populations (data not shown; for more information please refer to Girisch et al. 2012 and Willhelm et al. 2012). Although reporting clinical uncertainty and thereby generating new research questions is a fundamental driving force for EBM, clinicians at the bedside will find the lack of specific recommendations frustrating and unhelpful (Willhelm et al. 2012). However, by identifying important gaps in the evidence, Cochrane reviews have the potential to promote high-quality RCTs (e.g., in the field of perinatology, collaborative quality improvement initiatives such as the WOMBAT Collaboration in Australasia (see http://www.wombatcollaboration.net/) (Willhelm et al. 2012). This can be illustrated by the fact that several recent large RCTs in perinatal medicine in industrialized countries have been undertaken when Cochrane reviews have highlighted important areas of clinical uncertainty. Examples relevant to pregnancy and childbirth management strategies have been well described (Dodd and Crowther 2006; Willhelm et al. 2012); recent examples of neonatal interventions include a) the Benefits of Oxygen Saturation Targeting (BOOST) and (b)Pulse Oximetry Saturation Trial for Prevention of Retinopathy of Prematurity (POST ROP) (Askie and Henderson-Smart 2001) and (c) the Caffeine for Apnoea of Prematurity (CAP) trial (Schmidt et al. 2007). Moreover, clinical researchers have conceptualized a research cycle that includes systematic review and observations of the effects in practice (Henderson-Smart et al. 2003).

Given the limited financial and human resources that are available in the medical arena in the developing world, future emphasis must be on long-term outcomes that are vital to infants and children and their families, as well as to healthcare workers. Importantly, in the future the effects of interventions not only on survival, but also on long-term morbidity, must be considered (Brok et al. 2009; Willhelm et al. 2012). This change in paradigm is particularly important in perinatal medicine, as there is potential for interventions to improve short-term outcomes but also to increase the likelihood of adverse longer-term outcomes in surviving neonates (e.g., administration of systemic corticosteroids in the first few days of postnatal life improves short-term respiratory function but also increases the rate of adverse neurological effects).

Our analysis has some weaknesses. Most importantly, there are many other trials and studies (non-RCTs) that have been performed in the developing world and published in the medical literature. Given the fact that only RCTs are considered for meta-analysis by The Cochrane Collaboration, the other studies and data were not analyzed in our work. However, the publication of Cochrane reviews may serve as a surrogate parameter for overall scientific endeavours in the medical arena.

Conclusions

In summary, this is the first systematic analysis of the potential role and limitations of Cochrane reviews in the fields of neonatology and neuropediatrics with regard to published reviews originating in low-income countries. Our findings demonstrate a need for more high-quality research that addresses specific medical problems and issues most relevant to countries in the developing world. It will be of paramount importance that funding and research agencies support research programs that address the most relevant issues in the field of pediatrics that are most pertinent to the developing world. Moreover, developing countries have to be active participants in researching these diseases; otherwise, they will not progress. If they invest their own money, they have a say in which health problems they want to tackle.

Our findings strongly suggest an ongoing need for high-quality research that addresses specific issues that are most relevant to the medical care of children in developing countries (e.g., treatments for drug-resistant tuberculosis; pediatric versions of HIV drugs; a test to determine the effectiveness of treatment of Chagas disease; new antibiotics, in the face of increasing resistance; and vaccines that do not need refrigeration or can be given without an injection).

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