

**Proceedings
of the
National Seminar
on**

Theme: “Mental Health: Initiate for Action”

Dates: October 31 – November 1, 2017

Venue: Aurobindo Hall, Shillong

**Department of Social Work
Martin Luther Christian University**

**Proceedings of the National Seminar
on**

Theme: “Mental Health: Initiate for Action”

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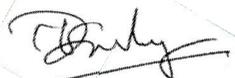
Message from the Vice Chancellor

It is heartening to note that the MLCU constantly endeavours to be relevant to the community in terms of the courses offered and thus, the knowledge and skills of the students have to be relevant to the changing and demanding context. With immense satisfaction, I take this opportunity to congratulate the Department of Social Work for organising the National Seminar which is one such endeavour that provided a platform for academicians, faculty and professionals from the region and outside to share knowledge based on research and for students to learn from such academic discourses. The Department has taken a very apt theme, 'mental health: initiate for action'. In a changing context where people especially the youth, women and elderly are faced with the contemporary challenges, and where overall mental morbidity in the country reported as 13.7%, discussing about ways to tackle such problems is therefore timely.

I hope that the seminar will not be an end in itself but the learning and insights learnt through the presentations and discussions will enable the Department of Social Work to take forward 'mental health' in its curriculum, conducting research so as to inform the curriculum of the needs and conducting community projects to address issues related to mental illness.

I take this opportunity to also extend our gratitude to the North Eastern Council and the Deputy Commissioner, East Khasi Hills District (Voluntary Action Fund) for extending their kind support towards the seminar.

With best wishes,



Dr. Vincent T. Darlong

Preface

The proceedings of the National Seminar contain the written version of the contribution presented during the National Seminar on "Mental Health: Initiate for Action" that was held on October 31 – November 1, 2017 at the Aurobindo Hall, Shillong.

The seminar provided a setting for discussing emerging issues in the field of mental health by various professionals who had vast experience in the field as well as the emerging scholars and researchers. The seminar had a good participation from eminent persons from NIMHANS, Bangalore, retired professors of AIIMS, New Delhi and the Lokopriya Gopinath Bordoloi Regional Institute of Mental Health, Tezpur and also emerging professionals from Mizoram, Assam, and Meghalaya.

The contribution of the speakers in each of the four themes was highly appreciated. It is important to note that the students, research scholars and practising professionals from the NGOs have also benefitted from the academic discourse. It is important to note that the articles in this volume are entirely the views and opinions of the authors and does not reflect the views of the University.

The seminar has also shed more light for the Department to include 'mental health' as an important component in the curriculum of social work. The gap in the limited number of mental health professionals is also felt and therefore training of mental health professionals at different levels is a priority. Moreover, it is evident that there is a gap in the knowledge of mental illnesses and its related issues in the state of Meghalaya and the region. Innovative community projects on mental health would also have to be taken up by the Department.

I would like to thank all the faculty of the Department of Social Work who tirelessly worked towards making the seminar a success. I would like to give a special word of gratitude to our sponsors, the North Eastern Council and Deputy Commissioner, East Khasi Hills District (Voluntary Action Fund) for extending their financial support towards the seminar.

I hope that the Department of Social Work would be able to spearhead many more seminars on emerging issues in future.

Dr. Melari Shisha Nongrum

Convener

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Key Note Address

Dr. Kasi Sekar, Professor & Registrar, NIMHANS, Bangalore

Dr Sekar discussed the geo, demographic and social profile of the country where he pointed out that the country has an increasing work force, age expectancy rising among men and women, dwindling female sex ratio, increase in the density of population per square kilometer, increase urban migration, climate change and forces of liberalization, privatization and globalization. This demographic profile along with the external forces are important factors that affect the mental health of the people. The mental health conditions would be felt commonly by children, teens, adults and the aged, 1 in 5 live with a mental health condition which half develops the condition by age 14 and three quarters by age 24 years. He stated that depression and anxiety are highly prevalent mental disorders with estimates indicating that almost one fifth of the population in high income countries worldwide are affected. The prevalence of mental disorders is greatest among younger people aged 16-24 years than at any other stage of the lifespan. They are also common in childhood and adolescents with 14% of those aged between 4 and 17 years affected. The high susceptibility of adolescents and young adults to develop a mental disorder is coupled with a strong reluctance to seek professional help. Dr Sekar said that speaking up and asking for help is a sign of strength and discussing it with others is the first step of seeking help. He further stated that there is a young adult epidemic where rates of depression and anxiety among teenagers have increased by 70 per cent in the past 25 years. The number of children and young people with a psychiatric condition has more than doubled since 2009. In a 2016 survey for Parent Zone, 93% of teachers reported seeing increased rates of mental illness among children and teenagers and 90% thought the issues were getting more severe, 62% dealing with a pupil's mental-health problem

at least once a month and an additional 20% doing so on a weekly or even daily basis.

The human resource and training institutes have increased over the years, from 40 social work institutes in 1980 to 450 social work institutes in 2015. All over the country, social workers are involved in various mental health initiatives. Premier MH institutes such as NIMHANS Bengaluru, CIP Ranchi and PGI Chandigarh have rigorous clinically oriented post graduate training. They are actively involved as multi disciplinary team members in provision of mental health care in varied areas. In 2012, the Government of India had stressed on the need for increased mental health manpower that includes Psychiatric Social Worker as it was only 3000 then.

Mental health of young people is also largely affected by technology. In today's context, the challenge is to educate young people to the changing context and emerging needs. The access to the internet and social media has increased in leaps and bounds. Cyber bullying and worries about body image (created partly by selfie culture) often cited as triggers for poor mental health. However, social media can also be used as a system to render help for individuals with mental health conditions where it can act as a support for young people, especially for those struggling with their sexuality (44 per cent of 16-24 year-old LGBT people have considered suicide) or feeling isolated.

Social Workers have a bigger role to play in the mental health scene because Social work in its various forms addresses the multiple, complex transactions between people and their environments, with its mission to enable all people to develop their full potential, enrich their lives, and prevent dysfunction. Professional social work is focused on problem solving and changes as such, social workers are change agents in society and

in the lives of the individuals, families and communities they serve. Social work is an interrelated system of values, theory and practice and this practice needs to be at local, community, state, country, regional, and global levels. Research informs practice and professional social workers should employ evidence based interventions and practice, promoting mental health on inter-sectoral strategies, apply community approaches to mental health, work with consumers and caregivers, promote advocacy and social justice and position social work in recovery model. He concluded his address by mentioning that we have at our disposal the knowledge and power to significantly reduce the burden of mental disorders and the paradigm shift to focus on populations instead of individuals, to create a happiness industry through community social work laboratories.

**PAPERS CONTRIBUTED
DURING TECHNICAL SESSIONS
Mental Health Integration in Educational
and Health Institutions**

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Abstract

The concept of mental health is viewed as a prerequisite for our holistic living in all spheres of life. With mental health becoming the buzz word all around with the declaration of National Mental Health Survey, 2016-17, the priority target systems that come into focus are the health and the educational sectors.

Conditions like schizophrenia, depression, mood disorders, tobacco use, alcohol/drug addiction, suicidal behaviours, anxiety, eating disorders, behavioural and emotional problems occur before the age of 24 years. It has been reported that 20% of young people are likely to experience one form of mental illness or the other.

With most youth still in the education system, schools, colleges and universities play a prominent role in safe guarding the mental health of the young people. Impetus needs to be given on in-cooperating mental health initiatives into the educational sector with specific practices that could become intrinsic to both the school and the higher educational institutions.

Initiating and sustaining mental health activities in any sector is not a viability if services are non-existent in the larger health systems around the society. An inequitable distribution and inadequacy of mental health services in two of the states of North-East India (Assam- NMHS Assam Report, 2017 and Manipur- NMHS, 2016) gives ample evidence and reason to re-look at each of the other NE states, to the availability of mental health services.

The magnitude of the mental health issues at the national level has been amply projected in the recent NMHS report (2016). The issues no doubt are looming large over us with its high degree of burden, a huge treatment gap, lack of awareness and stigma.

Specific strategies for integration need consideration in the educational sectors and the health secretariats of the states. Without a mandatory policy, plan and program being adopted by any state, no integrative process is viable and achievable for the any health system or for any institution in society. The larger goal of holistic integrated health and development needs exploration with a combination of top-down and bottoms-up approach of community development where stakeholders also contribute in the system.

Key words: Mental Health Integration, Educational Systems, Health Sectors, NMHS (2016).

Introduction:

The World Mental Health Day was celebrated on the 10th of October with theme ‘Mental Health in Work Place’. Very recently, the National Mental Health Survey of India 2015-16 concluded and a National Report of the survey was released. The report stated that every 6th Indian needed mental health help. The nation is now abuzz with ‘India needs to talk about mental health’!!

Going over the definition by WHO, mental health has been defined as a state of wellbeing in which every individual realizes his or her own potential, can cope with normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community. In other words , this simply means that if our state of mind is not healthy then it is difficult for us to lead a fulfilling and satisfactory life to the fullest extent. Hence, mental health is integral to every sphere in our lives and we cannot as a society abrogate our responsibility to prevent mental disorders and promote mental health and wellbeing.

Does Mental Health matter in North East?

With two states of north-east, Assam and Manipur, having undergone the NMHS survey, what is it that the survey informs us?

Table 1: Prevalence of Mental Health problems and Treatment Gap in Assam and Manipur in Northeast

Types	Assam	Treatment Gap	Manipur	Treatment Gap
Common disorders	5.3 %	82.4	13.3 %	87.4
Severe disorders	0.6 %	87.5	1.1%	93.8
Alcohol use Disorder	3.0 %	88.0	5.1%	90.8
Depressive disorder	1.4 %	94.4	3.7%	83.3
High Suicidal risk	0.7%	-	1.4%	-

Source: NMHS, 2016

The national prevalence of mental health morbidity, excluding tobacco use disorders shows 10.6% across the country while the current morbidity in Assam is shown as nearing 5.85% and in Manipur 13.9% (NMHS, Assam State Report, 2017 ; NMHS, 2016). The table above shows the prevalence in various categories of problems and the treatment gap in Assam and Manipur. Though,

geo-politically and socio-economically comparable, the findings across the states seem varied. Extreme insurgency, economic blockades, political instability and ethnic clashes may be seen as reasons for the higher mental health prevalence in the state of Manipur. It can only be presumed the situation may not very be different for the other north eastern states, even though the variations could be present.

In this context of the national and regional indications, it is very appropriate that the mental health integration in educational and health institutions be deliberated on, as they all play a vital role in shaping the lives of people and build the future of the nation.

Mental Health in Educational Institutes

Mental disorders are found to be the single most common cause of disability in young persons. Untreated, unaddressed mental disorders can impact the overall physical and psychological health of the youngsters, socially isolate them, and can cause impediments in their contributions to the society and the nation.

As per India's Census 2011, 19.1% of India's total population is constituted by youth (15-24 years). That is, youth constitute one fifth of India's total population. With the most chronic and incapacitating mental illness are found to occur before the age of 24 years. This is the time when most of the youngsters are still in the education system. Hence the educational institutes play a big role in safe guarding the mental health of the young people.

It has been found that approximately 10-30 percent of young people in India have health impacting behaviours and conditions. Many conditions are due to personal choices, environmental factors and influences and lifestyle changes. Malnourishment and over nourishment is one among the many problems seen among the youth. This has direct and indirect mental health

implications. It has been reported that 20% of young people are likely to experience one form of mental illness or the other. Depression, mood disorders, tobacco use, alcohol/drug/social media addiction, suicidal behaviours, anxiety, eating disorders, behavioural and emotional problems are found to be common among this age group (15-24 years).

Another important mental health problem seen among the young people is stress. Family stress, financial stress, social stress and academic stress are commonly reported among young people. With so much emphasis on passing examinations with high scores and facing a possibility of unemployment, the academic, familial and societal pressures on the young people are enormous. The onslaught and impact of the social media and its addiction is another area that's taken our young adults to a different level of functioning.

India has taken a great leap by bringing forth the new Mental Health Policy and Mental Health Care Act. While there is a lot of emphasis on youth development, the Youth Policy and the programs do not seem to have emphasis to enhance the psychological wellbeing of the young people.

In the educational institutions too, we can see a lack luster approach to mental health problems. While there is an increased awareness to the mental health needs and wellbeing of the young people, the ground reality is that, very few educational institutions provide adequate mental health services and are hardly involved in the promotion and prevention activities. The structure of our educational system leaves little room for taking up mental health promotion at a larger level.

The educational system offers several opportunities to enhance mental health awareness. By including mental health narratives

in their curricula, the educational system can help to de-stigmatize the highly discriminated and stigmatized notions towards mental health problems. By creating awareness, and training the teachers and other stakeholders, it is possible to detect mental health problems early and give simple and timely interventions. This can help prevent further deterioration and disability that mental health problems and disorders can bring it is wake.

While, mental health of school students and teachers has rightly attracted some attention, with CBSE providing counsellors to schools, embedding life skills approach and prevention of substance abuse and other relevant mental health issues in classroom room teaching, there is hardly any acknowledgement or proposal to address the mental health needs of the students and teachers in higher education. It should be noted here that after a series of adverse events in universities across India, UGC has recently instructed a students' counselling system' to be established for redressal of students mental health concerns.

The way forward

Educational systems can actively participate in promoting mental health and integrate strategies for different tiers of intervention for mental health problems along with focus on educational achievement. There should be a convergence of education and health policies so that a comprehensive service can be provided to the students and teachers in higher education. Mental health policies should be incorporated not just in the school level but also in the higher educational level.

The universities and other places of higher education should provide a space for students and teachers and other staff to access and express their mental health concerns. Routine workshops and programs to promote psychological and mental wellbeing should

be made available for the young people as well as the teachers and staff. Mental health information on substance use and abuse, suicide, common mental disorders and positive wellbeing can be made freely accessible in the form of booklets, leaflets, and digital media. Apart from these, trained mental health counsellors like the psychiatric social workers, psychologists/clinical psychologists etc should be appointed to give specialized care and make appropriate referrals for those who may require it.

The Universities and colleges can establish counselling centres that have strong linkages with available mental health services. One pronged approach has been proved to be ineffective. Best practices followed and suggested in some of the western countries need also adaptation. The resources and structures in the West are different from that of ours, but we can adapt some of the best practices followed in these places as per the need and resources of our nation.

Best Practices in Promotion of Mental Health and Prevention of mental health problems in Higher Education

- a. Draw up a mental health policy and plan for the university/institute
- b. Provide/build infrastructure and human resource
- c. Identify persons at risk by introducing medical history forms that encompasses mental health information. Mental health screening could be taken up from time to time by trained staff to identify persons at risk.
- d. Train teachers, staff and volunteers in identifying mental health problems and strategies to intervene.

e. Encourage help seeking behaviour- online line assessments, counseling and information about in campus and off campus mental health services can be set up. Identify peers who can be trained for peer counseling

f. Establish and provide mental health services- counseling centers can be set up in the campus for those persons seeking either help in person or through telephone. Crisis management should also be part of these centers. They should have clear guidelines and procedures. The college or the university could also have wellness centers where specific programs to promote wellness can be initiated from time to time.

g. If the University/college has departments of Social Work and/ or Psychology, the counseling and mental health services can be also set up by them

h. Build adequate linkages, network and resources in mental health.

i. There should be strict policies towards use and sale of alcohol, tobacco and other addictive substances in campus.

j. Promote mental health literacy among students, teachers and staff.

With the collective will of all the stakeholders involved in education, health and other sectors like the youth welfare, some of these suggestions can be made a reality. Efforts should be made to reach out to those young persons and others in need of mental health services otherwise they fall out of the system just like the many whose mental health needs go unnoticed, untreated and unattended to, in the general health system.

Mental Health and its Integration in General Health

Health encompasses mental health and so attaining good health without mental health is an impossibility. With the magnitude of the mental health issues looming large over us, it is imperative that the Alma Ata declaration be relooked and be taken with utmost seriousness. This is all the more vital as mental disorders are known to cause high degree of burden due to illness and a huge treatment gap due to lack of awareness, affordability, accessibility, availability of mental health professionals and stigma. These reasons often make persons with mental health issues to seek treatments from faith healers and general practitioners with little training in psychiatry.

With the realization that mental health care can be possible through general health care, India's National Mental Health Program envisaged integration of mental health services in the primary health care to deliver the District Mental Health Program. The medical officers were to be trained to identify and treat mental disorders. The National Mental Health Survey 2015-16 found that the District Mental Health Program is on a limp in many states. Structural and administrative barriers and lack of state mental health policy have been the major roadblocks for the success of the NMHP.

The Way forward

First and foremost, there has to be a political will and commitment to take the mental health agenda forward as an integral component of general health addressing all aspects of mental health problems like suicide, severe and common mental health disorders, child mental health, psychosocial rehabilitation and stigma. Some concrete steps that can guide the integration process are as follows:

a. A comprehensive state mental health policy must be developed.

- b. There should be a time-line driven state mental health action plan with a detailed workable plan addressing the activity components, roles and responsibilities of every stakeholder, budgetary provisions and monitoring mechanisms.
- c. Strengthen the existing public health system by
 - i. creation of regular posts for mental health professionals in the periphery.
 - ii. allocation of adequate beds in each district hospitals specifically for psychiatric disorders.
 - iii. regular training of primary health physicians and other staff.
 - iv. regular supply of necessary medicines at all district and state hospitals.
 - v. set up a standard operating procedure for referrals and multidisciplinary interventions.
- d. Human resource and capacity strengthening at various levels
- e. Re-strategize DMHP by emphasizing augmentation of human resources, appointing psychiatrists, other mental health professionals and the support staff exclusively for DMHP. There should be regular flow of funds and strict monitoring of programs.
- f. Budget allocation and mobilization of mental health with a separate budget head and a substantial amount for mental health included in the overall health budget.
- g. Rehabilitation by involving NGO and community
 - i. Legal provisions of disability benefits should recognize disability induced by mental illness.

- ii. Increase the number of NGOs working exclusively in the field of mental health.
- iii. State government should establish more day care centres, half way homes, long stay homes and centres for suicide prevention.
- iv. Public private partnerships should be encouraged to bring in more stakeholders into the field.
- h. IEC activities should be undertaken on a larger scale to generate awareness among the masses regarding mental illness, service availability and reduction of stigma.

To conclude, addressing and preventing mental health problems and promoting the psychological wellbeing of the nation requires a concerted multi pronged inter-sectoral approach. Policies and services of the health and educational systems need to converge and work towards promotion of mental health and prevention of illness.

The larger goal of holistic integrated health and development may have to be explored with a combination of top-down and bottoms-up approach of community development where stakeholders also contribute in the system for mental health care.

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Career Support Systems in Schools in Meghalaya

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Abstract

The school –to-work transition is one of the challenges that many students face. Work, in the form of career requires not only the basic skills for survival, but also other aspects such as becoming eligible to execute a particular task. The changing global and national market trends, the increasing rural-urban-rural migration, information technology, economic and environmental transformation require individuals to adapt to radically and rapidly changing occupational structures. Students who are not prepared to adapt to these changes may be experiencing a career development lag that may be affecting their overall mental health status that can sometimes lead to low academic motivation, fatalistic career beliefs, or educational discontinuation. Furthermore, there is a growing need for theoretically sound, culturally and psychologically validated, career counselling services to be made available at a large scale for use in the Indian situation. This requirement becomes all the more special in the case of tribal populations whose cultures are quite unique. It is with this back ground that a study was conducted on the career orientations and career counselling in 14 rural and urban high schools in Meghalaya. This paper focuses on various recommendations extracted from the study for development of cultural relevant career support system in schools and in the community to cater to the practical needs of the youth in the state as they face, enter and adjust to the changing and widening world of work.

Keywords: career counselling, career support systems in Meghalaya

Mental Health and Career

Issues related to youth, education, and employment are some of the most urgently felt concerns in Meghalaya (Lyndem & Kumar, 2004). These issues can be direct or indirect influences to the state of one's mental health. The mean rate of unemployment in Meghalaya over the past three decades, for instance, was estimated to be 43.61 percent (Planning Department, Government of Meghalaya (2009). As of 2006 report, 6.4% in rural areas and 7.6% in urban areas of unemployed persons were highly educated youth (Ministry of Labour and Employment, 2006).

Disturbed self-esteem, anxiety, self-doubt leading to alienation and depression are just few impacts of unemployment on a person's mental health (Goldsmith, Veum, & Darity, 2012). In the US in 2009, a survey shows that unemployed individuals were four times more likely to report mental health related symptoms including thoughts of self-harm (Luciano & Meara, 2014). Others report that one of the causes of unemployment is the mismatch between available jobs and skills of applicants (Amadeo, 2017). In a study conducted in East Khasi Hills, students felt that the courses offered in the institutions in Meghalaya were suited only for government jobs and do not provide scope for self-employment (Lyngdoh, 2000). Even so, the posts available and offered by the government or private institutions do not fill up the lacunae in employment. The effect of these realities seems to be implied in the statement of one of the students when he said, "*Miss, I feel it's no use studying. I've got a brother and uncle who finished B.A and M.A but no job*" (Male, 15 years, Class 9, Rural Meghalaya).

MBOSE Pass Percentage

In the past five years, the pass percentage has been recorded as 56.31% in the Meghalaya Board of Secondary Education (MBOSE booklet, 2013-2017). Stringent evaluation process, shortage of qualified Science and Math teachers, low English language proficiency, and lack of interest and motivation are some of the causes of this low pass percentage (TST). The effect of these can be seen in one of the responses of the students, "*I will fail in Maths, Miss, I'm gone case*" (Female 14 years, Class 9, Urban Meghalaya).

Comments like this can be a sign of fatalistic career beliefs prevalent among the students. These beliefs may prevail when they do not have planned alternatives or when they have been made to believe that only math and science related careers will fetch them a livelihood. If they continue to nurture such thoughts, their grit to persevere may be hindered.

School Drop Out Rate

The rate of educational discontinuation in the state is alarming. The past five years (2013-2017) recorded a total of 1,09,495 across all the districts (TST, March 21, 2017). From the same reference, the causes were narrated being poor economic conditions of rural masses, low intelligence, repeated failures of students, security reasons, absentee teachers/lack of trained teachers, poor infrastructures, having household responsibilities, and migration for employment. Wide range of literature tell us that issues like these are closely related to mental health disorders (Oshaka, 2005)

Rural-Urban Migration

The Census of India (2011) revealed that Meghalaya was rated 2nd highest inter-state migration between 1991 and 2001. The

migration was mostly due to work/employment purposes, followed by business and education purposes. The high disparity of technological advancement between the educational institutions in Shillong and in other states may also be a reason for this trend. Lyngdoh (2014) reported in her survey that there is a high adjustment related difficulties faced by students who study outside the state and even as they come back for work or further studies. For migrant workers, unfortunately, reports say that some are often severely exploited by urban employers (Kalyanram, Gopalan, & Kamakshi, 2014).

While observing the related literature closely, there seem to a bi-directional trend between mental health and career: Poor mental health leading to poor school performance and development of risky behaviours and low school performance or academic discontinuation leading to poor mental health. It is against this background that the need for bridging the gap between schooling and work has surfaced. There is an increasing need to provide support to students in their academic pursuit as well as help prepare them through school-to-work transitions. If not catered to, the youth who are in schools and those who are out of school may be at risk of emotional and psychological stresses. Hence, career counselling has been a strongly felt need among school students and even across the academic levels.

Career Counselling

Motivation theories say that “When an achievement task is perceived to have no relationship to future endeavours, achievement motivation is not aroused”. The future goals are self-relevant and self-defining goals are self-determined goals (Ryan & Deci, 2000). Similar to Bandura’s (1989) outcome expectations, these goals include, but are not limited to, important personal aspirations such as getting an education, striving for a

career or job. One of the research questions asked in the study reported in this article is whether providing career counselling to students will increase academic achievement motivation and increase career preparedness.

Career counselling has been defined as services and activities intended to assist individuals, of any age and at any point throughout their lives, to make educational, training, and occupational choices and to manage their careers (Organization for Economic Cooperation and Development OECD, 2003). There are several types and models of career counselling. The one tested in this study is perhaps the only approach that has been developed specifically for Indian clientele. The approach to assessment is based on a mixed methods approach that incorporates psychometric devices with qualitative information related to the student’s culture, academic history, hobbies and accomplishments (Arulmani, 2010).

A Glimpse on the research: “*Career Orientations and Career Counselling*”

This study was conducted between 2012 and 2014. It is a school based intervention study of urban and rural indigenous high school students in the East Khasi Hills District, Meghalaya. The main objectives were to determine the career preparation status, academic achievement motivation as well as the career beliefs pattern of the students. The other objective was to determine the relative effectiveness of a specific career counselling model.

The curriculum used as the intervention program in the research is an adaptation of the Jiva Approach to Career Guidance and Counselling, developed by The Promise Foundation, Bangalore, India (Arulmani, 2010). From Jiva curriculum, a Three-Day Career Counselling Programme and One-Day Career Counselling Programme were developed for the use in the study. The research

is an experimental study using pre and post with control group design was employed with data collected using the Stratified Random Sampling in selecting schools. There were a total of 492 girls and boys from classes 9 and 10 from a total of 14 rural and urban schools in the district who fully participated in the study.

Major Findings

Pre Intervention: At the pre-intervention stage, the sample fell into the lowest category of career preparation status and academic achievement motivation as per the norms of the scales used although female students showed higher motivation than the male students. Assessment of negativity in career beliefs showed that the sample was placed in the category of high negativity in the CBPS. Male students showed higher negativity than female students. Rural students showed higher negativity in their career belief patterns but all sub groups fell in the high negativity category of the in the CBPS norms.

Post Intervention: After providing career counselling programmes to the students, the career preparation status and academic achievement motivation increased and negativity of career beliefs decreased to a remarkably greater extent for both the Experimental Groups when compared with their Control Groups. These findings suggest that the students in both the experimental groups have benefitted from both the Three-Days and One-Day career counselling programme as compared to the students in their corresponding Control Groups.

These findings further suggest that the Three-Day intervention has had a more positive outcomes in career preparation, motivation of students to engage with academic tasks, and in acquiring better skills measured by the MGI such as decision making, opportunity awareness, transition skills, and self-

awareness compared to the students who were given only the One-Day intervention. It also indicated that the Three-Day intervention was more effective in reducing the negativity of students' career beliefs. Nevertheless, the One-Day intervention was still recorded to have been beneficial.

Social Structure in Meghalaya

The Khasis, the Jaintias and the Garos have a matrilineal structure of society. Descent is traced through the mother. Traditionally, the youngest daughter is to inherit the property and look after the parents. Structures like this need careful consideration when providing career guidance. Being a collectivist society, career decisions may not be done individually but along with parents or other significant members in the clan, for instance, the *Mama* or big uncle among the Garo Tribe (Laloo, n.d).

If the structure of the society allows collective decision making, and planning, perhaps the kind of career counselling services for this region may be designed to be culturally relevant to ensure efficiency. More comments of a participating students support this argument when they said, "*Miss, since I am the youngest in the family, I have to look after my parents, so it is difficult for me to go out of state to study or work*" (female, 16, rural). While another student said, "*Even if I am the youngest, but I can go out because my married elder sister is already there with my parents*". (female, 15, urban). In cases where a conflict between parental expectation and students aspiration is present, career counselling sessions that includes deeper understanding of Gottfredson's (1981) concepts of circumscription and compromise may be considered.

Other important aspects that need to be considered by career counsellors in the context of Meghalaya include a general observation of the political, economic scenario, and social trends.

Few of the examples are people in the State are known to be highly musical (Suting, 2017) and sports fan (TNT, ; many have preferences towards acquiring government jobs; there is lack of factories, companies, laboratory, infrastructure, investors; and lack of market management for retail, wholesale, import and export trades.

Trends of Career Services In Meghalaya

Till date, there is no existing system for career counselling services in Meghalaya. A trend that only comes once in a year includes education fairs promoting college and universities in India and abroad. Some schools do invite guests once in a while to give a lecture on careers and ambitions. A small number of prominent schools, mostly in the urban areas, do have full-time counsellors who provide career guidance among the students. Most of the schools do not have counsellors. There is no provision for a post of a full time counsellor in many educational institutions. Very few small private educational centres are thinly spread in Shillong and towns, but are mostly providing after class tuitions or coaching classes for already known careers such as Medical and Engineering courses.

Recommendations

Some of the major recommendations of the research are as follows:

- a. Provide career guidance services

Career counselling programmes should be provided for all high school students in both rural and urban location in the State. It should include but not limited to facilitating wider understanding of the current market demands, career eligibility, subject requirements, tasks required by certain careers, developing career

alternatives, and many other information that prepares the students for the world of work. The counselor will serve as a facilitator. Also, translation of concepts to vernacular language should be considered.

- b. Include other stakeholders:

Parents, teachers, and even community leaders should be active participants in the whole process of increasing the career preparation or students. Emotional, social, and financial support are all essential components of facilitating career development.

- c. Build capacity

Perhaps the most urgent need is to increase platform for training interested individuals who may have related qualification and passion for working with the youth may be trained further for career counseling. This is essential as career structures are rapidly evolving.

- d. Development of Policy

The Meghalaya Education Policy must include a creation of post for a Counselor for all educational institutions in the State. With this provision, counselors will be made available in each school and perhaps career counseling may then be integrated in the school curriculum. It is also highly recommended that the core member of the committee drafting the policy should include a professionally trained counselor. Further on this, the policy should also provide a budget on organizing Career Mela in every block of the State.

- e. Conduct future researcher

Recognizing the limitations of the current study, it is highly recommended that

f. More research should be conducted in relation to the career development. Perhaps comparison of different kinds of intervention, development and testing of original interventions, examinations of traditional occupations as viable career options are some areas to be explored.

g. Suggested model for career counseling among the indigenous high school students in Meghalaya (Viray, 2014).

The model presented in this section encapsulates the overall experience of the researcher throughout the period of conducting this study. The model below is suggested to be tested by future researchers who may consider exploring more suitable and relevant career counselling interventions among the youth belonging to indigenous populations such as the sample in this study.

Community-based Career Counselling model (CCC model)

PART 1: Community participation and sensitization

In this model, the first step is to approach the community heads such as the headman, Seng Kynthei (Women group) and Seng Samla (Youth Group) which are traditionally and politically recognized by the indigenous peoples in Meghalaya. These heads will be involved in holding capture meetings for general awareness programme on career and livelihoods among parents as well as among the youth. Barefoot counsellors will be identified and trained for door to door awareness programme, conducting survey, and analysis to use for follow-up sessions.

PART 2: School-based career counselling

A career counselling team lead by a team leader with specified relevant qualification and experience with youth may be formed. The team will initiate all activities in Part 1 and also train barefoot

counsellors. A focus group discussion will be held among the Barefoot Counsellors. The themes that will be extracted from the discussion along with other important data collected during the process of Part 1 and initial stage of Part two may lead to the creation of a curriculum for conducting career counselling among the youth. Once a curriculum has been developed or adapted, this needs to be tested in the selected Model Schools. With the support of the MLA, Inspector of School as well as the local community leaders, the Model Schools will be identified. A longitudinal and cross sectional study will now be carried out as the career counselling sessions are going on in the Model Schools.

PART 3: Career Mela

In the locality where the model school is located, a career mela open also for nearby villages will be conducted. The Mela may include promotion of traditional occupation and green careers, educational loans and scholarships, job openings and opportunities, entrepreneurship, career information, training and entrance exams, names and details of various educational institutions in the state and other parts of the country.

Conclusion:

The strong link between mental health and careers is evident enough to propose the need to provide career related services in the State, particularly among the school going students. Although the students were found to have low career preparations and motivations, they post intervention results show that they are receptive to career counselling services.

The research tested in the state and presented in this paper has shown that even a short yet comprehensive and relevant career counselling programme has increased the career preparation status and academic achievement motivation of the students. It has also reduced their negativity in their career beliefs.

There is a dearth of research conducted in the region related to careers. More research on the relation between career counselling and mental health are required. This paper has explored through wide interaction with students, teachers, parents, and community leaders that career decisions may be a collective process rather than individual. Therefore or any future career counselling model to be further effective, it must consider family dynamics, culture, economic conditions, and career viability. However, delivery of career counselling services cannot be addressed fully by professionals alone. Strong support by the stakeholders are equally important, more importantly, the inclusion of these services and its implications in the Education Policy of the Government of Meghalaya.

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Meaning in life as experienced by Mizo women in midlife

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Abstract

Meaning in life has been consistently linked to overall well-being. Midlife is a normative developmental stage and further research is still required, there is literature on the changes that are characteristic of this stage in life and in particular to the nature of transition to the second half of life. This study explores the meaning Mizo women assign to midlife this is done through a quantitative questionnaire and qualitative interviews.

Meaning in life has emerged in positive psychology as one of many variables. It was Martin P. Seligman who put forward the idea for the focus of mental health to be not on problems or disorders or the disease model but on actions that 'lead to well-being, to flourishing communities'.

The Meaning in life questionnaire by Steger et al., in 2006 was used to collect the quantitative component. In the qualitative component interviews, pre-interview discussion, semi structured interview guide, hermeneutic phenomenological exploration, was adopted in the present study. Seven hundred and forty three women in midlife completed the quantitative questionnaire and five women participated in the qualitative in-depth interview. For the qualitative analysis, thematic network analysis was applied to extract themes. Descriptive, chi-square test and correlation analysis for the quantitative questionnaire revealed the following: meaning in life for the Mizo women in midlife are linked to having

a hobby, the family income, having high education, religion and postmenopausal experience. Four themes emerged from the in-depth interviews: Family care and support give meaning, Serving God provides purpose in life, Searching for meaning is a life long project, Midlife provides independence and the ability to contribute to society. The findings of this study provide important implications for counsellors and psychotherapists who work with adult women. This study also revealed that today's Mizo women in their midlife were active and vibrant quite unlike the cultural stereotype that exists that sees midlife women as unattractive, menopausal, frustrated and depressed. The women do not see meaning is complete: they are continuous exploration of new avenues to enhance meaning in life. This may also raise consciousness to health care planners to develop effective awareness on midlife women's health and develop programs to promote wellness.

Keywords: Logotherapy, Search for meaning, Meaning in Life Questionnaire, Positive psychology, Midlife Mizo women, Thematic network analysis

Introduction:

Why meaning? As people's problems are not pathological, but which instead arise out of a sense of meaninglessness. This may take a variety of forms: a general dissatisfaction with their life; feelings of uselessness; low self-worth; an emptiness resulting from lack of strong commitments to anyone or anything; the reverse, being overwhelmed with commitments that appear to have no unifying purpose and which fail to provide, for all their activity, any significant meaning or value.

According to Martin Seligman (1988), today's high depression rate can be attributed to a loss of meaning. Seligman believes

that to find meaning requires that one must be attached to something larger than just oneself. Perhaps in line with this theory is the finding that religiously active people in surveys worldwide, report higher levels of happiness (Inglehart, 1990) and that those who have deep religious faith are much less likely to get depressed (Friedrich, Cohen, & Wilturner, 1988). Meaning in life has emerged in positive psychology as one of many variables. It was Martin P. Seligman who raised the question of what makes life worth living in 1999. Seligman (1999) put forward the idea for the focus of mental health to be not on problems or disorders or the disease model but on actions that 'lead to well-being, to flourishing communities'.

Concept of meaning in life is increasingly the focus of psychological research studies and has also been the focus of research in both sub-disciplines of existential and positive psychology. In this paper, meaning is defined as – 'the sense made of, and significance felt regarding, the nature of one's being and existence' (Steger, Frazier, Oishi & Kaler, 2006).

Human beings, as far as we know can think, dream and are the only organisms that contemplate and wonder why and think about our thinking. It is a natural phenomenon for individuals to question why they exist and what is the meaning of their existence; this helps to make sense of our lives and that our lives matter. It's the understanding we develop of who we are, what the world is like, and how we fit and relate to the grand scheme of things (Heine, Proulx and Vohs, 2006). So the question of Meaning in Life involves deep self-probing questions such as 'Who am I?', 'Why am I here?', 'What is my role in this universe'? As one grows and starts to ponder and question about life, she/he becomes mature in his/her way of thinking. Pondering on meaning in life helps us discover our true nature and help us develop meaningful

goals and make us experience the process of moving from bondage to liberation. Having a meaningful experience, a life task, feelings of being part of a greater whole, and belief in a deeper meaning in life (Schnell & Becker, 2006)

Research has shown a strong relationship between the experience of meaning in life and psychological well-being. Brassai, Piko, and Steger (2011) reported that a lack of life meaning was associated with poor psychological health and quality of life among Romanian adolescents. That meaning may play a protective role in physical health behaviours (e.g. drug use, sexual health, physical inactivity and diet). Meaning in life is critical to reducing suicidal trends in youth. Wilchek-Aviad (2014) examined meaning and suicidal tendencies in Ethiopian immigrant youth and native-born Israeli youth of 277 samples. People who present a consistent meaning of life are more resilient against life stressors, while people with a weak meaning of life seem more vulnerable to emotional problems, and more likely to succumb to hopelessness (Mascaro, Rosen & Morey, 2004).

Individuals who do not feel they have meaning or purpose in life may experience depression, boredom, hopelessness, and discontent and may feel there is no reason to live (Pinquart, 2002).

Meaning in life is seen as a positive human strength, and has been assumed as a factor contributing to overall well-being in individuals (Lent, 2004). People who feel that their lives are full of meaning are more optimistic (Kelly, 2002), have higher levels of self-esteem (Steger et al., 2006) and positive emotions (King et al., 2006).

Cultures are thought to influence self-concepts along an independent (or individualistic) to interdependent (or collectivistic) continuum. Culture provides individuals with an understanding about world, it influences their thinking about the

world including individual's experiences on meaning in life (Steger et al., 2008). Steger and his colleagues found that for members of interdependent cultures life is not expected to become more and more meaningful; rather, presence of meaning unfolds into search for meaning, which in turn transforms into greater meaningfulness (Steger et al., 2008).

In a cross cultural study with American and Japanese young adults, the Japanese participants reported searching for meaning more. Search is cast in a negative light in America and in a positive light in Japan (Steger et al., 2008). Thus, culture must affect how people construe the search for meaning.

Traditionally, menopause was seen as a natural event of aging and considered a point of positive role and status change in Korean women but the Korean immigrant saw it as ugly appearance, decrease work capacity, hopeless feeling. Chinese Singaporean described it was uneventful (Im & Meleis, 2000; Lim & Mackey 2012). The biological/medical model is the most familiar and widely researched, and results are widely known. This model assumes that the midlife transition is one of a state of deficiency whose only remedy is that of life-long treatment with hormone replacement (Lindh-Astrand, Hoffman, Hammar, & Kjellgren, 2007). Arpanantikul (2002) study among 32 Thai midlife women in Bangkok had a notion of being stereotyped, transforming, prone to poor health, adapting and thinking ahead.

Religion and spirituality seen as a buffer to life challenges, Lee (1996) reported less anxious, have clearer sense of meaning in life. Hong and Lee (2006) religious life ease emotional crisis and provide higher life satisfaction.

Reinhoudt (2005) in her qualitative study explored factors related to aging well in a group of 188 adults. The results showed that existential meaning, which is awareness of meaning and purpose

in life contributed significantly to well being in general, maintaining mental health on an optimal level, and increasing vitality and social functioning.

There is a lack of in-depth knowledge about middle-aged women's experience of meaning in life. This study can promote an understanding of Mizo women in their midlife and contribute to their well being.

The available literature regarding midlife women may contain ageist, sexist, biased perspectives (Banister, 2000). Negative aspects has been the focus, Poorly understood – either medical and menopausal transitions of hot flashes, osteoporosis, heart disease, estrogen replacement therapy, depression, empty nest and other midlife crises, and less on the wealth of new opportunities that this group of women have at their disposal (Perrig-Chiello & Perren, 2005).

Research has established that the midlife years for women may begin a process of increased energy, independence, freedom, and psychological growth (Apter, 1996; Hydock, 2004; Lippert, 1997). This phase of life for women has been described as a time of finding comfort with oneself and as a time of gaining confidence (Helson & Wink, 1992).

I hope to contribute to the field of counselling psychology a more nuanced and textured understanding of women's experience. My hope is to bring to professionals working in the area of counselling psychology an awareness of the concerns that inform the experience of women in the midlife transition.

The specific questions this study sought to answer were:

1. Are sociodemographic factors related to meaning in life for the Mizo women in midlife?

2. What is the level of presence of meaning in life and search for meaning in life for the Mizo women in midlife?

3. What do Mizo women in their midlife consider meaningful in their life?

Methodology:

This study used a quantitative research method followed by qualitative interviews in order to find answers to the research questions. Data was collected through the administration of the Meaning in Life Questionnaire form (MLQ; Steger et al. 2006) along with demographic survey to a total of 743 women. In-depth interviews to explore meaning in life with 5 women. This was largely exploratory to provide the basis for future hypothesis-driven research.

Marchel and Owens (2007) stated that 'qualitative research is based on a belief that truth is constantly evolving and is a cultural construction deriving from an interaction between experiences in the world and the human mind'.

The MLQ has been used to help people understand and track their perceptions about their lives. It has been included in numerous studies around the world, and in several internet-based resources concerning happiness and fulfillment. It has been translated into over two dozen languages and shows robust psychometric properties across gender, age, racial, and international groups.

The participants for this study were 743 women aged between 40 – 55 years. All living in Mizoram. (*M* age =46.54).

The marital status of the participants was married 562 (75.7%), single 30 (4.0%), divorced 52 (7.0%), separated 10 (1.3%) and widowed 88 (11.9%).

Thirty four participants having completed post graduate (4.6%), 140 were college graduates (18.9%), 154 completed higher secondary school (20.8%), 214 had completed till high school (28.8%), 199 did not complete high school (26.8%), and only 1 was illiterate (.1%)

Hermeneutic Phenomenological Exploration: Heidegger, a student of Husserl, moved from how do we know, what we know, to studying human beings in their everyday practical engagements within a socio historical context (Packer, 1985). ‘The goal of phenomenology is to describe our experiences, which are composed of the objects brought into our consciousness and the meanings ascribed to them’ (Hein & Austin, 2001).

For the psychologist it is necessary to know the phenomenological philosophy, because it provides a rich source of information about how to examine and comprehend lived experiences (Smith et al., 2009).

Data analysis: Chi-Square test was run to investigate whether sociodemographic variables was related to meaning in life. A correlational and frequency analysis was done of Presence and Search of the MLQ. Thematic network analysis helped to unearth themes within the interview transcripts, utilizes web-like map networks to organize and represent qualitative data (Attride-Stirling, 2001). In order to create a thematic networks, a researcher must develop a coding framework that is used to analyze the text. After the development of a coding framework and extraction of the text, themes are identified and refined. Themes are then organized to basic themes, grouped into organizing themes, and then global themes are identified that represent the data

Findings

Meaning in life for the Mizo women in midlife are linked to having

a hobby, the family income, having high education, religion and postmenopausal experience.

The presence and search scores of the MLQ are; 72 % are searching for meaning and 1.5% have high presence of meaning in life. The search for meaning is high among the midlife Mizo women. This finding that emerged here is consistent with Steger and his colleagues (2008) study with American and Japanese young adults where it appeared that search for meaning is related to somewhat more meaning in life in Japan. Search for meaning would be positively related to presence of meaning in interdependent cultures (Steger et al., 2008).

Table 1: Meaning in Life Questionnaire measures frequency and percentage of presence and search

Presence and Search	Frequency	Percentage (%)
High presence	11	1.5
Low presence	23	3.1
High Search	534	71.9
Low search	175	23.6

From the in-depth interview 4 global themes were derived-Family care and support give meaning; Serving God provides purpose in life;Search for meaning is a lifelong project;Midlife provides independence and the ability to contribute to society.

Meaning may be found in the high social status and recognition that accompany higher education level in the small Mizo community. The nature of occupation pursued following higher education is likely to be meaningful, or education cultivates a way of thinking and living that increases meaning in life as supported by a study done by Waddell (2012).

Religion and Serving God; All the women were ‘content’ with who they were, with what they did, not aiming to obtain success

or advancement from their careers, but rather were grateful to God. Participants focused on the meaning in life from a godly perspective (Song, 2011).

In this study a positive relation between family income and meaning in life was found. Previous research supports this finding, linking income to well-being and meaning in life for midlife women (Smithson, 2011).

Having a personal pay check and professional identity may be important for women in this age group as they evolve and reflect on their lives. For Mizo women this is a paradigm shift past traditional roles of marriage and staying at home to raise children and care for the family.

In this study a significant relation was found between hobby and MIL. Respondent Pi E mentioned enjoying reading and when she was waylaid by cancer, reading books written by cancer survivors has helped her prepare to face her terminal illness. Respondent Pi C enjoys the new experience that gives broader view and traveling allows experiencing different cultures. It also gives her time to reflect on her life, when she is outside her normal life. Meaning in life based on menopause status show statistically significant relationship in this sample. This could be because menopause is not considered as a threat but a natural event. Amongst the interview participants, health status was not particularly mentioned. Of the five qualitative interview participants, two experienced significant health problems. The two respondents discussed how their health difficulties and thought of death made them reflect more on their life meaning and the future.

In a study of Chinese women executives making meaning in midlife, Woo (2012) observed that contrary to prevailing assumptions that the experience at any life stage is generally the

same for all women, the participants in her study demonstrated they were physically fit, attractive, financially independent. Internally they were engaged in self-exploration, realising the need for more time for self. Consistent with the finding of Woo (2012) engaging in self-reflection and self-exploration the Mizo women could look beyond the present and imagine the future and find ways to balance what is important in their lives, leading to renewed energy and optimism about the future. The participants in this study were attractive, fit and always on the go, had an infectious 'can do' spirit, were involved in projects outside the home, had several interests, were confident in themselves and had a positive outlook.

In the West, menopause is intertwined with aging, loss of youth, loss of sexuality and so there is silence surrounding this (Herzig, 2006). However for women in India, Thailand, Japan, Zimbabwe and Israel welcomed the freedom from menstruation related worries.

Viktor Frankl (1963) is commonly cited in meaning in life research as a founding inspiration. Frankl argued that people function best when they perceive a sense of meaning and possess a life purpose, a unique mission to strive for throughout their lives. One explanation for high search for meaning in this sample could be the women continue to seek out richness in their experiences and the need for new roles in the midlife transition (Steger, 2009). The finding was further supported by the qualitative interviews, where the third global theme states, search for meaning is a lifelong project. Respondent Pi B mentioned; 'I have a good sense of what makes my life meaningful- this is somewhat true. I know I can do more to find meaning and purpose in my life but I do not know it completely. Humans we keep changing our life. As long as we live in this world this will never end... in our everyday life there are things that we need to get rid of, we need to dispose of them.'

Meaning in life thus refers to the understandings that we develop of who we are, what the world is like, and how we fit in with and relate to the grand scheme of things (Heine, Proulx, & Vohs, 2006). This echoes what Pi C said, 'It's always there... while I am here in this earth, in his tapestry I have a place in the weave. God has a purpose for me in this world and I want to fulfil that purpose. I look at life and I know my life's meaning'.

Pi C in her self-exploration saw that she has a place in the grand scheme of things. A possible reason that women in this study search for meaning, it's not that their life is devoid of meaning. Rather, they may be continuously exploring avenues to enhance meaning in their lives. This was recognised by Erik Erikson (1964) a developmental psychologist known for his theory on psychosocial development of human beings, who says that in the second half of life people close the circle of their life. This closing is not done linearly. It points to the possibility of a new beginning, to renewal. That renewal can happen in the second half of life.

Family is significant in having meaning in life. This could indicate that being in a family as Low and Molzahn (2007) found that emotional support was a significant predictor of purpose in life. A study among 100 married and unmarried corporate employees in north India examined their construct of meaning in life, revealed the married employees perceived their families to be of most important to spend time with and give consideration to in the face of crisis. On the other hand the unmarried employees gave recreational activities the maximum importance (Singhal and Rastogi, 2015).

Midlife provides independence and ability to contribute to society. Midlife is seen as time for possibilities and not a crisis as we see in the lives of the women interviewed in the current study. The women in a midlife developmental stage and based on their own

self-evaluations, were not experiencing a psychological emergency that diminished their usual physical and mental capacities. It is noteworthy that at midlife four of the five women participants were involved in voluntary activity in some form or the other. One woman was involved in training and mentoring marginalised women and women who were HIV positive through assisting in setting up small scale business ventures. One was involved in non-government organisations that provide awareness on prevention of HIV and AIDS and working with youth with depression.

Conclusion

We can thus conclude that for midlife Mizo women it appears there is high search for meaning and this can be construed as Mizo community are interdependent and collective, where search for meaning does not mean there is no presence of meaning, that presence does not mean an end all, but life is ever evolving and changing. Prolonged effort of searching for meaning may be united harmoniously with the outcome of greater presence of meaning (Steger et al., 2008).

This study is a discovery of Mizo women through the lens of Mizo women's eyes. Therefore the insight gained from this study can contribute to understanding Mizo women's perspective on middle age, quality of life, meaning in life and well being.

This is valuable for Counsellors who will be working with women in their midlife and how their experience affects them psychologically. This may also raise consciousness to health care planners to develop effective awareness on midlife women's health and develop programs to promote wellness.

Counsellors can benefit from developing an awareness of the life tasks of this population and becoming educated on the importance

of self awareness and self exploration. Different domains that are central to women in midlife should be discussed including: culture, family, career, education, parenting, relationships and spirituality. Counsellors need to encourage women to reflect on life goals and perhaps reappraise aspirations as they enter midlife. Counselling professionals may be working with midlife woman adjusting to new roles, caregiving, being a new wife, newly single or widowed or returning student. Some may feel overwhelmed at the transition meeting them. By using strengths-based approach and wellness orientation, counsellors can educate the midlife clients about making choices. A variety of counselling methods can be used to facilitate this exploration including art therapy, genogram creation, career goal exploration. Family and couples counselling are valuable to enrich marital life, as this is a time when the children have flown the nest or moved out of town for further studies or for jobs and now its just the both of them.

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Community Based Participatory Research: its relevance in addressing social issues in Meghalaya

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Abstract:

All research is based on some underlying philosophical assumptions about what constitutes 'valid' research and which research method(s) is/are appropriate for the development of knowledge in a given study. The research paradigm encompassing ontology, epistemology and methodology, determines the nature of the enquiry and the methodology thereafter. In research processes, many a times the researchers perpetuate the hidden structures of domination and power over the 'researched' and thus studies have found that the researched are even exploited. Such dominant research paradigms have existed in most disciplines. However there are other alternative research paradigms that provide a space for social participation of the 'researched' in processes that eventually affect their lives. The community based participatory research (CBPR) is one such paradigm that provides the stakeholders of a research study especially the 'researched' a space for decision making in the process of research. Several researchers around the world have used CBPR to address issues in mental health and public health. This paper aims to analyse the relevance of CBPR in social work research in the context of Meghalaya. The reference point for this analysis is from the research project entitled 'Applying principles of community based participatory research in developing a mental health programme in rural Meghalaya'. The

CBPR approach has engaged the local people in addressing mental health in which local capacities have been built leading therefore to a sustainable model in addressing issues in health. This is hoped to open ways to also address other social issues through the CBPR approach.

Key words: Community based participatory research, CBPR in Meghalaya

Introduction:

Social reality can be studied through different approaches and researchers have to choose from a variety of research approaches. These research approaches are not simply selection of samples or methods of data collection but are based on particular ideas about the world and the nature of knowledge that a researcher considers as 'valid'. Often than not, there is a tendency to regard research simply as a procedure for which people can be 'trained', with rules and guidelines (Rolfé, n.d.). It is important therefore to understand that the ontology, epistemology and theoretical perspectives, all referred to as research paradigm influences the choice of a research methodology (Gray, 2004). While ontology embodies the understanding of 'what is', epistemology provides a philosophical background for deciding what kinds of knowledge are legitimate and adequate (Gray, 2004). The theoretical perspectives can be categorised into three types; positivist, interpretivism and critical postmodernism. On one hand, the positivist paradigm based on the philosophical ideas of the French Philosopher August Comte propounded that observation and reason are the best means of understanding human behaviour and true knowledge is based on experience of senses and can be obtained by observation and experiment. At the ontological level, positivists assume that the reality is objective and can be therefore quantifiable (Henning, Wilhelm, & Brigitte, 2004). On the other

hand, interpretivism looks for 'culturally derived and historically situated interpretations of the social life-world'. There is no, direct, one-to-one relationship between ourselves (subjects) and the world. The reality consists of people's subjective experiences of the external world (Crotty, 1998). The third theoretical perspective, critical postmodernism aims at social transformation to displace the existing structures of power and domination by opening opportunities for social participation among persons previously excluded and dominated.

Examining the research approaches, the dominant research paradigm has been quantitative research wherein the theoretical perspective is positivism which views the researcher as the ultimate source of authority. This has led to a power relations between the researcher and researched (Karnieli-Miller, Strier, & Pessach, 2008). The inequitable power relationships between the researcher and the researched results in a relationship of distrust and therefore the research is not an empowering process rather it is a process of exploitation (Israel, Schulz, Parker, & Becker, 1998).

In the context of the social work profession, social work research has a distinctive characteristic whereby social work research tries to evolve remedial action on identified problems by conducting empirical studies (Devasia & Kumar, 2009). Almeda (2015) reiterates that social work research should not be confined only to understanding the social phenomenon or developing adequate methodologies to analyze it but also to bring about structural changes through its research findings (Almeda, 2015). The Joint University Council Social Work Education Committee in Britain states that the aim of social work research is to achieve usefulness of the results to the practitioner, contribute to decision making and theory and to work with stakeholders in different aspects of the research process and manages the complex power

relationships involved (Joint University Council Social Work Education Committee, 2006).

As Social Workers and professionals, what research paradigms are we engaging or have engaged in? Are we engaged in the dominant research paradigm that creates inequitable power relations between the researcher and researched or is our research process aimed at empowering the weak and the marginalized, the indigenous people? Hence the aim of this paper is to analyse the relevance of the community based participatory research as a research approach in addressing social issues in Meghalaya.

Methodology:

This analysis is based on the project entitled “Applying principles of community based participatory research in developing a community mental health programme in rural Meghalaya”. This project funded by the Indian Council for Medical Research and implemented by the Martin Luther Christian University between 2015 and 2018. This project was implemented in two community and rural development blocks, Mawphlang CnRD Block and Pynursla CnRD Block in East Khasi Hills District of Meghalaya. These villages were selected as they had similar demographic profile. A random allocation was made for the control and intervention block; Mawphlang block was selected as the experimental block and Pynursla block was selected as the control block. According to the project protocol, 100 to 150 patients with mental illness were to be identified in each block. To achieve this, 2240 household visits were conducted in 5 villages. In the control block, the same number of patients was to be identified and 1436 household visits were conducted in 7 villages.

The process followed in order to carry out the project based on the principles of the community based participatory research was to recognize community as a unit of identity, builds on strengths

and resources within the community; facilitates collaborative, equitable involvement of all partners in all phases of the research; integrates knowledge and action for mutual benefit of all partners; promotes a co-learning and empowering process that attends to social inequalities; involves a cyclical and iterative process; addresses health from both; positive and ecological perspectives; disseminates findings and knowledge gained to all partners; involves a long-term commitment by all partners (Israel et al., 1998).

Based on the above principles, the researchers met the village heads and had a brief discussion on mental health and about the project. The headmen had asked the researchers to sensitize about mental health, mental illness and community on community mental health programme. After the community was aware of the importance of mental health, working committees were formed in the villages. These working committees consisted of villages leaders including women , youth and school teachers. The grassroot functionaries of the government programmes such as the ASHA worker and Aganwadi worker were inevitably included. The identification of patients with mental illness was done through home visits conducted by a local volunteer accompanied by the researcher. Through these home visits, suspected cases were identified and were confirmed by a Psychiatrist. These cases were presented to the working committee so that they would be aware of the prevalence and thereby provide support. The local volunteers known as Barefoot Counsellor (BFC) were also trained on the importance of mental health, common mental illnesses, how to identify patients and how to provide basic support and referral. Further, the caregivers of the patients were also trained on how to support the patients while on medication or otherwise. The other professionals who could extend support to the patients were also identified and training on mental health was conducted. These were the medical doctors and nurses of the primary health centres.

Findings and Discussion:

The Community Based Participatory Research (CBPR) is widely recognized as an appropriate and valid research approach to work with diverse populations, types of communities and target problems. In the context of social work profession, CBPR is a congruent approach to social work values, representing a balance between research and community empowerment. Social workers can increase the translational ability of their research efforts to create sustainable community change in rural communities through the use of community- based participatory research (CBPR) (Baffour, 2011). Leung, Yen, and Minkler (2004) suggested that CBPR represents a shift in the power base away from sole ownership of the research process by scientists through the “deconstruction of power and democratization of knowledge” (Leung, Yen, & Minkler, 2004).

In trying to analyse the relevance of CBPR as an approach in research in tackling social issues, literature review was conducted from Pubmed and JSTOR in order to understand the extent to which the CBPR approach was utilised by researchers. Ninety six peer reviewed journal articles were identified to have used CBPR as an approach in research. Of these, 4 studies were related to mental health in India and 36 studies were also on mental health in other countries. There were 16 studies that used CBPR for other health conditions such as HIV in India and 40 studies were from other countries. It is evident from this review that CBPR as an approach in India has not been a prominent approach used by researchers in the country and the few that have used, were mainly on health related issues. The question that arises is that, is CBPR relevant in tackling social issues in Meghalaya?

Relevance of CBPR in tackling mental health in Meghalaya

Homogeneity in village communities: The experiences from the project leads one to conclude that CBPR is relevant as village

communities in the state are largely homogenous communities in terms of ethnicity. This largely reduces communication barriers in terms of verbal communication. Moreover, the researchers could work with existing village administrative structures without necessarily creating new groups in the village. However, care has to be taken so that essential people such as women and youth are not excluded the existing groups.

Use of Local Resources: Local human resource could be utilised as local volunteers and are a very important asset in the community. These could be the ASHA worker or the Aganwadi worker. The existing workers or new volunteers could be what is known as ‘barefoot counsellor’

Knowledge is disseminated to the stakeholders: Information about the cases and activities of the research project is shared with the working committees.

Challenge existing inequalities: Through the sensitization and trainings on mental health, it has bridged the gap between those who have the information and those who do not e.g. patients and caregivers. Caregivers are knowledgeable about the ways to care and support the patients and this has also reduced the stigma and discrimination associated with mental illness.

Empowering process: Capacity of BFCs has been enhanced and these have become the nodal person to discuss about mental illness in the villages. Their knowledge has made them confident to provide basic support to the patients and also provide information on services that are available locally or outside the villages.

Relevance of CBPR in tackling health issues in Meghalaya

It has been indicated through literature that the CBPR approach has been used to tackle health issues in other parts of the country.

In Meghalaya, there has no known research study that has used CBPR as an approach in tackling health issues. For instance, child health is taken as an issue. It is documented that child health is poor in a large majority of the child population in the state. Table 1 shows the number of children who are malnourished.

Table 1: Number of children malnourished

Normal	Moderately malnourished	Severely malnourished
272895	50663	268

Source: Directorate of Social Welfare (as of September 2016)

According to the NFHS 2015-2016, the wasted children under 5 years – 15.3%, severely wasted (children under 5 years) is 6.3%, underweight (children under 5 years) is 29% and anaemia (6 months – 59 months) is 48% (IIPS, 2015) .

In spite of the Integrated Child Development Services in place in the state, the status of children’s health is very poor. There are 5896 centres out of 6839 villages in the Meghalaya. One of the monitoring bodies at the village level is the ALMSC (Aganwadi Level Monitoring And Supported Committee). This is constituted of 14 members, few from the village. Through the CBPR approach, the monitoring of the Aganwadi centre and its services could be strengthened. This would bring about a positive change in the status of children’s health. In a study in Wardha, India, a community-led initiative for control of anaemia among children 6 to 35 months of age and unmarried adolescent girls in rural Wardha, India it was found that participatory women’s groups and counselling through home visits has led to a decrease in anaemia in the children and adolescents.

Relevance of CBPR in tackling social issues in Meghalaya

The concept of child well being is holistic as it includes all components that are essential for a child’s growth and development. Bradshaw et.al., (2006) recommended six dimensions, including 18 components and 40 indicators for child well being. The six dimensions are material well-being, health and safety, education, peer and family relationships, subjective well-being and behaviour and risk (Bradshaw et al., 2006).

UNICEF (2013) has included five dimensions of the children’s lives to understand the child well being; these include material well-being, health and safety, education, behaviours and risks, and housing and environment (UNICEF, 2013).

For instance, ‘safety’ as an indicator of well being. How do we ensure safety for our children? Rising crimes against children is witnessed, According to the Meghalaya Police, in 2016, there were 240 cases of crimes against children and in 2017 (August 2017), there are 236 cases. Would a CBPR approach work in this instance? A study in Nigeria and Sierre Leone showed that by applying community-based participatory research, it was found that the researchers could better understand and improve kinship care practices and therefore understood the dynamics in the welfare of children in need of care and protection.

Conclusion:

Through the experiences of applying the principles of CBPR in tackling mental health in rural villages in Meghalaya, it can be said that this approach is very relevant for addressing mental health issues. It should be conducted in other villages of the state as well. This approach will be relevant to address other health problems faced by especially children and women. It could also be used in addressing other social issues

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Community Mental Health -Role of stakeholders

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Introduction

During the last three centuries, care of the persons diagnosed with mental disorders has seen major progress in the areas of what are considered mental disorders, where they should be cared for, who should care for them and the rights of the persons diagnosed with mental disorders. The shift can be seen in the terms used, from bad to mad to sad and the places of care from jails to asylums to mental hospitals to the community. These changes are a reflection of the advances in the understanding of human behaviour, especially that of the functioning of the brain and the progress in the human rights field. The current goal of care is to assure quality life to persons diagnosed with mental disorders, in the community.

The current situation places a number of challenges and opportunities for the different stakeholders, which is the focus of this article.

Changing mental health scenario over the last century

The development of mental health care all over the world is best described as a developing process. The World Health Report, 2001, by the World Health Organisation, described the changes over the last two centuries as follows:

“Over the past half century, the model for mental health care has changed from the institutionalization of individuals suffering from

mental disorders to a community care approach backed by the availability of beds in general hospitals for acute cases. This change is based both on respect for the human rights of individuals with mental disorders, and on the use of updated interventions and techniques. The care of people with mental and behavioural disorders has always reflected prevailing social values related to the social perception of mental illness. Through the ages, people with mental and behavioural disorders have been treated in different ways. They have been given a high status in societies which believe them to intermediate with gods and the dead. In medieval Europe and elsewhere they were beaten and burnt at the stake. They have been locked up in large institutions. They have been explored as scientific objects. And they have been cared for and integrated into the communities to which they belong. In Europe, the 19th century witnessed diverging trends. On one hand, mental illness was seen as a legitimate topic for scientific enquiry; psychiatry burgeoned as a medical discipline, and people with mental disorders were considered medical patients. On the other hand, people with mental disorders, like those with many other diseases and undesirable social behaviour, were isolated from society in large custodial institutions, the state mental hospitals, formerly known as lunatic asylums. These trends were later exported to Africa, the Americas and Asia. During the second half of the 20th century, a shift in the mental health care paradigm took place, largely owing to three independent factors, namely (i) psychopharmacology made significant progress, with the discovery of new classes of drugs, particularly neuroleptics and antidepressants, as well as the development of new forms of psychosocial interventions; (ii) the human rights movement became a truly international phenomenon under the sponsorship of the newly created United Nations, and democracy advanced on a global basis, albeit at different speeds in different places and (iii) social and mental components were firmly incorporated in the definition of health of the newly established WHO in

1948. These technical and sociopolitical events contributed to a change in emphasis: from care in large custodial institutions to more open and flexible care in the community. Community care is about the empowerment of people with mental and behavioural disorders. (emphasis added). In practice, community care implies the development of a wide range of services within local settings. This process, which has not yet begun in many regions and countries, aims to ensure that some of the protective functions of the asylum are fully provided in the community, and the negative aspects of the institutions are not perpetuated”.

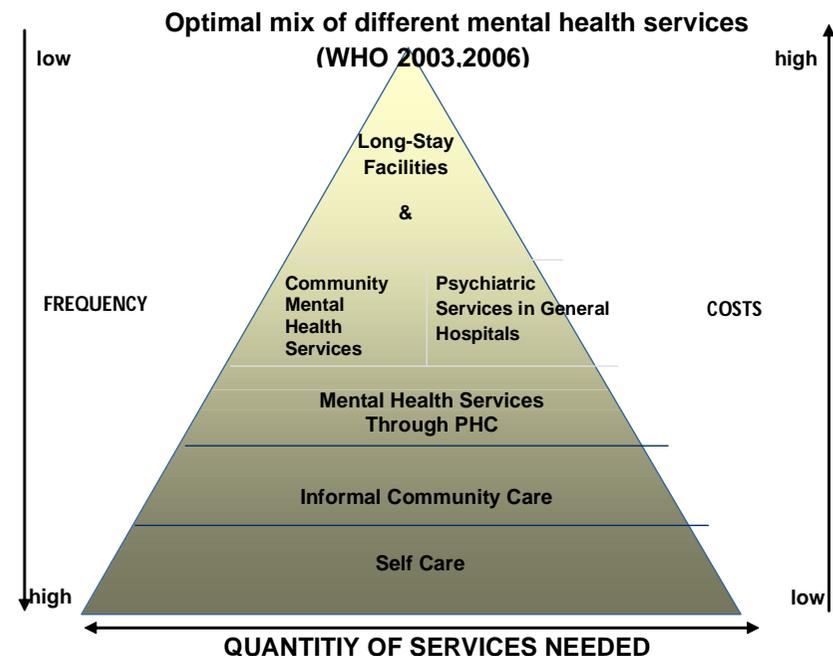
Another important development of the last two decades occurred in 1991. The United Nations General Assembly adopted the Principles for the protection of persons with mental illness and the improvement of mental health care, emphasizing care in the community and the rights of individuals with mental disorders (United Nations 1991). It is now recognized that violation of human rights can be perpetrated both by neglecting the patient through discrimination, carelessness and lack of access to services, as well as by intrusive, restrictive and regressive interventions. A more recent document is the United Nations Convention on Rights of Persons with Disabilities of 2006.

Another important common issue in mental health care is the issue of stigma. The universal challenge of stigma was highlighted in the US Surgeon General’s Report of 1999 (DHHS 1999). The report noted

“Despite the efficacy of treatment options and the many possible ways of obtaining a treatment of choice, nearly half of all Americans who have a severe mental illness do not seek treatment. Most often, reluctance to seek care is an unfortunate outcome of very real barriers. Foremost among these is the stigma that many in our society attach to mental illness and to people who have a mental illness.”

In summary, the past century witnessed an evolution of care towards a community care paradigm. This is based on two main pillars: first, respect of the human rights of individuals with mental disorders; and second, the use of updated interventions and techniques. In the best cases, this has been translated into a responsible process of de-institutionalization, supported by health workers, consumers, family members and other progressive community groups.

A very important implication of this is the new approach to think of mental health services (Fig 1)



It is significant to note that self-care and informal care are the important components of mental health services.

Mental Health Care in India

The mental health in the community encompasses a wide variety of needs. These include (i) serious mental disorders in the community; (ii) persons with Acute conditions; (iii) persons with long-standing(chronic) mental disorders;(iv) mental disorders in primary health care; (v) mental health of women; (vi) children and adolescents- school going and out of school; (vii) special groups like refugees, survivors of disasters, (viii) persons attempting suicide; (ix) public mental health education; (x) persons in institutional settings;(xi) prevention of mental disorders and (xii) promotion of mental health.

At the time of India's Independence, there were almost no mental health services in the country. For a population of about 300 million, there were only 10,000 psychiatric beds, in contrast to over 150,000 psychiatric beds for about 30 million in United Kingdom at that time. The initial period of 1947-1966 focussed on doubling of the psychiatric beds, along with development of training centres to train psychiatrists, clinical psychologists, psychiatric social workers and psychiatric nurses. The period of 1960's 1970's saw the emergence of general hospital psychiatric units in a big way both as service providers and training centres. The community psychiatry initiatives were taken up initially in the 1970's and in a big way from the 1980's, following the adoption of the National Mental Health Programme(NMHP) in August 1982.

Government of India felt the necessity of evolving a plan of action aiming at the mental health component of the National Health Programme and for this, an Expert Group was formed in 1980. This Group met a number of times and had discussion with many of the important persons concerned with mental health in the country as well as with the Director, Divisional of Mental Health, W.H.O.,

Geneva. Finally, in February, 1981 a small drafting committee met in Lucknow and prepared the first draft of National Mental Health Programme for the country. This was presented at a "Workshop" of experts(over 60 professionals) on mental health drawn from all over India at New Delhi on 20-21st July 1981. Following the discussion the draft was considerably revised and the new draft was presented at the second workshop on 2nd August 1982 to a group of experts belonging not only to psychiatry and medical profession but also to education, administration, law, social welfare. The final draft was submitted to the Central Council of Health, the country's highest health policy making body at its meeting held on 18-20 August, 1982, for adoption as National Mental Health Programme for India. The Council discussed this programme a length and adopted a resolution for implementation in the states and Union Territories of the country as follows:

"Mental health must form an integral part of the total health programme and as such should be included in all national policies and programmes in the field of Health, Education and Social Welfare. Realising the importance of mental health in the course curriculae for various levels of health professionals, suitable action should be taken in consultation with the appropriate authorities to strengthen the Mental Health Education components. While appreciating the efforts of the Central Government in pursuing legislative action on Mental Health Bill, the joint Conference expressed its earnestness to see that the bill takes a legal shape at the earliest."

The NMHP outlined the following objectives:

- (i) to ensure availability and accessibility of minimum mental health care for all in the foreseeable future, particularly to the most vulnerable and under-privileged sections of population;

- (ii) to encourage application of mental health knowledge in general health care and in social development;
- (iii) to promote community participation in the mental health service development and to stimulate efforts towards self-help in the community.

Approaches to the statement of programme objectives were diffusion of mental health skills to the periphery of the health service system; appropriate appointment of tasks in mental health care; integration of basic mental health care into general health services; linkage to community development and mental health care. The service component will include three sub-programmes-treatment, rehabilitation, and prevention .(DGHS, 1982, Agarwal et al, 2004).

Barriers to implementation of NMHP in India
<ul style="list-style-type: none"> • <i>Shortage of trained manpower in the field of mental health;</i> • <i>Social stigma and lack of knowledge of psychiatric patients and their families;</i> • <i>Negative attitude of general practitioners, primary care physicians and other specialists;</i> • <i>NGO/voluntary organizations do not find this field attractive;</i> • <i>Inadequate staff and infrastructure of mental hospitals and psychiatric wings of medical colleges;</i> • <i>Uneven distribution of sparse resources limiting the availability of mental health care to those living in urban areas;</i> • <i>Inadequate funding for mental health, which remains a relatively low priority area.</i>
<p>(from Annual Report-2006-7; Ministry of Health and Family Welfare, Government of India. New Delhi. Page140.)</p>

Progress during 1982-2017

A striking aspects of the developments of mental health services in India, is as much the location of the care in the community (where most of the ill persons were already living) as the utilisation of a wide variety of community resources of the community. For example, in the initial phase, the existing general health care infrastructure was the primary focus of integration

of mental health services. Soon, the increased use of family members, volunteers, counsellors, mentally ill persons, survivors of disasters, parents of children with mental disorders, the education system occurred. *In this way the three principles of community psychiatry –meeting population based needs, use of range of resources, and accessibility were partially addressed.*

During the first 10 years of the NMHP, the initial small scale models of care(1975-1984) by integrating mental health care with general health care were systematically evaluated (19-22). Recognising the limited mental health resources in the country, from 1985-1990, the district level model in the Bellary District of Karnataka was developed and evaluated. These efforts dominated in the first decade of community mental health movement in the country, and often it is confused as the only community psychiatry model in the country. During the next 15 years,(1993-) the district model called the district mental health programme(DMHP) was initially extended to 27 districts and later on to 100 districts and currently to over 300 districts. Thus within a relatively short time the basic approach to integrate mental health with general health care was taken to a larger coverage of the population. A large number of mental healthtraining resourceswere developed for the training of non-specialists.

It is important to recognise that there were simultaneously other community mental health care initiatives in the country. For examples, even as early as the 1950’s various approaches to involving the family members in the care of their ill family members was in operation at centres like Amritsar, Vellore and Bangalore. A number of other initiatives, specially by the voluntary organizations , have enlarged both the scope of mental health care as well as the role of care providers. These initiatives

have included setting up of day care centres, half-way homes, long-stay homes, suicide prevention centres, school mental health programmes, disaster mental health care, community based programmes for the care of the mentally retarded, elderly persons, persons with dementia, substance abuse.

A recent document bringing together over three dozen experiences of 'Mental health by the people' the initiatives have not only the health and education sectors but included the family carer initiatives for mentally ill and mentally retarded, the parent movement for learning difficulties, initiatives to reach the elderly population, suicide prevention by volunteers, disaster mental health care by non-professionals, efforts by voluntary agencies to fight stigma and discrimination.

One very India specific development of significance is the increasing role played by the family members both for self-help, mutual support and towards advocacy. This development, to a large extent, has occurred with the partnership with the professionals, unlike in some of the western countries where there is this lack of cooperation between patients, families and professionals.

Current Situation

The developments between 1946-2003 has been critically and comprehensively covered by different professionals in a recent book by the Director General of Health services(DGHS). Though NMHP came up in 1982, the subsequent three five year plans did not make adequate funding allocation. Further even the funds allotted were not fully utilized. It was only in the 9th Five year plan that a substantial amount of Rs. 28 crores was made available and it was increased in the 10th five year plan to be about Rs. 140 crores. The availability of funds in 1995 for the DMHP has shown

that once funds are available States are willing to take up intervention programmes and professionals are willing to be part of integrating mental health with primary health care and taking up a wide variety of initiatives for mental health care. In 2012, the NMHP was reformulated to set up centres of excellence, strengthening of medical colleges and inclusion of suicide prevention and school and college level mental health.

There are some limitations of the above developments of the last 35 years of efforts, since the formulation of the NMHP. Firstly, the extension of the district model has brought to the forefront a number of managerial and care issues. *“India’s NMHP did envisage the diffusion of mental health skills to primary health care centres at the village and district levels, and the integration of mental health care with primary health care. However, poor monitoring and lack of coordination with the local state governments meant that such diffusion and integration efforts were not implemented, with the exception of a few sporadic programmes”*

As of now, the DMHP, still requires a lot of fine tuning (the amount training for the programme managers, finalization of training material, public mental health education, lack of measures to monitor the effectiveness and the impact of the programme, lack of a supportive team at the central, regional and state levels, etc). Finding professionals to work as part of the basic mental health team at the districts has been a problem in a number of states, especially the non-medical mental health professionals. Though professionals have accepted the NMHP, the effort to give a solid foundation to the DMHP is still insufficient. There is a need to know about what proportion of persons with mental disorders seek care, what could be achieved in the best case scenario and what it will take to achieve this in a phased manner. The failure in this field is all the more striking when the rest of

the world is moving towards mental health in primary health care. India which initiated this approach, 30 years back has not maintained its leadership in this area of work. Secondly, the voluntary agency initiatives have been isolated to pockets of the country, limited in reach, and have not been adequately supported with funds, by the government, both at the state and centre. Thirdly, in spite of the many positive developments, the state level planning has occurred to a limited extent. Fourthly, there are areas, of mental health programme that have not been given adequate attention. Of these the following are important. The nationwide, ICDS programme has not received the effort to make pre-school education an effective mental health development force. The life skills education for adolescents and youth is still in its initial phase in few centres. In spite of the attention to suicide by farmers, the number of centres providing suicide prevention is limited to few dozen centres when it should be available in few hundred centres. The excellent models of disaster mental health care has not been part of the past NMHP efforts. Fifthly, the undergraduate training of basic doctors is extremely limited. The human resource development to meet the total mental health needs have not been fully addressed. Sixthly, the issues of rapid social change, along with the many changes in the social institutions like the family, community and the ways to help populations experiencing the ill effects of these changes is still not a subject of adequate attention. Seventhly, the current models are largely rural population oriented and viable models for urban populations is far away from development.

The other recent criticism of community psychiatry in India is that (i) it is top down; (ii) it is not based on the cultural aspects of the country; (iii) it is not effective; (iv) it is driven by WHO policies; (v) the community voices have not been included; and (vi) the programme is a singular approach of DMHP. This criticism is not valid as can be seen from the review of the

developments of the last four decades. Community psychiatry in India has been driven by the realities of the country (eg. Involvement of families from 1950's when the rest of the was viewing the family as 'toxic'). The development of the models of care were based on one decade of field work to understand and meet the needs of the community by two academic centres and not in response to the WHO. These two centres based their interventions on the 'community voices' and these have been well documented. The development of policies of WHO were as much as influenced by the Indian professionals as Indian movement being driven by WHO. It is salient to note that throughout the last thirtyfive years Indian professionals have played important roles in the WHO as regular staff at the Geneva office and the Regional offices.

As pointed out in the book 'Mental Health by the People' by Srinivasa Murthy, in 2006 and by Patel and Thara in 2003, in their book 'NGO innovations in India' the community psychiatry in India is not a 'single model' programme but a wide variety of initiatives involving community resources.

The most important developments of the last three years is the reformulation of the National Mental Health policy in 2014 and the Mental Health Care Act 2017, states '*Every person shall have a right to access mental healthcare and treatment from mental health services run or funded by the appropriate Government*'. This is promise of the State with tremendous potential for changes.

Future of Psychiatry in India

The past efforts had laid greater emphasis on care of persons with mental disorders, though there have been smaller scale attempts at promotion of mental and prevention of mental

disorders. The growing recognition of the impact of social changes on the mental health of the population (eg. growing suicide rates, domestic violence, violence in children, elderly mental health, migrant populations, displaced populations, etc) requires that the future mental health programmes should include promotion of mental health, prevention of mental disorders and care and rehabilitation of persons with mental disorders.

In order to address the above mental health needs in India there are a number of requirements in India. These are at three levels, namely, professional level, community level and policy level.

Professional challenges:

There is a need to simplify mental health care skills and continually review and develop innovative approaches to deliver them, in order to meet the reality of the community needs and expectations. For care to be undertaken by health workers, teachers, volunteers, family members, there is need for simple interventions. Professionals have to develop the appropriate information in a simple format and identify the 'level of care' and 'limits of care' to be provided by these personnel. These should include choosing priority mental disorders to be addressed in training, limiting the range of drugs to be used by the general practitioners, develop strong referral guidelines and the non-pharmacological interventions to be used by non-physician personnel. There should be willingness to share the mental health caring responsibilities with non-specialists, overcoming the fear of some professionals of losing their work, identity and income. The method should be not to convert the non-specialist into a mini-psychiatrist, but to identify what is relevant, feasible and possible for the specific non-specialist to undertake. There is a need to decrease the amount of time devoted by specialists mental health professionals to individual clinical care and increase the

time for training, support and supervision of other personnel. This is a big challenge for clinicians who value directly caring for ill people by themselves. This change in role becomes meaningful when it is recognised that training of other personnel has a multiplier effect in providing mental health services to the population. There is need to devote significant time to periodic support and supervision of the non-specialists. Reports of mental health care in developing countries have repeatedly shown the importance of support and supervision by psychiatrists to the non-specialist personnel. Fortunately, the easy and inexpensive availability of mobile phones, internet and satellite communication for telepsychiatry, allows for distant support to the non-specialists on a continuous and interactive basis. There is a need for professionals to acquire the skills to work with the community, education sector personnel, welfare sector personnel, voluntary organizations, and policy makers. This includes understanding the planning process, fighting for priority for mental health in health programmes, becoming familiar with legislations and budget procedures, and developing skills to negotiate with different stakeholders.

Community Level Challenges

In India, and in other developing countries, there is a paradoxical situation of limited services and poor utilisation of the available services, due to problems of stigma and lack of information in the general population. There is a need for bringing about a major shift in the thinking of the community in terms of understanding of the mental health and mental disorders, decreasing the stigma and discrimination of persons and families with mental disorders, and the creation of a wide range of community care facilities and services. There is also need to develop simple self-care information modules. For those requiring long-term care there is

need to develop measures (for example using the mobile phones, internet, community radio) to help in monitoring the progress of mental condition at the home level.

In addressing these needs to cover the total population and in a manner that requires limited travel, there is need to use fully the modern technologies like the world wide web, mobile phones, telemedicine, community radio to reach and continuously support the persons and families with mental disorders. Already some small scale initiatives have been made and there is need for both widening these initiatives and the wider application to cover the total population of the country. The use of information technology in spreading the agricultural information should give hope for similar success in the mental health area.

Policy Level

There are a number of requirements at this level. The important ones are: (i) greater amount of allocation of funds for mental health programme; (ii) recognition of human rights of the persons and families of persons with mental disorders in all development programmes, especially in the areas of education, welfare, housing, employment; (iii) strengthening of the programmes to support the families ; (iv) legislative support for non-specialists to provide mental health care and (v) building of a large number of community based care facilities.

Who are the stakeholders?

From the review of the progress, it is clear that mental health of the population is not to be seen as referring to small proportion of the population(from 2-10%)but the total population. More importantly, the important players are not only the highly trained professionals but all of the population. This is what offers many challenges and opportunities.

Role of stakeholders

People: There are excellent examples in other health and social issues, the important role played by the persons living with medical conditions(eg: HIV/AIDS) and marginalised persons(eg. persons with different sexual orientations). Unfortunately, till recently, persons living with mental disorders have not been in the forefront of the mental health movement. However, it is necessary that persons living with mental disorders would come to lead the movement. The live-in narratives and experiences have to be the foundation for the development of services. They can contribute by Sharing of their live-in experiences; Acquiring knowledge and adapting the same to their local situations; acquiring mental health skills for self-care; Joining hands with others in a similar situation for support and acting collectively for policy changes

Non-Professionals: Other caregivers, like volunteers, non-specialist professionals (eg. NGO personal, teachers, social workers, counsellors) can be the first level of care and referral for specialised care. They can generate local experiences and collate needs of the local populations; build on the strengths of the community; provide regular and continuous support; mobilise State support; work towards policy changes and knowledge creation that can help professionals to provide solutions.

Specialists: Specialist non-medical mental health professionals(Clinical psychologists, psychiatric social workers, psychiatric nurses) and specialist medical professionals (Psychiatrists) are vital as technical information support. They need to think out of the box to find solutions to empower people and non-specialist carers. They should be free to share skills of caring. They can form partnerships with non-professionals. An important need is for them to take up leadership for change,

especially at the policy level. Another very important role is to undertake research and evaluation.

Each of these groups should be engaged in generation of knowledge and adaptation of mental health skills so that self-care and informal care reaches all of the population.

Conclusion

Development of mental health services all over the world, countries rich and poor alike, have been the product of the larger social situations, specifically the importance society gives to the rights of disadvantaged/marginalised groups. Economically rich countries have addressed the movement from the institutionalised care to community care building on the strengths of their social institutions. India has begun this process and made significant progress. There is need to continue the process by widening the scope of the mental health interventions, increasing the involvement of all available community resources and rooting the interventions in the historical, social and cultural roots of India. This will be a continuing challenge for professionals and people in the coming years.

The challenge in countries rich and poor is to provide services to all the persons with mental disorders, which is not happening at this point of time(Wig,1989). Should we focus only on scaling up (Chisholm et al,2007a, Chisholm et al,2007 b) or think of new approaches to care. This is not suggest that scaling up is not required but to point out scaling up alone is not the answer. I would like to outline a few alternatives to address the needs of persons with mental disorders in the next section.

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Understanding Qualitative experiences of parents caring a child with Autism Spectrum Disorder

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Abstract:

In order to provide professional assistance to parents caring a child with ASD, it is important to understand their experiences. This study is conducted with the aim to find out the meaning of experience in caring a child with ASD. A qualitative study was conducted where purposive sampling was employed with six parents from one special school in Shillong recruited directly via key informant. Semi-structured interview was used for the process of data collection and thematic analysis was used to analyze the data collected. Experiences of parents caring a child with ASD emerge as the major theme that consists of 6 sub-themes. The study concludes that raising and caring a child diagnosed with autism is a difficult journey experienced by parents who were seen as primary care giver.

Keyword: Autism Spectrum Disorder, Autism, qualitative research, parents, child, experiences

Introduction

Autism is a childhood developmental disorder (“Is a group of disorder characterized by the impairment or delay in function related to the central nervous system that affect a single area of development” (WHO, 2013) that is collectively known as ASD (NIMH, 2011). The onset of ASD is before the age of two and a

half years or later in their childhood (Ahuja, 2006) for some children might exhibit symptoms of the disorder right at their early infancy and some at their second or third year of life. ASD is 3-4 times common among males with a prevalence of 0.4-0.5 per 1000 population (ibid: 176). It is a worldwide disorder that is seen across all cultural and social boundaries (Belfer, 2008 cited in Phetrasuwan and Miles, 2009:157). ASD is characterized by the impairments in communication, social interaction, and the unusual way of receiving and processing information that disrupts the daily functioning and has an impact in the child's educational and social attainments (WHO, 2013). The term „Spectrum“ is used to represent its range and severity as some might be mildly impaired and other might be severely impaired by its symptoms that include impairment in skills and the level of impairment or disabilities in a child diagnosed with ASD. Children diagnosed with autism look relatively „normal“ in their appearance, but the only difference that differentiates them from other typically developing children is their disturbing behavior and their disengagement from social interaction. In addition, children diagnosed with ASD lack in maintaining friendship or socially isolated themselves due to their socially challenging behavior.

According to the World Health Organization, in 2013 the global prevalence of the ASD is estimated to be about 1 child in 160 this accounts for 7.6 million that is 0.3% of the global burden of disease. Autism Spectrum Disorder stood as the 3rd most common childhood developmental disorder (Barua and Daley, 2008).

Raising a child diagnosed with autism is a difficult journey experience by many families especially parents who were seen as primary care giver. A number of literatures have suggested that parents raising a child with ASD experienced considerable amount of challenges where it requires external support (Daley,

2004). It is evident that individual and families affected by ASD experience a lot of challenges (Kiu, 2007: 3) that has an effect on their psychological and emotional well-being (Matenge, n.d.).

Bringing up an autistic child demands a unique ways of supporting and caring and it is seen as the most stressful than raising a child diagnosed with other childhood disorders (Sanders & Morgan, 1997) as the reason of ASD is because of its unique conditions (Sawyer et al., 2010). Priorities in life changes when a child is diagnosed with ASD as a lot of changes are encountered by the parents. Caring a child with autism has impacted the role as parents (Woodgate *et al.*, 2008). Parents of children with autism experienced social stigma as a result they lack social interaction (Baba, 2014). There is a possibility that parents may experience withdrawal from various social & cultural activities (Koegel *et al.*, 1984). They may also fail in maintaining relationships be it with family or with friends (Trute & Hauch, 1998). Autism has dominated the life of parents and has been the cause of marital distress (Cullen and Barlow, 2002).

It is apparent that most of the families will hide the diagnosis in order to avoid societal discrimination. For many of the families labelling a child with autism has never been easy and most of these families go through many difficulties. The diagnosis of a child with ASD has gave a sense of relief but on the other hand it turns out to be a frustration to most of the parents especially at the time when they have to seek professional support or any related assistance. However, to some extent the diagnosis of autism has made some families to accept and be more tolerant which in turn made them to advocate for the betterment of their children.

Understanding parent's experiences in caring autistic children requires keeping a close contact with the parents and exploring their feelings, attitudes and perspective about their children

through qualitative research. As it is understood that autism is a public health issue that required various professions from various disciplines to intervene, it is believed that understanding the meanings of the parents “experiences in taking care of their children with autism can provide a good guidance for health care assistance that provide necessary care and identify basic needs based on parents perception”

Caring a child with Autism is a global phenomena and it is also common among the parents in Shillong². Traditionally parents are the primary caregivers and are mostly in charge of the child care. Even though the challenges of caring children with ASD is considered worldwide, but there aren't enough data that highlights the experiences of parents who were involved in taking care of these children in Shillong. Although many research studies on the experience of parents of a child with ASD were carried worldwide, Autism Spectrum Disorders in Meghalaya in general and particularly in Shillong is at infancy. Since the knowledge of this phenomena in Shillong is unclear and ambiguous, there is a need to know and required to study more.

The purpose of this study was carried out in order to understand the parents' experiences in caring for a child with Autism. The study hoped that its finding will provide necessary and valuable information and bring together all professionals to keep a close contact with parents in order to promote effective care and support for children with ASD and their parents and family as a whole.

Methodology

Research design are plan activities for research that provides a details decision about the method of data collection and analysis (Creswell, 2009). In understanding the subjective experiences of particular phenomena, the researcher felt that qualitative method

would be more appropriate in understanding the subjective meaning and quantitative method will not do justice to such an inquiry. Therefore, the study is purely qualitative in nature. Qualitative research is a method that is use for exploring and understanding the meaning that an individual or groups attributed to a „social or human problem (Creswell, 2009). It lays emphasis on the way how people or groups of people perceive the reality. It studies the behaviour in a natural setting and is concerned in developing an explanation of social phenomena (Hancock *et al.*, 2007).

The study is a part of a larger study for MPhil dissertation in Social Sciences with the purpose to explore the experiences of parents of a child with Autism Spectrum Disorder.

Sampling method: The current study found it appropriate to employ a purposive sampling in the selection of the participant. The researcher applied a purposive sampling based on the inclusion criteria and the readiness of the parents to participate in the study. Purposive sampling helps to produce a sample that can be considered „*representative* of the population (Battaglia, 2008).

The researcher applied a purposive sampling as there is very limited number of representatives within the population under study. Therefore, parents of children with autism were recruited directly from one special school in Shillong via key informant (Principal of the school). These selected participants are those parents of children who were already identified as meeting the criteria of ASD. The current study involved 6 participants i.e., 3 mothers & 3 fathers of children diagnosed with ASD. The inclusion criteria were both fathers and mothers from three families. All the participant taking part in the study were Khasis³ and all of them speak the Khasi language⁴ and they all belong to

a nuclear family. They were all parents of male children ranging in the age group of 8-13 years.

In order to recruit participants in the study, one identified special school in Shillong, Meghalaya, India was contacted. Permission was received from the principal of the school when the nature and aim of the study was explained. The key informant provided the names and address of the participants for the study. The researcher made an appointment through telephone with a list of ten participants who were identified to participate in the study and later during the process of data collection only 6 participants from three families volunteered to take part in the study were as the remaining four participants from the other two families showed disinterest about their participation. Two to three visits were made at the respondents residence prior to the interview so as to build rapport with the participants. The participants were given a choice as to whether they want to interview both as a couple or whether they want to be interviewed individually.

With prior permission the interview was conducted individually on a separate day and time. In the process of these visits, participants were explained about the purpose of the study and a permission letter was handed over to the participants after explaining the purpose of the study. Informed consent was distributed to every participant for which after their willingness to participate, the interview process started. The interviews lasted for about 50-60 minutes. Questions were strictly based on the experiences of parents with their child diagnosed of autism. All the interviews took place at the residence of the participants. The interviews were audio tape recorded and data collected were transcribed and analyzed verbatim.

Data collection: The present study administered a semi-structured face to face interview as it is felt that a semi-structured interviewed

could do justice in answering the research questions and has a provision of probing. This method helps the researcher to explore the different aspects of the study. Further, the study used an interview protocol of open ended questions and prompt questions. Two interviews were carried whereby the first interview help to gather some of the basic information about the family and the child diagnosed with autism. The first interview is one way of building rapport with the participant and the second interview was specifically carried out with parents. During the process of interview, all information was collected through field notes and audio-tape recorder in order to collect accurate data. As mentioned earlier all these information were collected based on the consent received from the participants.

Data Analysis: Thematic analysis was used to analyze the data collected from the field. Field notes and audio-tape recorded interviews were transcribed verbatim into English and analysis of the transcript were analyzed individually and comparison were matched with other cases so as to understand the experiences and the life situation that the participants tend to describe. When the transcript was done the researcher code the data and some of the common themes were extracted from the data collected using thematic analysis. The researcher followed step by step procedures using Braun & Clarke (2006) guidelines to thematic analysis.

Ethical consideration: Participants consent was obtained and all information collected through audio tape recorder and field notes ensured anonymity and deemed to remain confidential. Participants were aware of the use of audio tape recorder and field notes. Participants were given the right to withdraw from the study at any time. Participants were assigned with different names (not using their real name) and the information collected from them was saved accordingly.

Findings:

Parents' experience emerged as the major theme from the process of data analysis and each of these themes was a reflection of the personal experiences that each parent has shared. Most of the parents in the study stated that caring a child with ASD is a difficult task and very challenging. They happen to experience a mixed emotion both negative and positive with regards to their child's disorder. They consider it to be a tough and challenging journey.

The major theme was explained in terms of 6 sub themes supported by common meanings. Each of these themes will provide a description of the experiences. The participants' narratives that will support the themes were presented. Safeguarding the confidentiality and anonymity, the names of the participants were changed.

The effect of the diagnosis

Initially the effect of the diagnosis was the first thing that the parents encountered. Parents in the study felt empowered as they were able to label and term their children with autism. The child's diagnosis has made the parents to experience a sense of relief because parent's lack of knowledge about their child's behavior was solved by getting their children diagnosed. Knowing their child's disorder, the parents felt at ease as they now know how to deal with the situation. Although the diagnosis has lessened their burden, the parents felt that it would add sorrow and that the meaning of their life would change. It also appears a number of emotions such as shock, disturbed, denial and sympathy.

Some of the reaction shared by the participants was: *"I was informed by the doctor that my son is suffering with autism till then I'm unaware to understand what autism is? It was only during*

the process of my son's treatment that I could understand what autism is. In fact it was a feeling of shock and sympathy but also a sense of love and affection for my son. But, the diagnosis has made easier for me for I now know what I am dealing with". (p2)

"My son was 2 or 3 years of age where the doctor told me that my son is suffering from a disorder called autism, which was the first time that I heard about such term. I was unclear and didn't know what autism is. I was scared and confused as this term is so new to me. Now that I know what is happening to my son, I need to have patience, love and acceptance in raising him. It is interesting now to work on something that I know". (p1)

3.2. Child's behaviour pattern

The parents participated in the study reported that their son's behavior was relatively challenging for them as care giver. Most of the parents experienced their children having as poor emotional attachment, they sometimes exhibit temper tantrum and further shared that their son's failure in their basic motor skills, lack in social skills, extreme aggression and failure to explain their wants has posed difficulties and has also add to their parental frustration. In addition, lack to follow parental instruction was also reported in the study. The parents noted that their experience as caregiver is challenging and stressful. Parents participating in the study reported to experience a number of emotions like frustration, anger, temper tantrum towards their children (with Autism). Fathers in the study stated that their son's disorder has really changed their behavior towards their son and sometimes felt that they lack in their role as a care giver. In addition to this, the parents felt that caring a child with autism challenged their patience as care giver.

Some of the experiences shared by the participants were:

“Paul always climbed the fence of our house if I don t take him out, he doesn t understand what dangers lies beneath and he just continues to do so. You know it is very difficult to handle”. (p2)

“You know, umm; when he gets aggressive he would love to scratch the walls and the entire rooms with a pencil. He won t listen but keeps on doing it I feel this is very difficult to handle”. (p6)

“My son would throw things here and there (Angry look) I use to be very mad at him and I would not talk to him for hours”. (p4)

3.3.Daily life style

Most of the parents especially the mothers reported their everyday life as a day at home.

The parent s points out that it has always been a hectic day for them and they consider it to be a habit and started living with it. The parents experience a lot of changes in them partly their personal space and everyday living has been impacted by their roles as caregiver. The study reveals that mothers spent most of their time at home as compare to the fathers.

“It s always a hectic schedule I should say, umm; headache, I sometimes behave in an ill-mannered. I get frustrated and angry when I don t finish my work. (p3)

“I m very busy that I even forget to eat my food I think sometimes I have also forgotten myself (laughing). But, you know this is my expected role so I m just giving my best on it”. (p2)

3.4.Marital relationship

Participants in the study has noted that the journey in providing

care to the child with autism has sometimes impacted the relationship with their spouse due to the failure in the responsibility and as such this experiences has affected their daily life. The participants points out that misunderstanding, conflict and frustration among the spouse has been a daily affair thing that creates havoc in the relationship. Caring a child with ASD sometimes affects their perception of their parenting roles when one is not performing the duties.

“My wife gets frustrated with me because I left her alone with the children for sometimes I got an urgent work to complete and there use to be a quarrel among us when I return back home and we stop talking to each other for days”. (p1)

“Sometimes there arise misunderstandings with my husband and we won t talk to each other because I feel that he failed in his role as a father”. (p2)

3.5.Responsibilities towards other siblings

Lack of responsibilities and attention towards other unaffected siblings is reported by the mothers in the study. There sometimes appears a feeling of guilt conscious among some of the parents for not giving proper or equal attention to the other children.

Some of the participants express their views as follows:

“My focus is more on him as I know that he needs more time as I understand that other children have the ability to take care of one-self but there comes a time where I sometimes feel guilty”. (p3)

“it s just that I deputed most of my time for him, sometimes I think I m being bias to my other children (upset face)”. (p5)

3.6. Coping with caring a child with ASD

Sharing of experiences was belief to have minimized the burden of most of the parents participating in the study. The findings suggest that these parents understand that when they communicate or share their experiences with other they felt that their burden is lightened. Further, the parents noted that they experienced exchange of knowledge especially when they happen to converse their experiences with their fellow parents. A sense of happiness and hope is noted by the parents when everyone listened to their experiences. Some of these parents participating in the study have expressed that sharing of experiences as caregiver helps them to grow stronger in terms of knowledge and motivation.

“Sharing the experiences especially with the one who undergoes through same experience is totally different as we learnt from each other through our experiences”. (p5)

“I love to share my experiences with Paul s teacher and sometimes among fellow parents. I learnt a lot from these sharing as I feel that we help to show each other and even get motivated”. (p1)

Discussion

The effect of the diagnosis reveals that accepting the diagnosis was difficult to the parents and this support various literature that reveals how parents or caregiver at the diagnostic stage are not in their position to accept their child being diagnose of ASD as found in (Mann, 2013; Bayat, 2007). The data further reveals that participants experiences emotional stress, shock and denial as also appeared in a number of literatures (Hartmann, 2012; Banach *et al.*, 2010; Gray, 1994; Benderix *et al.*, 2006; Bayat, 2007; Mann, 2013; Divan *et al.*, 2012) but at the same time the parents in the present study were grateful and relief to learnt what was happening to their children and see this as a positive sign to

avail treatment for their child s betterment and this findings is consistent in a studies conducted by (Martins *et al.*, 2007).

Caring a child diagnosed with ASD is a difficult and challenging task for which the participating parents in the study consider it to be a tough and a challenging journey. As reported, autistic children failure in basic social skills and motor skills, aggressive behaviors, failure to explain their wants and their temper tantrum is a challenging experience expressed by the parents as also describe in various literatures by (Cashin, 2003; Cullen & Barlow, 2002). Further, the study also found that the parents sometimes experienced frustration and exhaustion as also described by (Cashin, 2003; Mann, 2013; Martins *et al.*, 2013). The autistic children inability to express about their ill-health, their needs and the lack of emotional expression enables the parents to have a negative perception about their parental role and the findings is found to be consistent with some literatures (Martins *et al.*, 2013; Cullen & Barlow, 2002).

It appears that the mothers of children with ASD participating in the study considered their everyday life as a day at home and the mothers experiences shows that the affect of having a child with ASD has negatively impacted the social life amongst the mothers as also highlighted in other studies on parenting children with ASD (Gray, 2002; Bashir, 2014).

Some of the parents participating in the study experienced to have encountered changes in their relationship in some way or the other with their spouse; these findings were found to be consistent to compare with previous literatures by (Gray, 2002; Bayat, 2007; Greeff & Walt, 2010). It also appears from the study that misunderstanding and frustration has been identified as a daily affair. Lack of responsibilities towards other siblings appears to be a sense of guilt feelings and biasness to the other children (Hartmann, 2012).

Sharing of experiences with others allow the participant to cope with the situation especially with their fellow parents who also raise a child with ASD, they are motivated as they exchange knowledge and ideas in order to improve their skills and responsibilities as caregiver. Parents in the study also expresses that when others listens to their experiences, it appears that these participating parents experienced to have grown stronger day by day as a caregiver.

Conclusion

Realizing the experiences of parents caring a child with ASD, this study was conducted with the aim to capture the meaning of experiences shared by these participants. A difficult journey for most of the parents as they were anxious and worried about their child s lack in development but then the diagnosis somehow has brought a sense of relief as they were able to term and label their children with some disorder. Parents felt that finally they are dealing with something that they know. Child s behavior appears to be a challenging task to manage. The study hoped that its finding will provide necessary and valuable information and bring together all professionals to keep a close contact with parents in order to promote effective care and support for children with ASD and their parents.

Limitation

Parents included in the present study were very small in number taken from a specific geographical area that may not represent all the parents caring a child with autism.

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Community Based Participatory Approach in setting up Community Mental Health Programme in Meghalaya India, with particular reference to enhance family supports system for Schizophrenia in Meghalaya, India

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Abstract

According to the World Health Organization, schizophrenia is the second highest contributor to overall burden of diseases, behind cardiovascular disease. The impairment caused by schizophrenia limits the ability of the sufferers to remain independent in various domains of psychosocial functioning. Patients with schizophrenia, therefore, require long-term support and care which may become burdensome to their caregivers.

A mixed method approach was used in the research. In this present study, the research starts with a discussion with the local leaders to identify key informants; followed by village meetings to select the Barefoot Counsellors for the household survey, an in-depth interview with the 20 caregivers and finally a presentation of the findings was made to the village advisory committee. Tools used for checking the level of burden includes ‘Zarit Burden Interview’ and self-administered questionnaires. Two FGDs were conducted, one with the caregivers and another with the women council.

The result of the study indicates that caregivers do express high burden in financial domain. At the focus group discussion, both

groups recommended that an awareness programme to educate the public on the disorder to reduce stigma and enhancing the support system.

These findings highlight the need to provide community-based services and formal comprehensive supportive framework to cater for the needs of patients with schizophrenia and their caregivers. Further studies are needed to confirm these findings and to develop interventions targeted in alleviating the burden on caregivers of patients with schizophrenia

Keywords: Schizophrenia in Meghalaya, Community Mental Health in Meghalaya

Introduction

According to the World Health Organization, schizophrenia is ranked as the second highest contributor to overall burden of diseases, behind cardiovascular disease (Murray & Lopez, 1996). About 24 million people world - wide suffers from Schizophrenia. The point prevalence of Schizophrenia is about 0.5 – 1%. Schizophrenia is prevalent across racial, socio – cultural and national boundaries. The incidence of Schizophrenia is believed to be about 0.5 per 1000 (WHO, 2001). The original name for this illness, “dementia praecox,” was coined by Emil Kraepelin, a German psychiatrist in the late nineteenth and early twentieth century.

Schizophrenia in Indigenous population

A recent study of the burden of disease among Indigenous Australians showed mental disorders caused 15.5% of the total disease burden experienced by Indigenous Australians; with anxiety and depression, alcohol dependence and harmful use, and schizophrenia contributing more than three-quarters of this burden

(Vos, Barker, Stanley & Lopez, 2007). Asian Americans and Pacific Islanders have the lowest rates of utilization of mental health services of any ethnic population. This may be attributed to cultural stigmas and financial shortcomings (Sherer, 2002).

Some African Americans may view mental illness has a form of punishment or as “spells” being cast upon wrong doing. The onset and the subsequent treatment may be perceived as a disgrace and may suggest the inability to handle responsibilities and threaten an African American woman’s position/role of mother (Amankwaa, 2003).

Family Support

In Asian cultures, like many other cultures, family members generally do not institutionalize members. They care for them in the home. According to Bae and Brekke (2002), Asian families are more likely to accompany the schizophrenic patient on clinic visits and to actively participate in treatment decisions, therefore, they may be involved in decision-making with the patient.

The family factor is one of the psychosocial factors that affect the clinical course and outcome of schizophrenia including its recurrence. Studies have shown that family and professional support plays an important role in preventing rehospitalizations and in improving quality of life of patients with schizophrenia. Activities such as, bathing, eating, cooking, dressing; taking drug, and checking up were help by caregivers.. However, when care is provided for longer time, family caregiver may experiences the burden that leads to negative consequences.

The burden of schizophrenia on caregivers

Family caregivers of persons with schizophrenia and other disorders experience high levels of burden. Caqueo-Urizar and

Gutiérrez-Maldonado (2006) conducted a study on forty-one relatives of patients with schizophrenia by using Spanish versions of the Zarit Caregiver Burden Scale. The results shows that all caregivers show a very high degree of burden, especially mothers, older, with low educational level, without an employment and who are taking care of younger patients.

The treatment goals for the moment are to identify the illness as early as possible, treat the symptoms, provide skills to patients and their families, maintain the improvement over a period of time, prevent relapses and reintegrate the ill persons into the community so that they can lead as normal a life as possible (Rössler et al, 2005).

The need for other social support

In some places, staff from a local community mental health center can evaluate an individual's illness at home if he or she will not voluntarily go in for treatment (Brian Smith, 2006). Enhancing social support helps to reduce the burden among family members of schizophrenia patients. A person's support system may come from several sources, including the family, a professional residential or day program provider, shelter operators, friends or roommates, professional case managers, churches and synagogues, and others. Often, a person with schizophrenia will resist treatment, believing that delusions or hallucinations are real and that psychiatric help is not required. At times, family or friends or police may need to take an active role in having them seen and evaluated by a professional.

Community Based Participatory Approach

The aim of CBPR is to increase knowledge and understanding of a given phenomenon and integrate the knowledge gained with interventions and policy and social change to improve the health and quality of life of community members (Israel, 2008). In CBPR

projects, the community participates fully in all aspects of the research process (Minkler and Wallerstein, ed., 2008). CBPR encourages collaboration of "formally trained research" partners from any area of expertise, provided that the researcher provide expertise that is seen as useful to the investigation by the community, and be fully committed to a partnership of equals and producing outcomes usable to the community.

Towards the end of the article on Improving Care for Older Person with Schizophrenia through an Academic- Community Partnership by Lindamer Improving Care for Older Persons with Schizophrenia through an Academic-Community Partnership Improving Care for Older Persons with Schizophrenia through an Academic-Community Partnership et al (2008) shows how the partnership between an academic research center and a large public mental health system received high ratings on the quality and the dedication of those involved in the collaboration and on innovative problem solving. This partnership had successfully evolved from two separate and complex organizations to a joint collaboration with shared goals.

Schizophrenia in Meghalaya

A psychiatrist at Meghalaya Institute of Mental Health and Neurological Sciences informed that majority of the inmates are suffering from schizophrenia, he lamented that lack of awareness among the families about schizophrenia and other mental illness has worsen the conditions of many patients. Ignorance about the illness among many families has also forced some patients to make the Institute their home.

The researcher found no research or documentation undertaken to ascertain the prevalence of schizophrenia in Meghalaya.

Problem statement

The World Health Organization (WHO) states caregiver burden as the “the emotional, physical, financial demands and responsibilities of an individual’s illness that are placed on the family members, friends or other individuals involved with the individual outside the health care system” (WHO, 2005). Highlighting the changing paradigms in family care and support, weakening identities, social stigma, low self-esteem, erratic behaviour, social boycott, community support, societal pressure and disappearing joint families, it is imminent that the need for an established support system becomes paramount. Also family support is poor due to poverty, ignorance, misconceptions, stigma and lack of available caregivers. The support system thus established would help to provide the necessary care in today’s disintegrating families, motivation through interaction, and acceptance by the society to prevent alienation and engaging the patients in various community related activities.

Objectives :

General: To determine the steps involved in setting up a Community Mental Health Programme with particular reference to enhance the support system for schizophrenic patients.

Specific:

- i. To recruit and train people of the community in identification and recording of the mental ill in the community
- ii. To develop a network of stakeholders in the community to help with the Community Mental Health Programme
- iii. To identify potential intervention, techniques in the community for the management purpose.

Scope

Schizophrenia is a leading mental health disorder in Meghalaya, and this research will help to strengthen the family support system in rural and urban areas through other support systems like, church, youth or women’s organization, NGO’s, etc. It will also help to identify how the national health system can be geared to provide necessary technical, medical and rehabilitative facilities to the families caring for patients with schizophrenia.

Operational definition

Schizophrenia- People with schizophrenia have an altered perception of reality, often a significant *loss* of contact with reality (American Psychiatric Association, 2000).

Caregiver- A caregiver may be a family member, a friend or an employee of a patient or of a nursing or other type of facility or an employee of any agency responsible for providing care.

Community based participatory research- is a partnership approach to research in which all partners (community members, organizational representatives and researchers) contribute expertise and share decision making and ownership.

Epidemiological aspects of Schizophrenia

Schizophrenia is a psychiatric disorder involving chronic or recurrent psychosis. It is commonly associated with impairments in social and occupational functioning (DSM-V). Schizophrenia occurs throughout the world. The prevalence of schizophrenia (ie, the number of cases in a population at any one time point) approaches 1 percent internationally. The incidence (the number of new cases annually) is about 1.5 per 10,000 people (McGrath et al, 2008). Slightly more men are diagnosed with schizophrenia than women (on the order of 1.4:1) (Abel et al, 2010), and women

tend to be diagnosed later in life than men. There is also some indication that the prognosis is worse in men (Grossman et al, 2008).

A number of risk factors have been associated with the development of schizophrenia, including living in an urban area (Krabbendam & Van Os, 2005) immigration (Werbeloff et al, 2012), obstetrical complications (Clarke et al, 2006), and a late winter-early spring time of birth (perhaps reflecting exposure to influenza virus during neural development). Advanced paternal age at conception has been associated with increased risk of schizophrenia in epidemiologic studies (Miller et al, 2011).

The course of schizophrenia, from early prodrome through to later outcome, is influenced by social variables, including socioeconomic position and marital status (Agerbo et al, 2004). The individual who eventually is diagnosed with schizophrenia is more likely to be single than others, and more likely to be unemployed than others. Recent studies from Scandinavia suggest that, if anything, the parents of persons with schizophrenia are likely to come from a higher, not lower, social position (Byrne et al, 2004). Family functioning of persons with schizophrenia differs depending on the course of the illness and presence/absence of schizophrenia in the family history (Dadiæ-Hero et al, 2013)

Patients with schizophrenia experience higher mortality rates than the general population, especially due to the suicide. Most patients with schizophrenia who commit suicide are likely to be young and males, with a higher risk around illness onset and hospitalization periods. Suicide risk is associated to psychotic positive symptoms, affective symptoms, depression and substance abuse (Gómez-Durán EL, 2012).

CBR in schizophrenia.

Lopez et al. (2000) conducted a study in the Philippines and used a qualitative approach of audit where records were reviewed, in-depth personal interviews were conducted with key informants and focus groups discussions were held. It was found that the CBR programme was perceived as important and accessible. The clients and their families were satisfied with the services and they were willing to help in the continuation of the programme.

A study was done in India with persons suffering from chronic schizophrenia it was found that the CBR model was more effective in reducing disability and within this group the compliant group had better outcomes than partially, or non-compliant individuals (Chatterjee et al., 2003).

Care-giving for persons affected by schizophrenia-Issues and Constraints

Possible support for home-cared schizophrenic patients and their families was investigated on Tsushima, one of the many isolated islands in Japan. Psychotic symptoms of schizophrenic patients were closely related to the mental state and QOL of their families. Family support was significantly correlated with hardships of family life caused by living with the patient (HF) and empathic attitude of the family toward the patient (EA). Moreover, the family support system was shown to be related both to the psychotic symptoms of the patient and the mental state of the family (Hamada et al, 2003)

A review on the burden of Schizophrenia was done by Awad & Voruganti (2008). The burden of care can be conceptualized into two distinct components (objective and subjective). Objective burden of care is meant to indicate its

effects on the household such as taking care of daily tasks, whereas subjective burden indicates the extent to which the caregivers perceive the burden of care. Several studies examined the role of gender, and reported that relatives of male patients with schizophrenia frequently experience more social dysfunction and disabilities than those of female patients.

Training for caregivers

Caregiver could benefit from various community-based programs such as removing stigma associated with mental illness and provision of better mental health facilities. Family education programs should help caregivers to improve their coping strategies (Raguram et al., 2004).

The Institute of Mental Health (2013) in their training for caregivers of schizophrenia include topics such as: Causes, symptoms and treatment options for Schizophrenia, common issues, concerns and challenges faced by caregivers, ways they can help their loved one in their recovery process, effective communication skills, skills & problem solving strategies to handle crisis and relapses, managing caregivers fatigue and effectively care for themselves in their caregiving journey and information and community resources for yourself and your loved ones. According to Kalra et al.(2004), training for caregivers of patients after stroke in basic nursing and facilitation of personal care techniques reduced costs and caregiver burden and improved psychosocial outcomes in caregivers and patients

Support systems for managing schizophrenia

Research has shown that a family with a schizophrenic patient does suffer from network contraction and condensation, which in turn, increases the vulnerability of the family to stressors due to lack of social support (Lipton et al., 1981). Families with fewer

or less available social supports outside the immediate family probably would have a lower tolerance for stress and deviance within the family (Brown et al., 1972; Vaughan & Leff, 1976). Thus, family members without social supports were assumed to be family members who were also high in expressed emotion (Anderson, Hogarty, Bayer, & Needleman, 1984).

Nevertheless, the importance of maintaining contacts outside the immediate family continues to be stressed for three reasons. First, social contacts can be useful as temporary distractions from experiencing the pain of the illness, as well as being of possible use in providing general support and recreation to help occasionally relieve the tensions of family members. Second, having social contacts can make it easier to divert the concentration of too much energy and attention on the patient. Third, social contacts can help family members in times of crisis by providing instrumental and practical support. Giving encouragement and providing these explanations may help to motivate family members to reestablish some of these vital links.

Community-Based Participatory Approach

The research process commenced and ended with a meeting attended by village leaders and advisory committees in the selected villages.

- a. Initial Meetings with Village Leaders to get permission.
- b. Village Advisory Committee meetings (to identify BFC for household survey).
- c. Meeting and training of the BFC's.
- d. Final Meeting with the Village Leaders (Presentations of finding and possibility of developing a CMHP)

Selection of Sample villages for the study:

- a. Random selection of five villages from Mawryngkneng Block, East Khasi Hills District
- b. Caregiver of patients diagnosed with schizophrenia from Wellspring Social Welfare Society, Mairang and San-ker Rehabilitation Centre, Mawlai for more information since the previously selected village has few cases of schizophrenia.

Data Collection Tools:

The tools that were used for the collection of data:

- a. Interview schedule for the village headman and key informants was developed to find out viewpoints, willingness to help and the steps to set up Community Mental Health Programme.
- b. Interview schedule was use for the Household Survey: the variables include; demographics of respondents, knowledge of mental illness.
- c. Zarit Burden questionnaires was used on the caregiver to check on the burden level in dealing with schizophrenic patient, the need of CMHP and the requirement of developing a CMHP.
- d. Primary Data Collection through Household Interviews.
- e. Qualitative and Quantitative methods were used to collect data.
- f. Focus Group Discussion (FGD): the variables include; caregiver of schizophrenic patients and Women's Organization, steps in developing a CMHP, the resources required, the using of the available resources for the CMHP.

Data Management and Statistical Analyses:

The data were managed using the word document file and excel sheets document. The data were statistically analysed using the average and percentile statistical tool.

Findings:

Household Survey:

Thirteen percent respondents accept the prevalence of mental illness, while 86.5 % are not aware of it. 61% have knowledge on Alcoholism, 10.8% on depression, substance abuse and mental retardation. While on Epilepsy (4.32%), and only 1.08 % have knowledge on schizophrenia and Anxiety disorder only 0.5%.

Burden on the caregiver

Based on the Zarit Burden Interview 70 % (14)of the primary caregiver scored between 41-60 which interpreted as moderate to severe burden and 30% (6) scored 21-40 which describe as mild to moderate burden. The family express high burden on financial domain where they said “hab shim da ka ram nakibriew” (loan), “hab die lutkisiyarkisniang” (selling of livestock) to spend on the patient's treatment, disruption in household routine, leisure activities, family interaction social life, physical health and mental health (strain/tension/sadness/anger/frustration).

Knowledge about the illness

The respondents have little knowledge or no knowledge at all about the symptoms of schizophrenia. According to the caregiver the causes of schizophrenia are- not taking care when the patient was sick, evil spirit, inherited, problems in life, life events, depressed due to skin disease (vitiligo), revival, alcohol abuse, when the patient kept to themselves and don't share with others.

Knowledge on the types of treatment that can help the patients, the caregiver knows only medicine and the others they said counselling, vocational training and other activities at home (household chores, gardening and livestock rearing).

Need of the family

During the interview the caregiver mention that provision for basic need (food, money) was difficult since they have to spend a lot on the treatment of the patient. They said that they need assistance in basic function like looking after the home, child care. They also said that they need help in managing the affected member in physical health, self-care, alcohol/drugs, safety of self (suicidal attempt) and others (harm or beat his or her family members), daytime activities and psychological distress (such as misery, resentment, hostility, boredom, confusion, fears and anxieties) that the patient may encountered.

Social support

The caregivers expressed the need of an organized support system or group in the community for

identifying the symptoms at the initial stage, providing necessary assistance and help in finding the right method of finding cure, management of the illness instead of visiting fake or traditional healers, witchcraft and harbouring superstitious beliefs.

Family Responses to the illness:

In the initial stage when the caregivers would learn that their relative had schizophrenia they were depressed and confused as they were not aware of where to go for treatment. Firstly they would seek help from fake practitioners' viz. traditional healers, church leaders and general physician and lastly a psychiatrist. Their expectations from the patient, the majority of them replied

“Ban tip ban sumar ialade” (be able to take care of themselves) while other replied “Ban trei ban ktah” (to perform their daily task).

Effect of illness on the affected member

Prior to being ill, the patients would be very active in the community and family as well. However, the patients now require demonstration, supervision and help of the caregiver to perform all tasks. More so, they would be able to be tasked with lighter work, as they become easily disoriented and needs constant monitoring.

Feedback for a Community Mental Health Programme:

The importance to conduct an awareness programme on mental illness and this will help make people aware that not all are “pang ksuid” (suffering due to witchcraft) and it will reduce the stigma against the mentally ill. In the community mental health programme services like counselling, physical health and mental health could be included. They also mention the training of the caregiver and other who would like to volunteer. They express the importance of involving the other members of the village administration such as youth and women's wing together with the Dorbarshnong. The community leader recommended conduct of basic skills in counselling to the village committee.

Key Informants In-depth Interview:

Shizophreniaprogress because the person is unable to cope and accept his /her situation, and also, because the caregiver has limited knowledge about the illness or they just choose not to listen even when they (mental health worker) tried to explain to them. They said that when the patient doesn't listen to them (caregiver), they would just leave them to themselves. After 3 or

4 months the patient was brought back to the hospital. When they enquire about the current situation, they were informed that the patient had stop taken medication.

The psychiatrist even said that there's limited knowledge among other health practitioners. They refuse to admit the patient in the CHC/PHC as they called them "Bieit" (mad people).

To start with CMHP, they said that first we need to get permission from the headman, then contact concern CHC/PHC and to include the ASHAs and Aganwadi who may help in identifying. They said that the role of the mental health worker is to educate the family about schizophrenia, chronic of the disorder and importance of drug compliance. Suggestion was given that at least one trained nurse in psychiatry should be in the CHC

Focus Group Discussion (FGD):

During the FGD all the members agreed that a Community Mental Health Programme would be very beneficial for the community at large. Suggestions like collaboration and approval from the village committee, awareness programme on symptoms of schizophrenia should be included to sensitize people. To sustain for such programmes, and for this the members comments that if the Durbar shnong would allocated funds for conducting any mental health programme (collecting contribution for conduct of the same from the households in the village in the lines of contribution towards village development) and if there's an emergency they usually collect among the members of the group.

According to them the best possible way is to work with the identified family and they suggests to train retired people providing help for the mentally ill since they are more free comparing with the other. Lastly, to conduct an awareness programme for the

women in the community together with the beneficiaries and their family members

Final Village Advisory Committee Meeting:

Suggestion was given to start the programme first by training people and also to include the BFC in the training. Other programme that can be included is awareness programme on Alcoholism and its affect and medical camp.

Model of Community Mental Health Programme to enhance support system for caregiver:

Result from the present study suggests that it is possible to set up CMHP. The first programme is a training program for the selected individuals, caregiver of mentally ill and the BFC to identify and refer to health services and counsel or support the family and to do follow-up. These members can provide basic counselling for acute mental health problem and psycho-educate the family members and setting up of group-based counselling as well as support groups for the caregivers and their family.

To make the programme sustainable, networking with other agencies is important. PHC and other health worker, church, youth and women council can be sensitized through various programmes in the community. Financially the community can have its own fund for the programme or to apply scheme from the government for the mentally ill.

Feasibility of CMH programs/ Role of Community Mental Health programme to support caregiver of schizophrenic patient:

Many researchers in Western countries noted that family caregivers not only provide the basic needs of care like long-

term assistance of housing and financial aid, but they also serve as agents of the rehabilitation process in the community mental health services (Hsio&Van Riper, 2010). They found that the mental health professionals made a sustained attempt to develop a partnership with service users including mental health service users and their families (Webb, 2008). However, many studies in Western cultures found that the family caregivers were vulnerable in providing the ongoing care and support demanded by their family members. These caregivers also struggled to manage unexpected situations, especially in societies that provide limited resources for mental health (Roick et al., 2006).

Care of persons with schizophrenia can be provided at community level, with active family and community involvement (WHO, 2014). The World Health Organization press release (2007) states that community mental health services are more accessible and effective, lessen social exclusion, and are likely to have less possibilities for the neglect and violations of human rights that were often encountered in mental hospitals.

Accessibility to mental health care of people with longer-term mental disorders is much better with community-based services than with the traditional psychiatric hospitals(Thornicroft&Tansella, 2003). Studies comparing community-based services with other models of care consistently show significant better outcomes on adherence to treatment, clinical symptoms, quality of life, housing stability, and vocational rehabilitation (Killaspy& Almeida, 2011).

Importance of CBR in developing CMH program

This present study shows the importance of CBPR through the involvement of the local heads, women council and the respondents in the household survey. According to the findings

all the respondents agreed the importance to have a community mental health programme. Participating in an evaluation from start to finish can give stakeholders a sense of ownership over the results. Recognizing local talents and expertise builds confidence and pride in the community, and among participants(Ann &Luluqisen, 2002).

Opportunities and Constraints in developing CMH among indigenous populations

In 2006, WHO estimated that 80 percent of the population in developing countries relies on traditional healing systems as their primary source of care. Creating alliances with traditional healers and incorporating their skills into national health care systems can help to combat both a lack of access and the distrust of indigenous people in the health care system (Pan American Health Organization, & The World Health Organization, 2006).

Historically, faith-based organizations have also served as an important gateway to services and care-giving for those living in poverty and in social exclusion. They have taken strong leadership roles in communities and provided job training, housing, economic development, educational support, meals and spiritual support to those in need.

Underinvestment in health care in the areas in which Indigenous people live is common due to their rural / remote nature (Tomei, 2005). The provision of health services is of poor quality in many developing countries, although the problem is more acute in areas inhabited by Indigenous populations. Service provision in these rural / remote areas is plagued by limited staff competency, noncompliance with evidence-based treatments, medication shortages, and poor staff retention. Geographical barriers prevent access to services provided to other populations due to distance, lack of affordable transportation and seasonal geographical

isolation. Even health care that is provided free-of charge has many costs associated with in practice, such as, accommodation, family care, medication and lost productivity (Canadian Coalition for Global Health Research, 2008)

In addition to issues with physical and financial access to care, the cultural barrier is the most complicated to overcome due to the lack of understanding of the sociocultural factors that influence the knowledge, attitudes and practices of health in Indigenous peoples (Pan American Health Organisation & WHO, 2006).

Pilot programmes in a few developing countries (e.g. India, Iran, Pakistan, Tanzania, Guinea-Bissau) have demonstrated the feasibility of providing care to people with severe mental illness through the primary health care systems by: appropriate training of the primary health care personnel; provision of essential drugs; strengthening of the families for home care; referral support from mental health professionals, and public education to decrease stigma and discrimination (WHO, 2014)

Other factors that might make CMH ineffective is the lack of social network, the traditional attitude toward dealing with the illness. The absence of financial incentives for community workers from the Village Health Teams also made them less effective in their work.

Role of BFC and Community –based Committees in CMH program

Community workers, like local head, Aganwadi, ASHA on establishing a rapport with the people of a village or community, often find counselling people to be major part of their work. According to Raja (2009) in his study Practice of Community Mental Health points out that diagnosis and prescription activities

may happen at primary health clinics but follow-up visits and supporting services often occur within the village or the home of the user. Being accepted as members of the community is a strength that can help them take on the role of a community counsellor.

CHW provision of peer-to-peer support for fellow community members may fill gaps in availability of traditional counseling services, and their participation as members of collaborative mental health treatment teams could increase patient engagement, leading to increased efficacy of care delivery (Collins et al, 1971; Dixon et al, 1998)

There is a broad range of activities: active case-finding of people with mental illness or epilepsy in their communities and refer them to the clinic. They also help set-up the clinic, ensuring that the venue is in order and supplies are on hand. The more literate community workers register service users and take down their family history. Following clinic visits, they conduct home-visits, during which they discuss the role of medication with users and carers and they check on the individual's overall progress, both in terms of health, livelihood and social integration (Basic Needs, Impact Report 2008)

The idea of using community workers to promote community health and empower individuals is not novel within the field of health, but it is innovative within global mental health. The field of HIV has long embraced community workers as an essential part of the treatment network. World Health Report 2004, which focused on HIV, devoted part of a chapter to the role of community workers. The concept of using community workers for treatment has more recently been referred to as task-shifting, referring to the shifting of certain responsibilities from health professional to lay-workers..

Community workers are a pillar to mental health and development interventions. While they have an important role to play in promoting mental health and raising awareness of mental illness, their activities extend beyond that perimeter to include basic components of mental health treatment, such as case-finding, referral, follow-up and medication supervision. Moreover, community workers welcome bio-psycho-social models of training and can serve as a complement or alternative to traditional healers. Thus, community workers form a much-needed additional cadre of human resources for community mental health in low and middle income countries. WHO 2004 has point out forcefully “Community health workers should not be viewed simply as local helpers who can temporarily take on tasks the formal health care delivery system lacks the resources to perform. They are not primarily a cheap way to deal with human resource constraints. Rather, community health worker programmes can and should be seen as part of a broader strategy to empower communities, enable them to achieve greater control over their health and improve the health of their members.”

Need based Counselling programs for stakeholders

Counselling is recognised as an effective tool to support people in the early stages of dementia and the carers that are struggling to cope with new responsibilities in their daily lives (Who, 2013). The need for counselling and support for care-givers stems from the significant amount of burden and distress that they experience. Once they take on the care-giving role, these individuals often struggle with negative effects in their health, finances, psychological well-being, and relationships (del-Pino-Casado et al., 2011). According to Lopez-Hartmann et al. (2012) intervention at the individual caregivers’ level can be beneficial in reducing or stabilizing depression, burden, and stress and role strain. Group

support has a positive effect on caregivers’ coping ability, knowledge and social support.

The aim of the study conducted by Björkdahl et al. (2007)was to evaluate whether counselling in the home setting reduces the caregiver burden and the findings suggest that information and counselling have a positive effect both on patient outcome and caregiver burden.

Logistics and Resources for an efficient CMH program

The inclusion and mainstreaming of mental health issues more explicitly within other priority health programmes and partnerships with those dealing with education, employment, disability, the judicial system, human rights protection, social protection, poverty reduction and development, are important means of meeting the multidimensional requirements of mental health systems and should remain central to leadership efforts of governments to improve treatment services, prevent mental disorders and promote mental health.

According to MHAP there should be collaboration with stakeholder. Motivate and engage stakeholders from all relevant sectors, including persons with mental disorders, carers and family members, in the development and implementation of policies, laws and services relating to mental health, through a formalized structure and/or mechanism. Build the knowledge and skills by introducing mental health into undergraduate and graduate curricula; and through training and mentoring health workers in the field, particularly in non-specialized settings, in order to identify people with mental disorders and offer appropriate treatment and support as well as to refer people, as appropriate, to other levels of care.

Conclusion

In this present study, the researcher were able to identify the burden on next-of-kin of schizophrenic patients and it was found that majority of caregivers have moderate to severe level of caregiving burden. There is a need to identify and build on strengths, resources, and relationships that exist within communities and contribute to the ability of community members to work together to improve health within the community. Involvement of Community partners and stakeholders in focus groups, interviews, and meetings is essential in planning, implementing and evaluating various activities. Educational efforts like awareness programme will increase the understanding of local people's knowledge of mental illness and what can be done to help their family members who have developed mental illnesses.

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No one left behind

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Introduction –

“No one left behind” is a new ethical imperative of new development agenda envisioning inclusive world in 2030. For Bethany Society this is a clarion call to be relevant and to measure its impact against internationally agreed upon indicators. It is a call to “Think Globally and Act Locally.” It is a call to go back to our roots and be true to our vision. It is also an encouragement and support that the Bethany Society thrust towards inclusion through mainstreaming strategies adopted to “Make The Right Real”, are on the right track and should be followed with even more rigor and vigor.

Bethany Society is an organization that aims at building an inclusive; rights based society for all persons with disabilities, including persons with mental illness. It pursues this through *mainstreaming* and since 2013 it has started a Mainstreaming Unit that endeavors to converge all activities to pursue this strategy. What is mainstreaming? Mainstreaming is about challenging discrimination. It involves supporting basic services to ensure that persons with disabilities are included, and enjoy equality of access to those services. It pertains to universal mainstream services such as education and health, which are not particularly focused on disability. (UNRWA.Org.). An organization

has adopted a twin- track approach which implements both disability specific programmes and disability inclusive to change systems so that they include.

Background:

As per WHO figures and confirmed by the experience of Bethany Society over its 20 years of interventions in the disability sector nearly 25% of the population will at some time in their lives be confronted with Mental Health challenges. Yet 90% of persons with Mental Illness do not have access to quality medical and non-pharmacological interventions. Their lives are characterized by isolation, lack of intervention and stigma and their families often sucked into a cycle of poverty.

Mental health is a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.

Community mental health (CMH):

- a. CMH is a strategy of community development that furthers the mental health of all community members through promotion of mental health and prevention of mental disorders.
- b. CMH services provide accessible, affordable, acceptable and quality mental health care in the community for people with psychosocial disabilities aiming at their social integration.
- c. CMH care is implemented with the active participation of service users, their families and communities together with health, education, social and employment services

In response to the above situation and considering the woefully inadequate services available, Bethany Society initiated a Community Mental Health Programme across Meghalaya. The goal of the project:

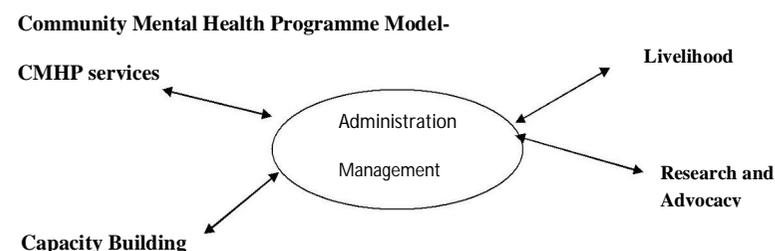
To promote mental well-being, prevent mental disorders, provide care, enhance recovery, promote human rights and reduce the mortality, morbidity and disability for persons with mental disorders, in community settings (*Mental Health Action Plan 2013-2020, WHO*).

The main aim of the project is to provide a Comprehensive Community Mental Health in pockets of Meghalaya leading to mainstreaming of Mental Health. The project is being integrated into the Community Based Rehabilitation (CBR) programme in 7 districts of Meghalaya, 15 blocks and 700 villages through the 6 NGOs/ CBOs and 4 units of Bethany Society who have been collaborating with the lead partner Bethany Society.

Community-based rehabilitation (CBR) was initiated by WHO following the Declaration of Alma-Ata in 1978 in an effort to enhance the quality of life for people with disabilities and their families; meet their basic needs; and ensure their inclusion and participation. While initially a strategy to increase access to rehabilitation services in resource-constrained settings, CBR is now a multisectoral approach working to improve the equalization of opportunities and social inclusion of people with disabilities while combating the perpetual cycle of poverty and disability. CBR is implemented through the combined efforts of people with disabilities, their families and communities, and relevant government and non-government health, education, vocational, social and other services (<http://www.who.int/disabilities/cbr/en/>). These CBR guidelines are relevant to all people with disabilities, including people with mental health problems – many of the issues affecting people with mental health problems are similar to those affecting any other impairment group and therefore other components should be referred to. Therefore, the Mental Health is being mainstreaming into CBR programme.

Objectives

1. Capacity building for field staffs on promotion of community mental health programme. 2. All identified persons with mental health challenges in 600 villages across Meghalaya have access quality services through Comprehensive Community Based Rehabilitation programme leading to inclusion. 3. Persons with mental illness and their families have access livelihood opportunities and support for coping with their challenges. 4. Promotion, prevention, and treatment of Mental Health have been mainstreamed into the National Health Mission.



Status of the programme clients that have been identified covered under the CBR Programme as on September, 2017

Serial No.	Districts	Block	Villages	Intellectual Impairment	Mental Illness- (Severe & Common Mental Disorders)	Epilepsy & others
1.	West Khasi Hills District	Mairang Block	86	105	59	92
2	West Khasi Hills District	Mawthadrashan Block	30	81	45	30
3	West Khasi Hills District	Nongstoin Block	30	55	74	45
4	South West Khasi Hills District	Mawkyrwat block	37	41	108	30
5	East Khasi Hills District	Mawsynram Block	30	30	90	30
6	Ri Bhoi District	Umsning Block	30	70	105	45
7	West Jaintia Hills District	Laskein Block	30	58	110	60
8	West Garo Hills District	Betasing Block. Dalu Block Rongram Block Selsela Block Zikzak Block Gambegre Block	37 40 70 36 70 60	150	170	140
9	South Garo Hills District.	Gasuapara Block Bhagmara Block	37 77	60	80	50
	TOTAL		700	650	806	522

Impact :

With the advantage of the support from The Hans Foundation it is evident that in the pockets where the programme is being implemented Mental Health and the challenges that persons with Mental Illness are facing has been mainstreamed. The lives of over 3000 persons with Mental Illness and their families have been impacted. Further 1534 clients are receiving direct professional services from Doctors at the Block Level. These are being followed up at the household level through the Community Based Rehabilitation (CBR) Field Workers at the household level. The training received by Field Level Staff has greatly enhanced the quality of services and has facilitated Social Inclusion and reduction of stigma. Adult persons with mental illness are members of Disabled Persons Organizations (DPOs), which consist of persons with disabilities from the different sectors, and Self Help Groups (SHGs) which gives them opportunities for advocacy and also access to livelihoods. Through the advocacy done collectively Persons with Mental Illness can avail of separate job cards under the NREGA scheme and also be included in SHGs under the National Rural Livelihood Programme. (NRLM)

All this would not have been possible without the collaboration of the partner NGOs and the local hospitals (Nazareth Hospital, Shillong; SANKER, Shillong; Ramakrishna Hospital, Shillong and Holy Cross Hospital, Shillong. Village Clusters (700 villages, 70,000 households) in 7 of the 11 Districts of Meghalaya have received basic awareness on Mental Health. The use of existing NGO partners has greatly reduced the time it takes to reach out to persons with mental illness and helps in social inclusion and reduces isolation. On the occasion of World Mental Health Day, International Day of persons with disability, PwMI have been able to speak in front of audiences and share their stories.

Gap areas and challenges:-

- a. Partnership challenges (resistance from public health sector mental health specialists, health workers).
- b. Public health psychiatrist in the district is reluctant to issue disability certificate as they believe that disability is permanent state and as such a certificate could not be issued to someone who has been experiencing symptoms for a temporary period of time.
- c. Integration of mental health into primary health care services is still a question since majority of the health workers have not received adequate training on mental health issues. Most primary care physicians have insufficient training in the use of psychotropic medications and are reluctant to be responsible for the complete health care of the patients with mental health disorder. Therefore, most of the patients are mainly depending on our project.
- d. No core team to addressing the mental health risk factors for suicide, prevention of harmful substance abuse and needs of special group (for example adolescents) in the project areas.
- e. Motivating families and patients is one of the biggest challenges. Unrealistic result expectations of the families and clients after getting professional support.
- f. Some people still seek help from traditional and local healers.
- g. No helpline service is available to the public, to enable the patients and caregivers to reach the Counselors when they are in need of advice, psychiatric condition-related information or immediate support of the home visit team in crisis situations such as when a patient had relapsed.

Conclusion

It can be concluded that the CBR programme has become more holistic- addressing the mental health issues, needs of the most marginalized and victims of Human Rights Violation that are facing has been mainstreaming.

Impact of Mental Health Research In India

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Abstract

India is making rapid strides in a number of fields. It is fast becoming a major player in the global scene in view of its consistent rise in GDP and a vast resource in terms of trained manpower. However, it is still lagging behind in some of the important social and health indices. India is still placed at a lowly position of 130 in the UNDP's Human Development Index. India spends only 1% of its GDP on health, and share of mental health is miniscule at 1% of total health budget. It has been said that if nations have to prosper, they must invest in the mental capital of its citizens. When far too many demands are chasing a small amount of money, how do we determine where do we spend our precious money, or how do we set priorities in terms of service delivery, capacity building, and development and progression of scientific field. None of this can happen in vacuum. We have to have objective mechanism to judiciously spend the limited funds. Research is one such mechanism, whereby we gather data systematically to reach new results and conclusions. That Indian mental health professionals are engaged in research is apparent indicators such as Development of Training centres, Development of GHPUs, Launching of professional societies, Publication of journals, Funding agencies, Short term and long term studies, Multi-centred & collaborative studies, International collaborative studies and Phase II & Phase III drug trials. We have to examine if research in India is progressing in right direction; Is research

pursuing the right agenda? Is it examining the right question in right way? Are the results communicated to : policy makers, service providers, clinicians? Do these people apply these results for people who matter?

However, research in India is constrained by a number of factors, such as Research output is much smaller than the West, limited local scientific publications, local publications not easily available and is not indexed, research does not reach Western medical press, priorities of western press different, rigid attitude towards publications from developing countries, and constraints and handicaps of research workers. There are further limitations, viz, lack of funds, lack of trained technical support, lack of time, lack of training in research methodology, poor library facility, limited internet technology and availability, lack of publication opportunities, lack of desired impact, little dialogue between research and policy.

For delivering cost-effective mental health care, India has to build its research capacity. That is possible by increased capacity for delivery of care, increased capacity for research, a robust research agenda to inform, research agenda to support primary care, operational studies to test techniques and strategies for their effectiveness in local setting, and having collaborative programmes. There are many ways by which impact of research can be tracked: publications, impact factor, more research grants, more multi-centred collaborative work, changes in service delivery and interventions, programme and policy changes, training opportunities, and employment opportunities. Robust functioning of professional scientific societies is also a healthy index towards research. At this time, there are several professional bodies working towards mental health: Indian Association for Mental Hygiene, Indian Psychiatric Society, Indian Association of Clinical Psychologists, Indian Association for Social Psychiatry, Indian Academy of Child and Adolescent Mental

Health, Indian Association of Private Psychiatrists, and SAARC Association. India has been publishing some quality journals too, many of which are pubmed indexed: Indian Journal of Psychiatry, Indian Journal of Psychological Medicine, Indian Journal of Clinical Psychology, Indian Journal of Medical Research, National Medical Journal of India, Journal of Personality and Clinical Studies, Indian Journal of Social Psychiatry, Journal of Human Behaviour and Mental Health, Journals from each zone of the Indian Psychiatric Society. A number of funding agencies are now available to Indian scientists: Indian Council of Medical Research, DST, DBT, CSIR, World Health Organization, Ministry of Social Justice and Empowerment, Ministry of Health, UNODC, NACO, WHO and Pharmaceutical industry.

Key words: mental health research in India, mental health research

Introduction:

Research is defined as systematic gathering of data, information and facts for the advancement of knowledge. Research comprises creative and systematic work undertaken to increase the stock of knowledge, and use it to devise new applications. It is used to establish or confirm facts, reaffirm the results of previous work, solve new or existing problems, support theories or develop new theories for betterment of society. Research is an important component in understanding the interaction between health and disease, and the environment. It is essential for mitigating the suffering due to diseases in the society, and for developing preventing and promotional strategies in the society.

Why Mental Health Research is Essential?

Mental health research is critical to guide rational policy development, program planning and the provision of mental health services. Evidence-based action can reduce the social impact and

economic costs of mental disorders to tackle health inequity, to prevent disability and mortality, and ultimately to foster country development.

Research for Evidence Based Medicine

Research allows us to provide evidence for any decision making in practice of medicine. Following are the steps of evidences in order of hierarchy:

- a. Expert opinion
- b. Case reports
- c. Follow up Studies
- d. Narrative Reviews
- e. Double Blind Randomized Controlled Studies
- f. Systemic Reviews
- g. Meta-analysis

World Mental Health Report 2001

World Health Report 2001 by the World Health Organization was devoted to the state of mental health in the world. It drew attention to the state of mental health research in various countries, and constraints of research in developing countries. It stated very clearly that Research gap was too wide in developing countries, Mental health efforts in developing countries were based on evidence from high income countries, Research must be relevant to the needs of developing countries, and that relevant research done in a developing country should assist them in reducing burden of common and disabling conditions. Hence it pointed out clearly that research was essential for mitigation of burden of mental disorders in the society.

The Institute of Medicine Report, 2001 lamented the fact that Mental and neurological health in developing countries is not seen as part of mainstream public health. Experts feel that these countries lack the means to implement recommendations of research and reports. Very frequently, the research does not always reach its main target group that are decision makers. Consequently, policy, programme, and services do not reach target groups leading to poor development of mental health services.

Research Capacity for Mental Health in Low and Middle Income Countries

On average, LAMIC invest less than 1% of their GDP in research and development, compared to 2.3% in high income countries. Developing countries account for only 29% of world researchers, with a ratio of fewer than 0.5 scientists per 1000 population, in contrast to 2 per 1000 in developed countries. The low priority given to mental health research in these countries is one of the reasons for the lower ratio of qualified mental health researchers and lower research output in comparison to other non-communicable diseases. Compounding the situation is the “brain drain” whereby well-trained researchers leave their countries in search of better work conditions. LAMIC bear the brunt of the burden of multiple risk factors for mental disorders. These include violence, war, illiteracy, income inequalities, poor physical health, poverty, natural and human-made disasters and lack of access to mental health services. Violence against women and children especially in these countries is an important cause of disease burden in these groups. These groups are often excluded from the research agenda and service provision.

Global forum for health research helped correct the 10/90 gap through the Commission on Health Research for Development. Eighty five percent of world population lives in developing world,

while the total health budget is less than 5% of GDP. Mental health budget is less than 1% of total health budget. 10% of the health research budget is spent on 90% of the world health problems. Correcting this gap would result in growth and development, reduction in poverty, and increasing global security.

However, multidimensional efforts needed to change mental health at global level. Mental health research would play a key role to achieve this. Research generated information is essential to determine needs, propose cost-effective interventions, monitor process of implementation, evaluate the changes, explore obstacles and research generated information will enable better utilization of meagre mental health resources.

Peculiarities of India:

India is a land of contrasts. It is the second largest country in the world, has poorly organized and less regulated health sector. Health and social indicators remain unsatisfactory inspite of rapid growth in its GDP. Some of the important indicators are as follows:

- a. Human Development Index : 128th position
- b. GDP :Rs 46,93,602 Crores (\$1160 billion)
- c. Per capita income : \$ 1160
- d. Budget allocation on health : 1.39% of GDP; 2.11% of total expenditure (per capita expenditure on health: Rs 200)
- e. Population & doctor ratio : 60 per 100,000

Development of Mental Health Services

Mental hospital and custodial approach: India inherited mental asylums from the British in 1947, where the approach was custodial in nature, and not therapeutic. There were severe human rights violations.

General Hospital based Psychiatric Units : In 1950s onwards, the focus of mental health care shifted to the community, since it was felt that was more therapeutic, and also allowed the patient to live within the family settings.

Private sector: In the last three decades, mental health care also became available in the private sector. There are now private clinics, and private psychiatry hospitals within the community settings.

Community care: It has been an endeavour of health providers to make mental health care available in the community setting, since people living in remote areas of the country can ill afford to avail mental health services located in distant urban areas.

Rehabilitation units: A significant number of mental ill people continue to live in shame and isolation owing to certain deficits and disabilities left behind a severe mental illness. Rehabilitation of such patients is part of the holistic management.

NGOs: Non-government organizations are doing yeoman's service in getting people their rights, which are often violated. Such organizations are a major force to establish liaison with the government to achieve this goal.

Development of Mental Health Research

There is no doubt that mental health research is gradually taking off in India. It may not have a major impact on the global level, but at national level, its significance is visible. The following could be cited as evidence for progress of mental health research in India such as development of training centres, development of GHPUS, launching of professional societies, publication of journals, funding agencies, short term and long term studies, multi-centred & collaborative studies, international collaborative studies and Phase II & Phase III drug trials.

There types if research studies conducted in India in relation to mental health are psychosocial tests and research instruments, psychiatric epidemiology, phenomenology, prognosis & outcome, delivery of mental health services, psychotherapy, psychosocial factors related to mental health, psychopharmacology & clinical trials, child and adolescent mental health, drug and substance use disorders and disaster mental health.

The common themes that are undertaken for research are epidemiological studies, efficacious and cost-effective studies, locally relevant interventions, awareness programmes, stigma and discrimination, war, conflicts, and natural disasters, child and adolescent mental health, depression , epilepsy, suicide and self harm, HIV and AIDS and alcohol and substance abuse.

Problems of Mental Health Research

The problems associated with mental health research are research output is much smaller than the west, limited local scientific publications, local publications not easily available, not indexed, research does not reach western medical press, priorities of western press different, rigid attitude towards publications from developing countries and constraints and handicaps of research workers. Moreover there are lack of funds, lack of trained technical support, lack of time, lack of training in research methodology, poor library facility, limited internet technology and availability, lack of publication opportunities and lack of desired impact : little dialogue between research and policy.

Mental Health Research : Some Questions

Some questions that are asked in relation to mental health research are Is research pursuing the right agenda? Is it examining the right question in right way? Are the results communicated to : policy makers, service providers, clinicians? Do these people apply these results for people who matter.

Tracking the Impact of Mental Health Research

To track the progress of mental health research, one could examine the publications and their impact factor, more research grants, more multi-centred collaborative work, changes in service delivery and interventions, programme and policy changes, training opportunities and employment opportunities.

Professional Societies and Journals

The professional societies that promote mental health care and research in India are Indian Association for Mental Hygiene, Indian Psychiatric Society, Indian Association of Clinical Psychologists, Indian Association for Social Psychiatry, Indian Academy of Child and Adolescent Mental Health, Indian Association of Private Psychiatrists and SAARC Association.

There are a few journals that also publish mental health related research articles. These are Indian Journal of Psychiatry, Indian Journal of Psychological Medicine, Indian Journal of Clinical Psychology, Indian Journal of Medical Research, National Medical Journal of India, Journal of Personality and Clinical Studies, Indian Journal of Social Psychiatry, Journal of Human Behaviour and Mental Health and Journals from each zone.

The funding agencies that provide research grants for mental health are Indian Council of Medical Research, DST, DBT, CSIR, World Health Organization, Ministry of Social Justice and Empowerment, Ministry of Health and Family Welfare, UNODC, NACO and Pharmaceutical industry.

Recommendations:

In the light of the challenges facing the development of mental health research in the country, it is essential to raise awareness of importance of mental health, integrate with health research

systems, establish governance and monitor progress in mhr, formulate and implement mental health research priorities, increase funding for mental health research, invest in mental health research capacity strengthening, develop research networks and public private partnerships, consider cross-cutting issues affecting mental health and connect with information networks in health research.

Conclusion:

To conclude, for delivering cost-effective mental health care, India has to build its research capacity. This is possible by increased capacity for delivery of care, increased capacity for research, a robust research agenda to inform, research agenda to support primary care, operational studies to test techniques and strategies for their effectiveness in local setting, and having collaborative programmes. Robust functioning of professional scientific societies is also a healthy index towards research. Mental health research (MHR) is essential component to equity and development. India has made very little progress in MHR. The challenge is to develop strategies for MHR, need to review and strengthen the management of MHR, greater funds to be allocated to strengthen research, capacity and infrastructure and to bridge the gap between policy and research. There is also a need to sensitize researchers about usefulness of involving policy makers in their research and the need to sensitize policy makers about the importance of good mental health research.

Mental Health: A Priority

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Abstract

Mental Health is a major concern in India. It has been estimated that one in ten people in India have a mental health issue, one in twenty suffer from depression and 0.8% have a “common and severe mental disorder” (Duffy, Kelly; 2017). There is the presence of the “huge gap” or the “treatment gap”, in providing for the needs of the mentally ill in the society. Poor awareness and limited availability of resources puts pressure on the treatment process. The need for strengthening the health systems have been recognized so as to make them responsive to the changing health priorities and concerns. There is a lack of comprehensive and integrated systems approach towards mental health care, resulting in poor functioning or the absence of mental health care facilities and services (National Mental Health Survey of India 2016). WHO recognizes that the best way to improve people’s mental health is through integrated participation from various sectors.

Keywords: Mental health, integrated support for mental health, health institutions.

Mental Health Advocacy and Policy in Meghalaya

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Abstract

Mental health policy in India has improved significantly with changes in the PWD Act and more recently, the passage of the Mental Health Care Act in 2017. The first National Mental Health Policy was framed in the year 2014. Other states in the country such as Kerala and Karnataka have implemented a State Mental Health Policy. However, in the state of Meghalaya, there is very little progress in this sphere. There is a State Mental Health Authority which looks into mental health issues at the state level. Despite almost 50 years of statehood, the state does not have a State Health Policy, let alone one for mental health. Only two districts out of 11 are covered under the District Mental Health Programme. Psychiatrists are available in the West Garo Hills, West Jaintia Hills, RiBhoi Districts apart from East Khasi Hills (Shillong). The bulk of treatment services are concentrated in the capital, Shillong where there are two speciality mental health institutions; MIMHANS in the government sector and SAN-KER in the private sector. There are designated psychiatry beds in various government and private hospitals and deaddiction centres that provide rehabilitative services for those with chemical dependency, which are again concentrated in a few districts. Advocacy regarding the cause of mental health is a low priority in Meghalaya. The only organizations that take up this issue are SAN-KER and MLCU. These two organizations have public programmes and functions on various international days in order

to sensitise the public towards mental health care needs. Bethany Society has also of late been involved in advocacy and reaching out to the mentally ill in the community besides their main focus on physical disabilities.

This overview of the mental health scenario shows the stark reality in Meghalaya. There is a need to have a coherent and well thought out policy to deal with the challenges that the state faces. The policy should take into consideration the unique cultural mores that are present, such as the matrilineal system and cultural beliefs that are thought to impact a person's mental health. Suicide is a serious public health concern which needs to be tackled on a priority basis, led by mental health professionals. Mental health policy should also focus on issues at the school level to tackle substance use disorders and early intervention for childhood disorders. Adolescent mental health policy should address issues such as sexuality and bullying. A focus of the policy should be on women's mental health, especially perinatal and maternal mental health. This is especially important in the state considering the high fertility rate. With people living for longer, elderly mental health needs to be another focus in the policy. The burden caused by common mental disorders is high and affects all spheres of life including family and work. There is therefore a need for policy makers in the state to realise the importance of mental health in all spheres of functioning and to encourage positive mental health.

Key words: mental health advocacy, mental health policy

Recommendations

The research studies presented in the seminar has benefitted all the faculty, students and professionals who participated in the seminar. As indicated, there is a large mental health gap in terms of professionals and research. The huge burden of mental illness in a country like India is enormous. The need therefore is to enhance the training of mental health professionals and also conduct research.

Thus there are three major recommendations for the Department:

- a. Include 'mental health' in the curriculum. The training of mental professionals has to be a priority for the Department so as to reduce the gap that exists.
- b. Research on issues related to mental health has to be taken up. There is a big lacuna in the knowledge of mental illness in the state and region. Students and faculty are to be encouraged to take up research on mental health
- c. Community projects to address the mental health concerns can be taken up. As part of the project, sensitization about the misconceptions about mental health could be one component which will reduce stigma and discrimination to a very large extent. This will be the start of improved mental health care for persons needing care and services.

Core Organizing Team

- a. Dr. Melari Shisha Nongrum, Associate Professor
- b. Dr. Marbabiang Syiemlieh, Assistant Professor
- c. Dr. S.Maxwell Lyngdoh, Associate Professor
- d. Dr. Ardonister Lyngdoh, Assistant Professor
- e. Ms. Ibasarlyne Thabah Synthiang, Assistant Professor
- f. Ms. Dawnthingla Shimray, Assistant Professor
- g. Ms. Nandaris Marwein, Assistant Professor

Annexure 1: Programme of the National Seminar

Day 1: October 31, 2017

10:00 am - Inaugural Function

12:00 noon **Sub-theme I : Mental Health in Education and Health Institutions**

Moderator – Prof R. Srinivasa Murthy

Session I : *Mental Health Integration in Education and Health Institutions*

- Prof Sonia Pereira Deuri

12:45 pm Session II : *Mental Health: A Priority*

- Ms. GamreChima R. Marak

1:15 pm Session III: *Career Support Systems for Schools in Meghalaya*

- Dr Maribon Moreno Viray

1:45 pm Lunch Break

2:15 pm **Sub-theme II: Mental Health Research Approaches**

Moderator: Prof. Kasi Sekar

Session IV: Prof. Sudhir Khandelwal

3:00 pm Session V: *Community Based Participatory Research: its relevance to addressing social issues in Meghalaya*

- Dr. Melari Shisha Nongrum

3:30 pm Tea Break

3:45 pm Session VI – *Meaning in life as experienced by Mizo women in Midlife*

- Dr. Debbie Zothanpari

4:15 pm Close – Day 1

Day 2: November 1, 2017

10:00 am Reflection

10:30 am Sub – theme III: Community Mental Health

Moderator: Prof. Sudhir Khandelwal

Session VII: *Community Mental Health: Role of Stakeholders*

- Prof. R. Srinivasa Murthy

11:15 am Tea Break

11:30 am Session VIII: *Understanding Qualitative experiences of parents caring a child with Autism Spectrum Disorder*

- Mr. Emideiwahun K. Rangad

12:00 noon Session IX: *Community Based Participatory Approach in setting up Community Mental Health Programme in Meghalaya India, with particular reference to enhance family supportsSystem for Schizophrenia in Meghalaya, India*

- Ms. Grace Mary Basanshrieh

12: 30 pm Lunch Break

1:00 pm Sub theme: **Advocacy and Policy for Mental Health**

Moderator: Prof. Sonia Pereira Deuri

 Session X: Mr. Mukul Goswami

1:45 pm Session XI - *Advocacy and Policy for Mental Health*

- Dr. Ila Lyngksiar Rynjah

2:15 pm Tea Break

2:30 pm Session XII: *No one is left behind*

- Ms. Darity Khongthaw

3:15 pm Valedictory Function