



Impact of mental health research on policy and practice in South Asia: stakeholders' perspective

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Impact of Mental Health Research on Policy and Practice in South Asia: Stake holders' perspective.

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Objective:

This paper reports the mental health research stakeholders' views on the impact of research on policy, practice and care from south Asia, citing multi-country qualitative narratives.

Methods:

Team of two researchers from six different countries of South Asia sent out questionnaires to professional and family organizations, university administrators and ministry officials in respective countries, asking specific questions regarding the status of mental health research and its interface with policy, practice and decision making.

Results:

A total of 254 questionnaires were sent out. Response rate was 27%. Mental health research stakeholders (n=71) reported epidemiological burden of illness and risk factors as the priority research area (88%) followed by social sciences and health system research (84 % and 85 % respectively). Clinical trials (47%) and basic science research (32 %) were cited as low priority areas given the dearth of evidence on etiology and management of mental illness from South Asia. Depression/anxiety disorders (69 %), substance use disorders (67 %) and childhood disorders (60%) were cited as priority disorder by almost third of the stake holders group. Majority (76%) reported personal interest as the main criteria for prioritization, followed by perceived burden of disease (72%), equity and social justice (70%) and policy makers' request. Children (78 %), women (74%), victims of violence/trauma (63%) were sighted as high risk marginalized population requiring prioritization.

Only 35 % of the policy makers' cited media as disseminating results while almost 30% thought that it sensationalizes mental illness in many ways. The survey clearly identifies the role of research in informing policy, citing various qualitative narratives and anecdotes.

Policy implications:

No formal research unit or systematic decision making matrix was identified from any of the countries in South Asia. In its absence universities, institutions and professional organizations are playing an important role in generating research evidence for policy formulations. Role of these organizations and institutions needs to be strengthened besides building capacity at the level of government ministry.

Introduction:

The Commission on Health Research for Development (1990) reported a huge discrepancy between the magnitude of disease burden in the world and allocation of research funding. This is referred as the 10-90 gap, to reflect the fact that of the US\$ 73.5 billion investments in health research (1998), less than 10% was spent for 90% of the world's health problems¹. It was felt that correcting this gap could contribute to growth, development, the fight against poverty and global security. Mental and neurological disorders constitute a significant proportion of the overall disease burden. The 2001 World Health Report estimated that mental and neurological disorders were responsible for 13% of the global Disability Adjusted Life-Years (DALYs), a figure that is poised to increase as many regions of the world witness a demographic and epidemiological transition². A further third of the global disease burden is due to the behaviour-related disorders. Despite this, there is comparatively little evidence to support policy and program development for mental disorders in low and middle income countries (LAMI) and there is a wide 'gap' between the needs and services for mental health in these countries³.

In 2002, the WHO proposed the Mental Health Global Action Programme (mhGAP) as the blueprint for international action in the fields of mental, neurological and behavioural health. An important conclusion was the urgent need for research to be undertaken in and by LAMI countries, directed to the special needs of these countries. A crucial question was the strength of the existing capacity of these countries to conduct research in the fields of mental, neurological and behavioural health and the priorities of researchers and stakeholders in mental health. Thus, the identification of research capacity and priorities in LAMI countries was a necessary follow-up to the MhGap-WHO initiative and studies revealing the high burden of mental disorders in developing countries. Since mental health is an important but, as yet, largely unaddressed component of the 10/90 gap, the Global Forum for Health Research joined hands with the World Health Organisation (WHO) to support projects aimed at mapping the research resources and agenda in LAMI countries. This would be a first crucial step towards correcting this imbalance.

The mapping project aimed to identify the constraints and challenges that impact on research resources, the research priorities, and the impact of research on policy and programme formulation in LAMI countries. The project was launched in April 2003 and implemented in South Asia through a coordinating team based in, Goa, India, with collaborating centers in Bangladesh, Pakistan, Nepal and Sri Lanka.

The general objectives of the project was to develop a regional map of research resources, to describe the current research agendas and the process of priority setting and impact of mental health research on policy. In this paper we report stakeholder's views on mental health research priorities along with qualitative narratives of research impacting policy, program and practice.

Material and Methods

Description of Project Team:

The project was implemented in South Asia through a coordinating team based in Sangath, Goa, India. Sangath is a mental health NGO (www.sangath.com) carrying out primary care and community based research on mental disorders. The project was led by Dr Vikram Patel, Reader in International Mental Health & Wellcome Trust Senior Clinical Research Fellow in Tropical Medicine, London School of Hygiene & Tropical Medicine. Vailana Castellino, Kishori Mandrekar and Smita Naik were the full-time staff employed on the project and were based in Sangath. Smita Naik was the Coordinator of the project. The country collaborators of the South Asian team were based in Bangladesh, Nepal, Pakistan and Sri Lanka.

The project was implemented in Bangladesh through a primary team based in the Centre for Health, Population and Development (CHPD) (www.iub.edu.bd/chpd/index.htm) at the Independent University, Dhaka, Bangladesh. The project was led by Dr. Omar Rahman, Executive Director of CHPD, and adjunct associate professor of epidemiology and demography at the Harvard School of Public Health and research fellow at the department of psychiatry, Brigham and Women's Hospital, at Harvard Medical School. Dr. Rahman was assisted by Mr. Moinuddin Khan, program officer at CHPD.

The project was implemented in Nepal through the Center for Public Health Research and Services, (CEPHERS), Nepal. Dr. Suraj B. Thapa, Coordinator for CEPHERS and research fellow at the University of Oslo, Norway, coordinated the project in Nepal with the local supervision of Mrs Nirupama Basnet, who was employed for the implementation of this project.

The project was implemented in Pakistan & Afghanistan, through a primary team based in the Department of Psychiatry, Aga Khan University (www.aku.edu), Karachi. The project was led by Dr. Murad M Khan, Professor & Chairman, Department of Psychiatry and Dr. Haider Naqvi, Consultant Psychiatrist and primary project officer on this project.

The project was implemented in Sri Lanka & Maldives through the Forum for Research and Development. The project team included Dr. Athula Sumathipala (team leader), Research Fellow at the Institute of Psychiatry, University of London; Dr. Sisira Siribaddana, Consultant Physician and Project Leader of the Sri Lankan Twin Registry; and Dr. Suwin Hewage, Medical Officer and Coordinator of the Bio Ethics Initiative.

Survey of Stake Holders:

Search for mental health stake holders was done centrally in Sangath Center, India. This was supplemented by individualized searches in each center.

The stakeholder questionnaires were modified versions of the researcher questionnaire. The questionnaire asked about demographic details, Professional background, including work place characteristics, Research experience (training, grant applications, reviewing,

and details regarding the three most recent mental health research projects), Research Resources (teaching programs, journals, technical support, ethical review boards, funding), Research Impact (dissemination, media, academic publications, conference presentations, policy impact) and Research Priorities (priorities by mental health research area, and reasons for choosing these priorities).

Questionnaires were sent to 254 stakeholders, from three groups (University administrators, Professional Associations and NGOs, and Ministry Officials) from the region via post.

A number of strategies was used to maximize the response rate. A self-addressed stamped enveloped was included in all posted questionnaires; respondents were offered either electronic or paper based formats for completions; reminder telephonic calls were made at their residence or institution; where email addresses were available, reminder emails were sent; reminders were sent by post to others. In this way, we allowed for up to four reminders before considering the respondent as a refusal.

A separate database in Access was designed to manage the stakeholder questionnaire data of the respondents. Data entry of filled postal questionnaires from other countries was done centrally in India by the Indian team.

Results:

We contacted 254 respondents from three groups of stakeholders: professional and family groups; university administrators; and Ministry representatives. We received 71 completed questionnaires. Table 1 provides the details by stakeholder type and country. A brief description of three groups is presented below followed by key findings.

Professional Associations/Groups: 47 individuals representing professional associations responded to the stakeholder survey. 56% classified themselves as support groups, 30% as advocacy groups, and 49% as research groups (multiple responses were allowed). Almost 80% of these associations (of those with non missing data, n=31) have a hundred or less members; 43% had been working in their respective areas for more than a decade. With regard to the focus of these groups most (74%) reported “mental health in general”, followed by depressive disorders (45%), alcohol and drug abuse (43%), psychosis (38%), learning disability (33%) , dementia (33%), and social justice (40%). Mental health research was identified as “very relevant” by almost 60% of professional associations. More than half of the professional associations were involved in direct conduct of research.

University Administrators: Seventeen individuals from various universities responded to the University stakeholder questionnaire. Fifteen were males. The institutional profile of these universities showed primarily involvement in mental health research (76%), training (77%) and services (71%), However, few were involved in mental health

advocacy (29%) and policy formulation (24%). Most of the universities have only one to five individuals working in the field of mental health research with less than 10% of their working hours spent in this activity. Further inquiry revealed that 70% of universities had 5 or less on-going mental health research projects. In almost 50% of these universities, no specific research training was available in the field of mental health. Only four out of the seventeen universities had a degree course in mental health research or short training courses. Most of the universities had access to free mental health literature and data-bases on the world-wide web. Only two institutions paid subscription charges for access to mental health research literature. 70% of institutions subscribe to at least one major national scientific journal, but only 18% of institutions subscribe to four or more national journals. Only 40% of institutions subscribe to any international mental health journal with only 12% of universities subscribing to 4-10 international journals. Almost 50% had no institutional funding for research in mental health while external funding was also lacking in a third of the universities. Although more than half reported some sort of international collaboration, only 30% had some sort of presence in the community.

Ministry Officials: Seven government officials from Health Ministries identified as mental health stake holders responded to the survey. Although the number of sampled individual were low, findings pertaining to the ministry officials are relevant to the subject of policy impact. Only 28% (2 out of 7) reported ever utilizing mental health research findings. Almost none of the ministries in South Asia were involved in direct training of mental health research. No research unit was present in any of the ministries while outside collaboration was also non existent. Majority (71%) however reported some sort of organizational mental health “policy”. Less than half of the group reported lending any support to mental health research in the last five years. Ministry officials expressed interest in research priority setting, planning, and dissemination. Key interest areas expressed by officials related to the implementation of mental health research findings. They also expressed interest in lending support to ethical review of proposals, direct funding and conduct of research (14%).

Mental health research priorities:

Mental health research stake holders (n=71) reported epidemiological illness of burden and risk factors as the priority research area (88%) followed by social sciences and health system research 84% and 85 % respectively. Surprisingly, clinical trials (47%) and basic science research (32 %) was cited as low priority given the dearth of evidence on etiology and effective management of mental illness from South Asia.

Depression and anxiety disorders (69 %), Substance use disorders (67 %) and childhood disorders (60%) were cited as the priority disorder by almost one-third of the stake holders group, altogether. Psychosis (49 %), suicide (49 %), personality disorders (36 %), learning disability (35 %), dementia (33 %) and epilepsy (30 %) were in descending order as priority disorders.

Children (78 %), women (74%), victims of violence/trauma (63%) were sighted as high risk population requiring focus as far research prioritization is concerned.

When criteria for research prioritization was explicitly asked majority reported personal interest as the main factor (76%). This was followed by perceived burden of disease (72%), equity and social justice (70%) and policy makers' request.

Media's role and involvement:

In most of the countries in South Asia "stake holders" reported that the media is playing a limited role as far as mental health issues are concerned. It mainly gives information and news pertaining to health in general (71%). Only 35 % respondents thought that media is used for dissemination of results while almost 30 % thought that it sensationalizes mental illness. Few thought that media is used for advocacy for implementation (26%) and emphasizing medical model of illness (23 %).

Impact of mental health research on policy, program and practice:

Although there were very few ministry officials in stake holders' survey, the picture in South Asian is generally the same. In the absence of any formal research unit at the level of governments, no direct relation between research and policy could be shown.

Only 28% ministry officials cited research as impacting policy and program as opposed to 57% of the professional associations and 47 % of the university administrators. However there are important anecdotal reports from professional associations, family groups and University administrators citing research as impacting policy, program and practice. Several professional associations cited various examples of the research impacting policy, program and practice at different levels. In Pakistan, a Mental Health Ordinance was formulated in 2001, based on research evidence and advocacy by groups of mental health professionals. The Ordinance replaced the Lunacy Act of 1912 which used to be the official document related to the legal rights and responsibilities of people with mental illness. Similarly in India, the 1995 Disability Act was drafted with the inclusion of people with mental illness. In addition a social welfare scheme was started for people with chronic mental illness. In India, a group reported an improvement in antenatal care, birth practices and child nutrition through rural child health (RCH) program to prevent mental disability in children. Several groups and networks were also working on issues related to child mental health e.g. child sexual abuse. One professional association from India reported: "We are working on the frame work of rehabilitation for mentally ill people, setting guidelines for social justice in mental health and quality assurance criteria in mental health. Another focus of our organization is home based mental health care model". Another example was India's District Mental Health Program (DMHP). The DMHP was initiated for providing mental health services at primary health care level (PHC). This was based on the knowledge generated in epidemiological studies demonstrating the burden of mental disorders in primary care. These findings also led to a study on urban mental health problems and service needs which are expected to provide inputs for expansion of DMHP to urban areas. The DMHP has now become an integral component of India's national mental health program

Another interesting example is of Bapu Trust, India, an NGO which is involved in conducting and implementing mental health research pertaining to women. Their

community based rehabilitation of trauma victims and care to prison population was reportedly influenced by research and advocacy of professional associations. Findings of mental health research & needs identification led to establishment of once-a week mental health clinic in Babu Jagjivan Ram Hospital, Delhi. Similarly to reduce stigma among people, the mental hospital in Shahdara, Delhi was renamed as "Institute of Human Behaviour & Allied Sciences, Delhi". There are other examples of improved clinical care and structured treatment program with minimum standards of care criteria for people with mental illness. An example from Pakistan refers to the model of care adopted by the government in dealing with psychological problems in the aftermath of a natural disaster (October 2005 earthquake). This model was derived from the findings of a randomized controlled trial on the effect of counseling by minimally trained community women in reducing levels of anxiety & depression in women of semi-urban community in Karachi, Pakistan.

University Administrators cited that inputs from research findings conducted in India have been used in formulation of international classification of diseases, both diagnostic guidelines and diagnostic and clinical care versions. Research findings have been incorporated in formulation of National Mental Health Program and Mental Health Act (MHA), 1987. In an example from Bangladesh, research data led to the creation of a post for a psychiatrist in prison hospitals at the level of district. In an example from Nepal, a university based researcher published a study on prevalence of alcohol dependence in small town of Dharan, Nepal. This led to local non-governmental organizations (NGOs) requesting the author for public lectures and discussions on the problem. This led to a community based anti-alcohol and drug awareness campaign in schools of the town. There were other examples of multi-disciplinary child development and child protection services being established in major public hospitals in Bangladesh since 1997, after evidence was published in research papers.

Discussion:

The south Asian region is one of the most populous region of the world. It suffers from very inadequate mental health research resources in terms of both financial support (funding for individuals and institutions) and professional support (e.g. involvement in research networks, access to the literature, training in research methodology). Though some examples of research impacting policy are available, in general there is little interface between research and policy.

To maximize the chance that research evidence will be used, it first has to reach potential users, it has to be disseminated either passively (e.g news letter, mass media) or more actively (e.g workshops, meeting with opinion leaders)⁴. The challenge of dissemination is to improve the accessibility of research finding to those one tries to reach. A recently published Synthesis note, Spreading the word: disseminating the research findings, gives a systematic overview of different pathways for disseminating or promoting the use of evidence, specifying the relative merits of these pathways⁵. Suggested Pathways can be working documents, Research reports, Refereed and Professional journals, conferences,

workshops, training manuals, internet, e-mails, mass media and participatory techniques. It is clear that selection of specific pathway or- or it will mostly be the case- combination of pathways depends on the specific information needs of the users of the information.

In our sample nearly 70% of professional association stakeholders reported using mental health research findings in some way. In the absence of any formal research unit at the level of governments, no direct relation between research and policy could be shown. Only 28% ministry officials cited research as impacting policy and programs. In most of the countries stake holders reported that the media is playing a limited role as far as mental health issues are concerned. However, stakeholders were able to identify a number of specific examples of how mental health research had influenced policy.

The most commonly cited research priorities cited by mental health research stake holders was epidemiological studies of the burden of disease and risk factors. This was followed by health systems and social science research. Similarly, in terms of mental health conditions, the priorities for future research, and the commonest research project subjects, were Anxiety-Depression followed by Psychosis and child mental health research as one of the top three priorities. Substance Abuse was also cited as high priority area. Women, children and adolescents, and the poor form the three most important marginalized populations for mental health stakeholder respondents. Victims of violence were also cited as a priority subgroup specifically by ministry officials. Generally burden of disease and social justice/equity was sighted as top two criteria for prioritization by mental health stake holders.

In our sample only 35 % of the policy makers sited media as disseminating results while almost 30 % thought that it sensationalizes mental illness in some ways. The role of media is important as it reached wide number of audience. One of its potential disadvantages can be that it dilutes the core message, as specified in the channels of pathway.

Decision makers and stake holders have to develop capacity for increased utilization of research evidence for evidence-based policies. This has to be supplemented by capacity strengthening of researchers in producing questions which meet decision-makers needs. The idea is that researchers and stake holders create and maintain high-quality ongoing interaction based on trust and credibility⁴.

Mental health research stake holders clearly identify role of research in policy formulation, citing various qualitative narratives and anecdotes. No formal research unit or systematic decision making matrix was identified from any of the countries in South Asia. In its absence universities, institutions and professional organizations are playing a substantial role in generating research evidence for policy formulations. Role of these organizations and institutions as “knowledge brokers” needs to be strengthened. “Knowledge brokering links decision-makers and researchers, facilitating their interaction so that they are able to better understand each other’s goals and professional

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cultures, influence each others work, forge new partnerships, and promote the use of research-based evidence in decision making”⁶.

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Table 1: Number of stakeholders contacted and responded by country

Country	Professional/Family Group		University Administrators		Ministry Officials		Total	
	Responded	Sent	Resp	Sent	Resp	Sent	Resp	Sent
Bangladesh	0	0	8	18	0	0	8	18
India	28	80	2	4	1	20	31	104
Nepal	7	10	3	6	1	4	11	20
Pakistan	3	8	4	8	4	4	11	20
Sri Lanka	9	90	0	1	1	1	10	92
Total	47	188	17	37	7	29	71	254