"Making them Count, Counting the Mentally Ill" Lessons from the Kintampo Health and Demographic Surveillance System (KHDSS)

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Abstract

Persons with Mental Disorders (PMDS) are among the most marginalised groups in developing countries, as they are socially excluded and overlooked in most development efforts. Health and Demographic Surveillance Systems (HDSS) platforms serve as unique opportunities for longitudinal studies on such marginalised groups. However, due to high levels of stigma and other operational difficulties, PMDS are often undetected in routine enumeration exercises. This study takes an in-depth look at the methodological aspects of social demography of mental illness in a HDSS setting. Five hundred and sixty-nine PMDS were identified and followed on longitudinal basis for their inclusion in the Kintampo HDSS. Following a "*targeted*" and "service *provision"* approach, coverage of PMDS went up to 68% in 2010, compared with previous levels of 54% and 49% in 2005 and 2008 respectively. A body of evidence for inclusion of PMDS and other groups, living with stigmatising conditions, currently exists that could potentially make a scientific contribution and inform policy.

Introduction

Mental disorders have far–reaching public health and socio-economic consequences and the enormous contribution of Mental illness to Global Disease Burden is well documented (WHO, 2010, Lancet, 2007). Mental disorders[i] disproportionately affect the poor and other vulnerable groups and have deleterious effects on efforts at realising international development targets such as the Millennium Development Goals (Skeen et al., 2010). However, Persons with Mental Disorders (PMDS) are among the most marginalised groups in Low and middle-income countries and are left out of most development efforts (WHO, 2010). The commitment of most governments and cooperate bodies towards mental disorders is abysmal (Murray & Lopez, 1995). The prevalence of mental illness in Ghana is estimated to be about 13% of the adult Ghanaian population and about the same percentage for children (WHO, 2007).This situation needs more attention in Ghana and other African countries because of the projected increase in the number of young people entering the age of risk for the onset of certain mental disorders (Gaisie, 2007, Flisher et al., 2007).

In order to address the specific needs of people with mental disorders, it is appropriate to develop and effectively evaluate such interventions. However, research evidence for policy formulation in most low and middle- income countries is insufficient (Saraceno et al., 2007). Basic epidemiological data on the prevalence and distribution of mental & neurological disorders is lacking for many low-income countries including Ghana. Reliable data is also lacking for particular age groups such as children and youth and for particular problems such as substance

abuse and epilepsy. Valid databases are needed to gauge the magnitude of these problems, the adequacy of mental health services and the groups at risk (Doku, 2007).

Health and Demographic Surveillance Systems (HDSS) provide an invaluable platform for measuring health inequity and developing and evaluating health interventions (Mwageni et al., 2006). The international Network of Health and Demographic Surveillance Sites (INDEPTH) is a group of research institutions which collects longitudinal data on demographic and health indices in defined geographical populations to inform policy and programme direction. The Kintampo Health Research Centre (KHRC) is one of three such research centres setup in the major ecological zones of Ghana (coastal, forest, savannah sahelian) by the Ghana Health Service Research and Development division in the Ministry of Health. The Kintampo Health Research Centre (KHRC) maintains unique identifiers of every individual in the catchment area and provides core updates on pregnancies, births, deaths and migrations every three months through its HDSS (Nettey et al., 2010). In addition, the Kintampo HDSS routinely collect information on socio-economic indicators such as household wealth, educational status and causes of death that are to provide extra information for analyzing population-health inter-relationships for policy.

However, a baseline study in 2005 indicated that, about 51% of PMDS captured by a Population based Psychiatric Case Register (PCR) were not captured in the KHDSS. Against this backdrop, a number of strategic programmatic interventions were introduced to address the situation. Similar evaluation exercises in 2008 and 2010 revealed that the coverage of PMDS by the KHDSS went up appreciably. This study sought to investigate and illuminate the strategies adopted to include PMDS and the value of such strategies for longitudinal studies and

interventions for PMDS and others living with stigmatizing conditions, in the context of the KHDSS.

Methods

This study employed quantitative and qualitative methods. The quantitative methods were used to assess the coverage of mentally ill people in the KHDSS, while the qualitative methods were employed to provide an understanding of the processes and the reasons for discrepancies in the coverage between the PCR and the KHDSS and to describe strategic responses that were adopted to rectify the anomalies.

The Kintampo Psychiatric Case Register

The Kintampo Psychiatric Case Register is a patient-centred longitudinal data base of people with psychiatric disorders, which records the basic demographic characteristics and other data of PMDS in the Kintampo North and South Districts of Brong Ahafo Region of Ghana. The PCR is used to describe the patterns of current and future referrals to mental health services, to describe the epidemiology of mental and neurological disorders, serves as the basis for a district-mental health management information system and to monitor demographic changes such as mortality, prevalence, incidence of mental health cases in the catchments area (*Genell L. Knatterud et al)*.Cases and their carers were first identified and referred by trained fieldworkers and Community Key Informants or ongoing studies. The International Classification of Diseases 10^{th} Edition, primary care version for mental disorders (ICD-10, PCV) was then used by a Community Psychiatric Nurse (CPN) to make clinical diagnosis. The case register was then linked to other surveillance systems and health records from other facilities in the study area.

The initial cases for the PCR were first identified through ongoing mental health studies since 2002. The studies included, epidemiological studies such as the Population-based case control study which aimed at assessing risk factors for schizophrenia and related psychosis, the risk factors for postpartum depression study, a study of psychiatric morbidity among the elderly, and anthropological studies such as the sources of healing for mental illness in Kintampo.

Strategic Response

The strategic response involved two interlink approaches. *The targeted approach* was primarily geared towards enhancing the ability of the KHDSS system to cover PMDS. This involved engaging the DHSS leadership on the problem at hand and discussing pathways of ensuring the inclusion of PMDS. This culminated among other things, in an enhanced field worker training to include identification and referral of mental illness; notably the fieldworker training also addressed issues of fieldworker's attitude towards PMDS and probing skills to illicit information about PMDS. Information on the Kintampo mental health case register was used to target households with PMDs. The wider community was also targeted through anti-stigma campaigns through community radio and other educational activities on special days such as World Mental Health Day.

The second strand of the strategic response was the *service provision* with the aim to improve mental health service provision in a district where there was no mental health service. The approach involved four interlocking components. The first arm was a district Mental Health Multisectoral Forum, which was established to act as a platform for non-hierarchical interaction between stakeholders in mental health and improved their commitment towards mental health service provision. It is noteworthy that this served as an avenue for engaging the managers of the

HDSS and convincing them on the need for an enhanced DHSS. The second arm was the CPN lead clinical service aimed at providing medication to PMDs at the community level through a task shifting approach involving general health workers who underwent training on the recognition and management of mental disorders and collaboration with traditional and faith-based healers. In recognition of the role of social determinants of managing mental illness, the third arm involved the formation of Mutual help groups made up of PMDs and their caregivers. The fourth arm was the establishment of a district level longitudinal database of PMDs and their caregivers, linked to the district level health information system and the KHDSS. This service provision model proved very useful in enhancing the capture of more cases for the case register.

Analysis

The information on cases were first entered into the PCR database and then linked to the KHDSS through their household identification and later through their individual unique identifiers (identifications). These cases were then followed on longitudinal basis for their inclusion in the KDHSS. This was done to determine the number of cases from the PCR that were enumerated by the KHDSS**.**

Semi-structured interviews

Semi-Structured Interviews (SSIs) were used for the qualitative aspects of the study. As stated earlier, the primary purpose of using these instruments was to develop an understanding of and the reasons for discrepancies in the coverage between the case register and the KHDSS database and to describe strategic responses that were adopted to rectify the anomalies. Sampling of respondents for the SSIs was purposive and issues were tailored to suit each subgroup. Fifteen

SSIs were conducted with various stakeholders including stakeholders of the KHDSS, members of the mental health unit, field workers and some heads of households with a mentally ill person. These interviews were repeated periodically with slight variations to capture new developments within the KHDSS.

Interviews were recorded and transcribed verbatim. Guided by the objectives of the study, content analysis was used to search for appropriate themes. QSR Nvivo software was used to categorise the data into themes and to discern patterns emerging from the themes.

Results from the preliminary analysis were shared with the field team and KHRC staff to solicit their inputs on the analysis.

Ethical concerns

The study was conducted in the context of two main mental health research studies in KHRC with full ethical approval. Before the discussions and interviews, the purpose and procedures of the study were explained to all participants and written consent sort.

Results

Socio-demographic Characteristics of PMDS in Kintampo

Table 1.a shows the socio-demographic character of PMDS in Kintampo, using the 2010 PCR. About 54.5% of people with mental illness were female. Notably, almost 40% of cases were between the ages of 18 to 34, with the elderly been only 6%. About 49% had no education at all, 66% of cases were not married, while more than 65% of cases did not have a health insurance.

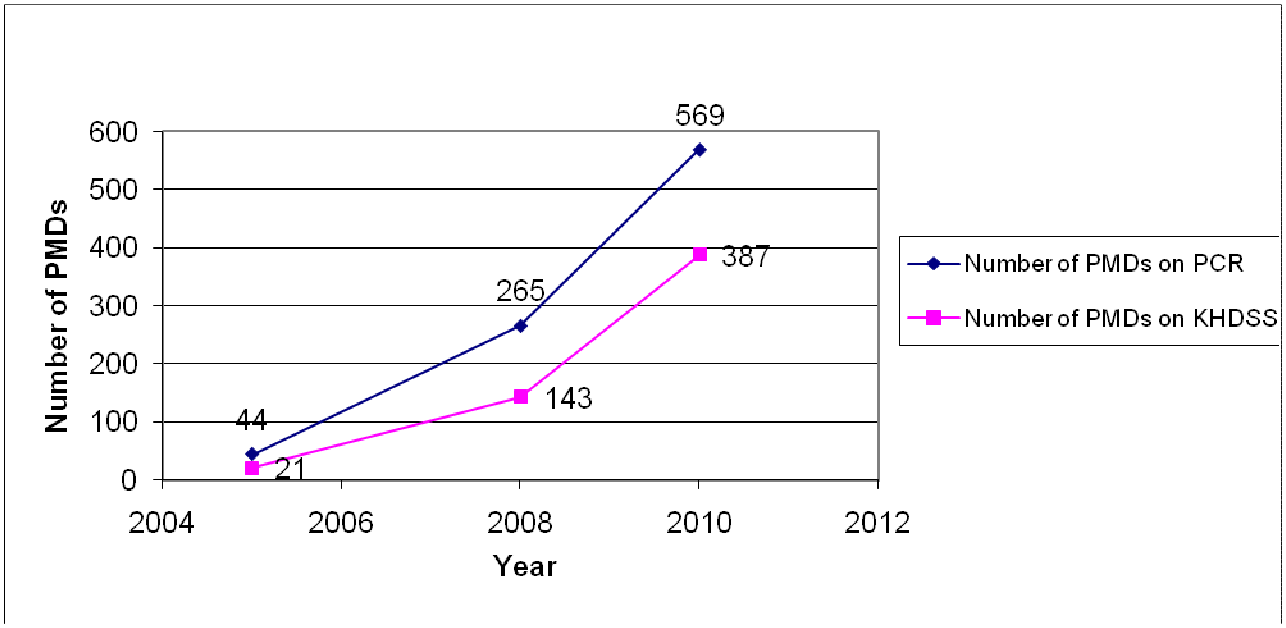
Table1a Socio-demographic Characteristics of PMDS in Kintampo in 2010

Variable	Population	Percentage
Case Type		
Mental Disorders	329	57.8
Epilepsy	240	42.2
Gender		
Male	261	45.9
Female	308	54.1
Age Group		
<18	135	23.7
18-34	223	39.2
35-64	175	30.8
65+	34	6.0
Education		
None	279	49.0
Basic	228	40.1
Secondary	30	5.3
Tertiary	11	1.9
Vocational	21	3.7
Marital Status		
Single	377	66.3
Married	135	23.7
Other	57	10.0
National health insurance scheme	198	34.8
Registered	369	65.2
Unregistered		
Note: the other category under marital Status comprised those cohabitating and widowed.		

Differentials in coverage of PMDs in KHDSS

Using the PCR as a gold standard, most PMDs were always captured compared with those in the KHDSS consistently throughout the period. In terms of the percentage coverage, more PMDs are now being registered and monitored by the KHDSS.

Figure 1: Yearly Trend of Coverage of PMDs in KHDSS



The above graph shows the yearly trend of coverage of persons with mental disorders in the Kintampo Health and Demographic Surveillance System. There had been a consistent yearly increase of coverage of PMDs by the KHDSS from an initial 49%, 54%, and 68% in 2005, 2008 and 2010 respectively. Using the Psychiatric Case Register (PCR) as a gold standard, the number of PMDs that were counted by the KHDSS was always below what are on the PCR. For instance, in 2005 when the PCR started there were 44 PMDs that were initially registered as against 21 (49%) captured by the KHDSS. In 2008, The PCR registered 265 PMDs of which 243

(approximately 54%) of them were found on the KHDSS database. These numbers increased to 569 and 387 (68%) on the PCR and KHDSS respectively in 2010.

Qualitative Findings

The results of the semi-structured interviews revealed that while household heads were required to provide information on all the members of their households in the periodic enumeration exercises and updates on vital events, due to stigma, some of them decline to add the members with a mental illness. As depicted in the quote below, family members with mental illness were not considered as part of the family and therefore not worthy to be counted.

> *"Whenever, you come and we are talking about people you insist on talking about name of respondent child", (IDI, Household Head).*

Similarly, field workers who are the community outreach agents of the HDSS, also harbored negative mental attitudes towards PMDS and lacked the awareness mentality to probe for the inclusion of persons with mental disorders. This situation was succinctly extract below.

> *"They (referring to fieldworkers) have a negative attitude towards these people with mental illness and therefore do not care if they are included or not",* (IDI, staff of KHRC)

Factors accounting for the 32% non inclusion of PMDS in the KDHSS database in the last census updates include: lingering stigma, pseudo names (aliases), and DHSS specific challenges. Interviews with fieldworkers and staff of the mental health unit indicated that some of the names

of PMDS in the PCR were not the same names they bore in the community and hence in the HDSS. This made it difficult for them to be traced. One of the respondents in the interviews said;

> *"One of the main reasons accounting for the discrepancies in coverage of PMDs between the PCR and KHDSS database is the fact that PMDs have several names and hence depending on who provides the information on household members to census fieldworkers, this problem will continue to persist",* (IDI Staff KHRC).

We conjecture here that this situation depicted a subtle attempt by members of families to delink themselves and protect the family from the stigma of having a family member with mental illness.

Discussion

The study revealed that there was a consistent yearly increase of coverage of PMDs by the KHDSS from an initial 49%, 54%, and 68% in 2005, 2008 and 2010 respectively. These numbers increased to 569 and 387 (68%) on the PCR and KHDSS respectively in 2010, as a result of the two pronged interventions adopted. Stigma reduction was directly targeted, as stigma was cited as the main reason for PMDs not being captured in the main enumeration exercises. This was not surprising, as stigma has been known to be the main cause of social exclusion for people with mental illness. Earlier studies in mental health in the area indicated that stigma and discrimination against people with mental illness was very high and deeply ingrained in the socio-cultural practices of the people (Read, 2009). This finding is not atypical of what pertains in other African countries, for instance in a survey in Nigeria over 80% of participants

said they would be ashamed if people knew someone in their family had a mental illness (Gureje *et al* 2005).

The enhanced KHDSS has intrinsic value for other mental health studies and for the inclusion of PMDs into mainstay social protection schemes. It is also now feasible to undertake studies on the risk and protective factors for mental illness. For instance, the Studies of Epilepsy Epidemiology in Demographic Sites initiative: Multi-site epilepsy prevalence, causes, outcome study, INDEPTH network was successfully carried out under an enhanced KHDSS. Other proposed studies such as: the mortality among the mentally ill study, mental health and malaria study, Adolescent mental health studies, Mental Health and HIV/AIDS and TB: cognition, depression, ART compliance (defaulter rates), also RF for HIV/AIDS, Mental Health and Aging: The data base of the KHDSS was also helpful in locating and including PMDS in government sponsored social protection schemes for the vulnerable. This is especially important in a context where were people with mental illness are mostly excluded from social protection schemes for the vulnerable.

Conclusion:

People with mental illness suffer from marginalisation and the violation of their fundamental human rights. Getting them counted is a first step towards addressing the needs of PMDS. The enhanced DHSS provides an invaluable longitudinal database for studying social determinants of mental disorders. Provision of mental health services is the surest way of addressing stigma and the marginalization of PMDS (Ripper and Piper). The services approach adopted by KHDSS, offers an important gateway towards providing recovery, addressing stigma and the marginalization of PMDS and ensuring that they are counted. Taking steps to include PMDS in main stream enumerating exercises is a fundamental right which must be granted.

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Common understandings of women's mental illness in Ghana: Results
from a qualitative studyANGELA OFORI-ATTA1, SARA COOPER2, BRIGHT AKPALU3, AKWASI OSEI4,VICTOR DOKU3, CRICK LUND2, ALAN FLISHER1, & THE MHAPP RESEARCH PROGRAMME CONSORTIUM.1University of Ghana Medical School, Korle-Bu, Ghana, 2Department of Psychiatry and Mental

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[i] Although epilepsy is not a mental health disorder, traditionally people epilepsy is treated as psychiatric condition.