A Report on

Pilot Study of National Mental Health Survey, Nepal

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Nepal Health Research Council

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Prof. Dr. Anjani Kumar Jha
Executive Chairman
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EXECUTIVE SUMMARY

Mental health is an integral part of overall health and wellbeing. The prevalence and disease burden of mental disorders have remained incredibly high globally and the treatment gap is also huge with about four in five people with mental illness in low and middle-income countries receiving no effective treatment. It is estimated that in Nepal 20-30% population are at risk of suffering from one or more mentally ill conditions and the sporadic studies done in different parts of the country indicate an increasing prevalence. However, there are no any national level studies on mental disorders conducted in Nepal till date. So, the aim of the national mental health survey, Nepal is to assess the prevalence of mental disorders in Nepal; to identify the help seeking behavior and barriers in accessing care among people with mental disorders; and to assess the impact and disability due to mental disorders in the Federal Democratic Republic of Nepal.

The national mental health survey, Nepal has been designed to be implemented after series of works in different phases. In the first step, necessary works on translation and validation of data collection tools including the pretesting has been completed. In the second phase a pilot study has been completed that will subsequently be followed by the comprehensive national level study. In this report we are sharing the major works performed for translation and validation of tools and the findings of the pilot study. The major tools of data collection were Mini International Neuropsychiatric Interview (MINI) tools for adult and adolescents, version 7.0.2. For the pilot survey, a total of 1647 participants were included and the data were collected using face to face interview with population aged 13 years and above. Besides the disorders included in MINI tools, other questionnaire on disorders such as epilepsy, dissociative conversion disorders etc., were also included. Questionnaire on barriers in accessing care and help seeking behavior were also administered with the participants aged 18 years and above. Pilot survey was conducted in three districts: Dhanusha, Bhaktapur and Dolakha; one from each ecological region.

The analysis of data from 1647 participants (1371 adults above 17 years, 276 adolescents aged 13-17 years) showed that the current prevalence of any form of mental disorders was 12.9%. Current prevalence of any form of mental disorders was found to be 11.2% and 13.2% among 13-17-year-olds and above 17 year-olds respectively. Current major depressive disorder was found among 0.7%, adolescents. Similarly, 1.8% of adolescents had taken any substance in past 12 months but substance use disorder was present among 0.7% only. Similarly, among participants above 17 years age, some of the major disorders found were: Major depressive disorder (current) (3.4%), alcohol use disorder (3.4%), substance use disorder (7.3%), current psychotic disorder (1.1%) and dissociative conversion disorder (6.1%). Suicidality was found to be high in both the groups. Current suicidality among adolescents was 8.7% and 10.9% among adults.

Among those with any form of mental disorder, only 18.4% received the treatment in last 12 months. The major barriers in accessing and receiving care were related to the knowledge and attitude related barriers. For example, about 79.8% of the participants who did not receive treatment did so because they wanted to solve their problem on their own followed by the feeling that the problem would get better by itself. Similarly, about 63% thought that they did not have any problem.

Experiences and findings from the pilot survey will be used for making necessary modifications in the tools, as well as to plan the national level survey. Given the lack of nationally representative data on prevalence of mental disorders in Nepal, this study will help to estimate the prevalence, treatment gap and help-seeking behavior of the people of the Federal Democratic Republic of Nepal.

TABLE OF CONTENTS

LIST OF TABLES

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LIST OF ABBREVIATIONS

BACE : Barriers in Accessing Care Evaluation

DALY : Disability Adjusted Life Years

DoHS : Department of Health Services

DSM : Diagnostic and Statistical Manual

EDCD : Epidemiology and Diseases Control Division

ERB : Ethical Review Board

FDCs : Field Data Collectors

LMICs : Low and Middle Income Countries

MINI : Mini International Neuropsychiatric Interview

NHRC : Nepal Health Research Council

PHCRD : Primary health care revitalization division

PPS : Probability Proportionate to Size

TPO : Transcultural Psychosocial Organization

TWG : Technical Working Group

TUTH : Tribhuwan University Teaching Hospital

WHO : World Health Organization

YLD : Years Lived with Disability

YLL : Years of Life Lost due to premature death

CHAPTER 1

INTRODUCTION

Mental health is an integral part of overall health and wellbeing and is a foundation for effective functioning of an individual and community [1]. Mental disorders among population of any country are an important public health concern. Poor mental health among young population affects them not only during their childhood but also in the long run during their adulthood and later life due to factors such as poor academic achievement, substance abuse, poor performance in work, poor reproductive health etc.[2]. Mental health of parents also affects the mental health of their children [3] reflecting the intergenerational effect of mental disorders. However, the prevalence of mental disorders remains remained incredibly high globally. According to global burden of disease study 2010, mental, neurological and substance use disorders accounted for 10.4% of global Disability Adjusted Life Years (DALY), 2.3% of global Years of Life Lost due to premature death (YLL) and 28.5% of global Years Lived with Disability (YLDs)[4]. Among mental, neurological and substance use disorders, mental disorders accounted for the largest proportion of DALYs[4]. Projections estimate that neuropsychiatric conditions will account for 15% of disability worldwide by the year 2020 including the unipolar depression alone accounting for 5.7% of DALYs[4, 5].

The treatment gap for mental disorders is huge all over the world; for instance, between 76% and 85% of people with severe mental disorders receive no treatment for their mental health conditions in Low and Middle Income Countries (LMICs) [6]. It is estimated that four out of five people with mental illness in Low and Middle-Income Countries (LMICs) receive no effective treatment[7, 8]. Lack of mental health professional and access to mental health services is an important health system challenge in these settings. There is a huge gap in mental health workforce in many LMICs. According to the mental health atlas 2011, the median number of psychiatrists per 100,000 population in LMIC is 0.05 whereas this number is 8.59 in high-income countries [9]. In some developing countries the rate of unmet need for mental health services is even 100% [10].

In Nepal also the burden of mental health problems in terms of morbidity, disability and costs to individuals, families and societies are overwhelmingly high. For example, the first epidemiological field survey conducted in the Kathmandu valley in 1984 showed a high prevalence of mental illness around 14 percent [11]. Similarly, a mental health prevalence survey conducted in two small towns of the Western region of Nepal identified 35% psychiatry morbidity in the region[12]. Similarly, multi-sectoral action plan for the prevention and control of non-communicable diseases (2014-2020) estimated the 18 percent of the NCD burden is due to mental illness[13]. Similarly, suicide is a key public health concern in Nepal especially among women of reproductive age group[14]. Different factors such as easy availability of toxic pesticides facilitate suicide attempts and belief that suicide is illegal hinder those affected from seeking help[14].

Nepalese people are at increased risk of developing mentally ill health conditions due to factors such as the ten years long armed conflict and political unrest, low socioeconomic status, labour migration, gender based discrimination, high vulnerability to natural disasters such as earthquake, flood, landslide etc[15-18].However, mental health is still a neglected issue in Nepal. People suffering from mental disorders are often seen as threats to Nepalese society leading to denial for seeking treatment and stigmatization. Then, there are cultural beliefs, myths, and religious convictions around causes and consequences of mental disorders that further discourage people to seek service from the health facilities. People suffering from mental disorders and their families in Nepal seek help from traditional healers. Though Nepal is signatory of the International Convention on Mental Health and different periodic plans of Nepal have incorporated gradual implementation of hospital to community based mental health care service in the country, barriers in accessing mental health care is still huge in Nepal.

1.2 RATIONALE

Mental health problems are a major public health problem worldwide. According to the global burden of disease study 2010, overall mental and substance use disorders were the fifth leading disorder category in terms of DALYs[19]. With this recognition, in the past few decades, national and international epidemiological studies have been conducted in relation to the prevalence, correlates and impacts of mental disorders. Most of these studies have been done in developed countries [20-22]. However, evidence from developing countries is also growing [23-25]. In this context, we are aiming to conduct a national level survey of mental disorders in Nepal.

Nepal is a country with almost thirty million population with a high vulnerability to natural disasters such as earthquake, flood, landslide etc. and has faced ten years long armed conflict and political unrest. Nepal also faced a devastating earthquake of 7.8 magnitude and the subsequent aftershocks in 2015 that struck western, central and eastern regions of Nepal. The earthquake lead to 8,702 the deaths, 22,303 injury and 605,254 completely destroyed houses rendering thousands of people homeless [26, 27]. Data from previous studies done in different parts of Nepal indicate an increasing prevalence of mental disorders in Nepal [11-13]. However, these studies are based on limited population samples limiting the generalizability of the produced estimates. There are no any national level studies on mental disorders conducted in Nepal to date. There is also difficulty in conceptualizing and measuring the mental disorders in the field of psychiatric epidemiology [28] which applies in case of Nepal as well. This uncertainty about diagnostic categories, criteria and measurement also limits the generalizability of the previous findings and make the findings difficult to understand. This also explains the need of a national level study in Nepal using a highly valid and reliable diagnostic tool. Promoting mental health and well-being, and the prevention and treatment of substance abuse are integral parts of the Sustainable Development Goals (SDGs). However, many low and middle-income countries, including Nepal currently allocate less than 2 percent of the health budget to the treatment and prevention of mental disorders[29]. Nepal is the signatory of an international convention on mental health to be included in urgent health service category and mental health care services are gradually implemented from community to hospitals. However, the area of mental health literacy has been neglected in comparison to physical health. The views of people regarding mental health are less known. Thus, it is important to know the concepts of Nepalese people about the mental health, the unmet need, the help seeking behavior of people with mental disorders and the major barriers in accessing and receiving mental health care services. So, this study aims to conduct a pilot survey regarding the status of mental illness, the existing barriers to care and health service utilization in Nepal followed by a national epidemiological study of mental health in Nepal.

1.3 OBJECTIVES

The objectives of the pilot survey were:

- To assess the prevalence of mental disorders in the study areas
- To assess help seeking behavior of people with mental disorders in the study areas
- To identify barriers of seeking treatment for mental disorders in the study areas
- To assess the feasibility for the national mental health survey, Nepal
- To refine the tools to be used in the national mental health survey, Nepal
- To estimate the time, cost and human resource required for the national mental health survey, Nepal

CHAPTER 2

METHODOLOGY

The details about the methodology used in this study are described below:

2.1 Study design

This study was quantitative in nature with a cross-sectional design.

2.2 Study site

For the pilot survey, three purposively selected districts: Dhanusha, Bhaktapur and Dolakha representing Terai, Hill and Mountain region respectively were included.

2.3 Study duration

The study was conducted from September 2017 to September 2018. Data collection was done June 20, 2018 to July 20, 2018.

2.4 Study population and unit of analysis

There were two groups of study population for this study. First, adolescents aged 13 to 17 years and second, adult population aged 18 years and above. All the study participants were non-institutionalized Nepali population. The population who were not able or willing to respond were not included in the study. The unit of analysis were the individual children/adolescent and adult participants.

2.5 Sample size calculation

Given the lack of population-based data on mental health in Nepal, we used the data from recent mental health survey of India, 2015-16 [24]. This was because India and Nepal share similar socio-cultural practices. Similarly, the mental health survey of India also used the MINI tools. The India mental health survey found the prevalence of F10-F19- Mental and behavioral problems due to psychoactive substance use as 22.2%. Using this prevalence estimate, margin of error of 5%, design effect of 1.5 and non-response rate of 23% [30], the total sample size was calculated to be 6855. Similarly, for children and adolescents, using the prevalence value phobic anxiety disorder (3.6%) among 13-16-year-olds from India mental health survey, margin of error of 5%, design effect of 1.5 and non-response rate of 23%, the total sample size for 13-17-year-olds was calculated to be 1377. Thus, the total sample size for the main survey was estimated to be 8232. Of this sample, 20% was taken for the pilot survey making a total sample size of 1647 (1371 sample for adults and 276 for adolescents). The research team agreed that the sample size calculated as above for the main survey will be used for the purpose of pilot survey and based on the findings of the pilot survey necessary modifications will be made in the sample size and sampling technique during the national mental health survey, Nepal.

2.6 Sampling technique

Nepal is divided into 7 provinces and 77 districts. Each district is then divided to different urban and rural municipalities which then are divided into wards. For pilot survey, three districts: Dolakha, Bhaktapur and Dhanusha representing Mountain, Hill and Terai regions respectively were purposively selected from different provinces. In this study, sample size was proportionate to the total number of households in selected districts as per the census report of 2011 [31] and wards were considered the primary sampling units (PSUs). A probability proportionate to size method was applied to identify PSUs at district level. From the selected PSUs, the household listing was done and 30 households were randomly selected per PSU. In case of more than one eligible adult in the household, lottery method was used for selecting the participant. In case of adolescents, only 6 households were selected, given

the small sample size and the participants were recruited using same technique as in adults.

2.7 Tools and techniques of data collection

Mini International Neuropsychiatric Interview (MINI) Adult and MINI-Kid version 7.0.2 were used to collect the data from adults and adolescents respectively. The MINI is a short, structured diagnostic interview developed initially in 1990 by psychiatrists and clinicians in the United States and Europe for DSM-III-R and ICD-10 psychiatric disorders. MINI is the structured psychiatric interview of choice for psychiatric evaluation and outcome tracking in clinical psychopharmacology trials and epidemiological studies. The MINI is the most widely used psychiatric structured diagnostic interview instrument in the world, employed by mental health professionals and health organizations in more than 100 countries. The MINI has been translated and linguistically validated in over 70 languages. The version 7.0.2 of the MINI assesses the psychiatric disorders by using Diagnostic and Statistical Manual five (DSM-V) criteria [32]. In our pilot study, we have included a total of 15 mental disorders among adults and 23 disorders among adolescents (refer to table 1).

We also used Barriers to Accessing Care Evaluation (BACE) tool and questionnaire on help seeking behavior. These questionnaires were administered to the participants who were diagnosed with any form of mental disorders from the MINI interview. There is preliminary evidence demonstrating the reliability, validity and acceptability of the BACE tool which is a 30 item-questionnaire [33] with a particular focus on stigma-related barriers, as well as covering a comprehensive set of other types of barrier such as attitude related barriers, knowledge related barriers, structural barriers, and economic barriers. It can be used to ascertain key barriers to access to mental health care which may help to identify potential interventions to increase care seeking and service use [33]. In the questionnaire on help seeking behavior, the variable such as who was contacted by the participant after having the mental health problems, the type of services received, completion of course recommended by the service provider e.g. medicine, counseling or any other forms of treatment, total expenses on treatment etc. The questions on barriers in accessing care and help seeking behavior were asked to all the participants who had any form of mental disorders in the past 12 months.

Licensure was obtained for the use of MINI tools in this survey. Similarly BACE tool was also used after taking the consent from relevant body. Besides the disorders included in MINI standard and kid version 7.0.2, additional disorders that are important in the Nepalese context such as epilepsy and dissociative conversion disorder were also added in questionnaire for adults. Similarly, epilepsy, dissociative conversion disorder and intellectual disability were added in the questionnaire for adolescents. Questionnaire for these additional disorders were prepared by a team of psychiatrists and psychologists which was then reviewed and finalized by the technical working group (TWG).

Though MINI tool is an internationally validated tool to assess mental disorders, it has not been translated to Nepali language. So, NHRC worked with the team of experts and the owner of the tool Prof Dr. David Vincent Sheehan to translate and validate this tool into Nepali language. The details on tools translation has been provided in the validity/reliability section below. Other tools described above were also translated into Nepali language. The technique of data collection was face-to-face interview.

Table 1: List of mental disorders used in the survey

Mental disorders among adults	Mental disorders among adolescents
Disorders from the MINI 1. Major depressive episode (current-2 weeks, past and recurrent) 2. Suicidality (current-past month and lifetime attempt) 3. (Hypo) manic episode (current and past) 4. Panic disorder (current-past month and lifetime) 5. Agoraphobia (current) 6. Social phobia (current-past month) 7. Obessive compulsive disorder (current-past month) 8. Post Traumatic Stress Disorder (current-past month) 9. Alcohol use disorder (past 12 months) 10. Substance use disorder (past 12 months) 11. Any psychotic disorder (current and lifetime) 12. Anorexia nervosa (current-past three months) 13. Bulimia nervosa (current-past three months) 14. Generalized anxiety disorder (current-past six months) 15. Antisocial personality disorder (lifetime)	Disorders from the MINI 1. Major depressive episode (current-2 weeks, past and recurrent) 2. Suicidality (current-past month and lifetime attempt) 3. (Hypo) manic episode (current and past) 4. Panic disorder (current-past month and lifetime) 5. Agoraphobia (current) 6. Separation anxiety disorder (current-past month) 7. Social phobia (current-past month) 8. Specific phobia (current-past month) 9. Obessive compulsive disorder (current-past month) 10. Post Traumatic Stress Disorder (current-past month) 11. Alcohol use disorder (past 12 months) 12. Substance use disorder (past 12 months) 13. Tourette's disorder (current) 14. Attention Deficit Hyperactivity Disorder (ADHD) (past six months) 15. Conduct disorder (past 12 months) 16. Oppositional defiant disorder (past six months) 17. Any psychotic disorder (current and lifetime) 18. Anorexia nervosa (current-past three months) 19. Bulimia nervosa (current-past three months) 20. Binge eating disorder (current) 21. Generalized anxiety disorder (current-past six months) 22. Adjustment disorders (current) 23. Autism Spectrum Disorder
Other additional disorder (not from the MINI module) 16. Dissociative conversion disorder (lifetime) • Conversion disorder • Trance and possession disorder • Somatic symptom disorder 17. Epilepsy (lifetime)	Other additional disorder (not from the MINI module) 24. Dissociative conversion disorder (lifetime) • Conversion disorder • Trance and possession disorder • Somatic symptom disorder 25. Epilepsy (lifetime) 26. Intellectual disability

2.8 Validity and reliability

Validity and reliability of tools have been ensured during the tools translation phase. The guideline for the translation of tools was designed based on the available literature [34-37] Consultation with our international advisors Dr. David Vincent Sheehan, the copyright holder of the MINI tools and Dr. Gopalkrishna Gururaj was also done. The steps of tools translation and validation used were:

1. Translation of tool in Nepali language by bilingual speaker

2. Review of the translated version by a group of mental health experts (who used the monitoring forms and provided their comments or any other alternative translation)
3. Evaluation of translated item by face to face interview with the prospective participants.
4. Blind back translation (by those unfamiliar with the original version of the questions)
5. Verification of the translation (Nepali and blind back English translation) by a team of experts
6. Revision and necessary modification

While reviewing/examining the translation, following criteria were evaluated:

1. Comprehensibility (is the translation understandable to the local population?)
2. Acceptability (would certain participants be uncomfortable to answer that question directly, may need to be modified to acceptable word)
3. Relevance (Is this question relevant to the local culture? e.g. in some setting such as those without any electricity; questions asking entertainment through video games, mobile games, television may not be relevant; and it may need to include other entertainment methods relevant there)
4. Completeness (Will the back translation relate back to the same concepts and ideas as the original question?)

Experts were consulted during and after the translation. The final tools were also reviewed and revised as necessary by the members of technical working group and steering committee. Thirteen BPH graduates and BSc Nursing graduates selected for the data collection were comprehensively trained on the tools before they moved to pretesting in the field setting. The trainers for this training were trained by Dr. David Vincent Sheehan, the copyright holder of the tool via zoom webinar. Necessary modifications in the tools were made after getting the feedback from data enumerators and supervisors who participated in the pretesting.

2.9 Pretesting

For the pretesting, two villages within Kathmandu district: Tokha and Dhapasi were selected purposively. The total sample size was 168 i.e. 138 adults and 30 adolescents respectively. After pretesting necessary modifications in the Nepali translated tools were made.

2.10 Data management and analysis

A multidisciplinary study team was formed consisting of psychiatrists, psychologists, mental health experts and public health experts having experience in mental health research. BPH and BSc Nursing graduates were trained for data collection from the field. Data was collected using paper version of the tool. After completion of data collection, questionnaires were checked for completeness; the collected data were verified and coded daily.

Data were entered in EpiData 3.1. version with pre-set checks and controls commands. All the entered data were rechecked for any errors. The data was then exported to IBM SPSS Statistics 23 for quantitative analysis. Data were analyzed using descriptive statistics, frequency and percentages were calculated and presented in tables. To calculate the current prevalence on mental disorders, only disorders that are included in MINI modules (excluding autism spectrum disorder that could not be ruled out and suicidality) were used.

2.11 Ethical considerations

The ethical approval for the study was taken from Ethical Review Board at the Nepal Health Research Council (NHRC). Written informed consent was taken from the adult participants. In case of children and adolescents, assent form was used that was duly signed by their parent/guardian. We also developed adverse event management protocol that was used to take appropriate action during the process of data collection. The protocol was used if any individual with suicidal tendency and or severe form of mental disorder were found and needed a referral for health facility/service.

Participants were given the right to refuse to answer any question without providing the reason for their

decisions and were allowed to withdraw from the study at any time. The information provided by the research participants was dealt with highest confidentiality and used only for this study. Privacy of the participants was fully maintained during data collection, analysis and storage.

2.12 Potential bias and limitations

Since mental illness is a stigmatized issue in Nepal, there are possibilities of reporting bias by the families having person with mental illness. One of the limitations of this study is it does not include population residing in some institutional settings for example hospitalized population, imprisoned population etc. Similarly, this is a pilot study that was conducted including only three districts. So, the findings of this study are not generalizable to the adolescents and adult population of Nepal.

Wellbeing is also an important component of mental health. However, in this study wellbeing has not been measured. Similarly, we could not assess the interrater reliability of the field data collectors (FDCs) because of the feasibility related reasons. However, due care was given during the selection and training of the FDCs & the supervisors.

CHAPTER 3

FINDINGS

Findings of the study have been shown in tables below. Disorders for which no any cases were found are described only in the paragraph and not listed in the tables. The average duration of interview for adolescents was 36 minutes (SD:9, Minimum:18, Maximum:90) whereas for adults the average time for the interview was 35.9 minutes (SD: 12.3, Minimum:15, Maximum: 103). The total non response rate in the pilot survey was less than 1%. Of the total participants included in the study, 212 (12.9%) had any form of mental disorder.

3.1 Socio-demographic information of the adolescents aged 13-17 years

Out of the total 276 adolescents included, more than 50% were in age group 13-15 years. Most of them were female, Hindu, from disadvantaged non Dalit Terai caste, nuclear family, and those with secondary level education (Table 2). The average age of participants was 17 years and most of them were unmarried.

Table 2. Socio-demographic information of adolescent participants aged 13-17 years

Variables (n=276)	Level	Frequency	Percentage
Completed age (in years)	13	47	17.0
	14	53	19.2
	15	53	19.2
	16	55	19.9
	17	68	24.6
Sex	Male	103	37.3
	Female	173	62.7
Marital status	Unmarried	270	97.8
	Married	6	2.2
Religion	Hindu	243	88.0
	Christian	3	1.1
	Islamic	13	4.7
	Buddhist	12	4.3
	Others	5	1.8
Ethnicity	Dalit	41	14.9
	Disadvantage Janajati	25	9.1
	Disadvantaged non dalit Terai caste	93	33.7
	Religious minorities	8	2.9
	Relatively advantaged Janajatis	47	17.0
	Upper Caste groups	62	22.5
Family Type	Single	162	58.7
	Joint/Extended	114	41.3
Participant's Education	Illiterate	6	2.2
	Informal Education	2	0.7
	Lower Primary Education	2	0.7
	Primary Education	19	6.9
	Lower secondary	80	29.0
	Secondary	131	47.5
	Higher Secondary	36	13.0

Father's Education (n=263)	Illiterate	39	14.8
	Informal Education	29	11.0
	Lower Primary Education	16	6.1
	Primary Education	33	12.5
	Lower secondary	41	15.6
	Secondary	62	23.6
	Higher Secondary	43	16.3
Mother's Education (n=267)	Illiterate	81	30.3
	Informal Education	76	28.5
	Lower Primary Education	12	4.5
	Primary Education	23	8.6
	Lower secondary	28	10.5
	Secondary	31	11.6
	Higher Secondary	16	6.0
Spouse's Education (n=6)	Lower secondary	2	33.3
	Secondary	3	50.0
	Higher Secondary	1	16.7
Participant's Occupation	Housewife	4	1.4
	Agriculture	1	0.4
	Business	1	0.4
	Daily worker	5	1.8
	Others	265	96.0
Father's Occupation (n=261)	Agriculture	49	18.8
	Service	36	13.8
	Business	63	24.1
	Daily worker	56	21.5
	Foreign employment	49	18.8
	Others	8	3.1
Mother's Occupation (n=268)	Housewife	147	54.8
	Agriculture	57	21.3
	Service	14	5.2
	Business	36	13.4
	Daily worker	13	4.8
	Others	1	0.4
Spouse's Occupation (n=7)	Housewife	1	14.3
	Agriculture	1	14.3
	Service	2	28.6
	Daily worker	1	14.3
	Foreign employment	2	28.6
Death of family members in last 12 months (n=275)	Yes	15	5.5
	No	260	94.2

Family member who died (n=15)	Aunt	1	6.2
	Niece/Nephew	1	6.2
	Father	1	6.2
	Grandmother	5	37.5
	Grandfather	6	37.5
	Mother	1	6.2

*Details on ethnicity is provided in annex section

3.2 Mental disorders among adolescent participants aged 13-17 years

Out of total adolescents 31 (11.2%) currently had any form of mental disorders. Table 3 below gives the status of mental disorders among adolescents aged 13-17 years during the pilot survey. Current major depressive disorder was found among 0.7%, panic disorder among 0.4%, agoraphobia among 2.2%, separation anxiety disorder among 0.4%, social phobia among 0.4%, specific phobia among 1.1%, and obsessive compulsive disorder among 1.1%. Of the total participants 1.8% had taken any substance in past 12 months but substance use disorder was present among only 0.7%.

Current psychotic disorder, GAD, anorexia nervosa and lifetime epilepsy was present among 1.8% participants each. Autism spectrum disorder could not be ruled out in 5.8% of the participants whereas about 12% participants felt that they had less intellectual capacity than other children of their age.

We did not find any adolescents with conditions such as manic and hypomanic episode, post-traumatic stress disorder, alcohol use disorder, tourette's disorder, attention deficit hyperactivity disorder, conduct disorder, bulimia nervosa, and binge eating disorder.

Table 3. Status of mental disorders among adolescent participants aged 13-17 years

Name of mental disorder (n=276)	Level	Frequency (percent)
Any mental morbidity	Current	31 (11.2)
Major depressive disorder	Current	2 (0.7)
	Past	5 (1.8)
	Recurrent	4 (1.4)
Panic disorder	Current	1 (0.4)
	Lifetime	3 (1.1)
Agoraphobia	Current	6 (2.2)
Separation anxiety disorders	Current	1(0.4)
Social anxiety disorder (social phobia)	Current	1(0.4)
Specific phobia	Current	3 (1.1)
Obsessive compulsive disorder	Current	3 (1.1)
Substance use disorder	Current	2 (0.7)
	Mild	1 (0.4)
	Moderate	1 (0.4)
Oppositional defiant disorder	Current	2 (0.7)
Psychotic disorder	Current	5 (1.8)
	Lifetime	12 (4.3)
Anorexia nervosa	Current	5 (1.8)
Generalized anxiety disorder (GAD)	Current	5 (1.8)
Adjustment disorder	Current	1 (0.4)
Autism	Autism Spectrum Disorder not ruled out	16 (5.8)

Dissociative identity disorder	Current	1 (0.4)
Somatic symptom disorder	Current	1 (0.4)
Conversion disorder	Current	1 (0.4)
Dissociative conversion disorder	Current	3 (1.1)
Epilepsy	Lifetime	5 (1.8)
Intellectual disorder	Feeling having less intellectual capacity than other child	32 (11.6)
	Able to live in society like other children	272 (98.6)
	Can say 'no' to illegal or harmful work	275 (99.6)

3.3 Suicidality among adolescent participants aged 13-17 years

Current suicidality was present among 8.7% of adolescents. Most of the suicidality was low in severity. Table 4 below gives the status of suicidality among adolescent participants aged 13-17 years.

Table 4. Status of suicidality among adolescent participants aged 13-17 years

Name of suicidality (n=276)	Level	Frequency (percent)
Suicidality	Low	18 (6.5)
	Moderate	4 (1.4)
	High	4 (1.4)
	Current	24 (8.7)
	Lifetime attempt	1 (0.4)
	Likely in near future	3 (1.1)

3.4 Socio-demographic information of participants aged 18 years and above

Total 1371 adult participants aged 18 years and above were included in the study. Table 5 below shows the socio-demographic information of the participants. Majority of the participants were female, married, Hindu, from disadvantaged non Dalit Terai caste, and living in nuclear family. Most of them were housewife, followed by those involved in agriculture as major occupation. About 61% of the participants said that their income had fulfilled the family needs (Table 5). Mean age of the participants was 39.4 years (range: 18 to 85 years, SD: 15.04).

Table 5. Socio-demographic information of the participants aged 18 years and above

Variables	Level	Frequency	Percent
Age group (in years) (n=1368)	18-24	271	17.6
	25-33	322	23.5
	34-48	424	31
	49-64	270	19.7
	65-78	104	7.6
	79-98	7	0.5

Sex (n=1364)	Male	462	33.9
	Female	901	66.1
	Others	1	0.1
Marital Status (n=1340)	Unmarried	127	9.5
	Married	1122	83.7
	Widow	81	6.0
	Divorced	10	0.7
Religion (n=1369)	Hindu	1216	88.7
	Christian	13	1.0
	Muslim	68	50
	Buddhist	42	3.1
	Others	30	2.2
Ethnicity (n=1334)	Dalit	192	14.4
	Disadvantaged Janajati	95	7.1
	Disadvantaged non Dalit Terai	450	33.7
	Religious minorities	42	3.1
	Relatively advanced Janajatis	246	18.4
	Upper caste groups	309	23.2
Family Type (n=1359)	Single	730	53.7
	Joint/extended	629	46.3
Educational status (n=1351)	Illiterate	336	24.9
	Informal education	233	17.2
	Below primary education	42	3.1
	Primary level	122	9.0
	Lower secondary level	137	10.1
	Secondary level	256	18.9
	Higher secondary	225	16.7
Occupation (n=1222)	Housewife	482	39.4
	Agriculture	252	20.6
	Service	70	5.7
	Business	202	16.5
	Daily laborer	88	7.2
	Others	128	10.5
Occupation of spouse (n=1118)	Housewife	224	20.0
	Agriculture	227	20.3
	Service	135	12.1
	Business	177	15.8
	Daily laborer	161	14.4
	Foreign employment	126	11.3
	Others	68	6.1
Has income fulfilled family needs (n=1355)	Yes	832	61.4
	No	459	33.9
	Don't Know	64	4.7
Family member death in last 12 months (n=1370)	Yes	86	6.3
	No	1284	93.7

*Details on ethnicity is provided in annex section

3.5 Mental disorders among participants aged 18 years and above

The current prevalence of any mental disorders among adult participants was calculated to be 13.2%. Table 6 below gives the status of mental disorders among adults aged 18 years and above. Major depressive disorder (current) was found among 3.4%. Though a total of 5.2% and 13.9% had 3 or more alcoholic drink within 3-hour period or on 3 or more occasion and had non-alcoholic substance in past 12 months respectively; only 3.4% and 7.3% had alcohol use disorder and substance use disorder respectively. Among those with substance use disorder most of them used tobacco and tobacco products. Similarly, current psychotic disorder was present among 1.1%, dissociative conversion disorder among 6.1% and epilepsy among 1% of the participants.

We did not find any cases of anorexia nervosa, bulimia nervosa and hypomanic episode in adults.

Table 6. Status of mental disorders among participants aged 18 years and above

Name of mental disorder (n=1371)	Level	Frequency (percent)
Any mental morbidity	Current	181 (13.2)
Major depressive disorder	Current	46 (3.4)
	Past	61 (4.4)
Manic episode	Current	4 (0.3)
	Past	3 (0.2)
Panic disorder	Current	10 (0.7)
	Lifetime	29 (2.1)
Agoraphobia	Current	8 (0.6)
Social Anxiety Disorder	Current	3 (0.2)
Obsessive compulsive disorder	Current	4 (0.3)
Post traumatic stress disorder	Current	2 (0.1)
Alcohol use disorder	Current	46 (3.4)
	Mild	14 (1.0)
	Moderate	13 (0.9)
	Severe	17 (1.2)
Substance use disorder	Current	100 (7.3)
	Mild	35 (2.6)
	Moderate	35 (2.6)
	Severe	29 (2.1)
Psychotic disorder	Current	15 (1.1)
	Lifetime	47 (3.4)
General Anxiety disorder	Current	19 (1.4)
Antisocial personality disorder	Lifetime	3 (0.2)
Dissociative identity disorder	Current	20 (1.5)
Somatic symptom disorder	Current	59 (4.3)
Conversion disorder	Current	19 (1.4)
Dissociative conversion disorder	Current	83 (6.1)
Epilepsy	Lifetime	14 (1)

3.6 Suicidality among participants aged 18 years and above

Current suicidality was present among 10.9% of adults. Most of the suicidality was low in severity (9.2). Table 7 below gives the status of suicidality among participants aged 18 years and above.

Table 7. Status of suicidality among participants aged 18 years and above

Status of suicidality (n=1371)	Level	Frequency (percent)
Suicidality	Low	126 (9.2)
	Moderate	9 (0.7)
	High	19 (1.4)
	Current	150 (10.9)
	Lifetime attempt	5 (0.4)
	Likely in near future	10 (0.7)

3.7 Help seeking behavior

Among total 325 participants who had any form of mental disorders in past 12 months, 171 i.e. 52.6% talked about their problem with someone and only 69 (21.2%) searched for the treatment followed by only 58 (17.8%) who received complete treatment in last 12 months (Table 8). Among those who talked with someone about their mental health problem, majority of them talked with husband/wife followed by friends and other family members, health workers, dhami jhakri, and jyotist/priest. Among participants who took mental health services from different sources, all of them said that the service was helpful.

The median amount of money spent for the treatment was NPR 39,041 (minimum:0, maximum: 300,000) whereas the median amount of money spent for transportation was NPR 3,000 (minimum:5, maximum: 50,000). Out of the total participants who received complete treatment, 17 (29.3%) were admitted to the hospital.

Table 8. Mental health services received

Variable	Level	Frequency	Percentage
Talked with someone (n=325)	Yes	171	52.6.3
	No	153	47.1
	Don't know	1	0.3
Received treatment in last 12 months (n=315)	Yes	58	18.4
	No	255	81.0
	Yes but did not complete	2	0.6
Received treatment with (n=45)	Psychiatrist	15	33.3
	Doctor	16	35.5
	Paramedics	3	6.7
	Dhami Jhakri	11	24.4

3.8 Barriers in accessing care

Among the participants who responded to the barriers related questions (n=263) were the ones who either did not receive any treatment or stopped receiving the treatment before completing the treatment. The following table shows 30 items representing the possible barriers to receiving care for these people with mental disorders. The major barriers found during the pretesting were related to attitude of the participants. Some of the them are: people with mental disorders wanting to solve their problem by themselves, thinking that the problem would get better by itself, and not liking to talk about their feelings and emotions with others (Table 9).

Table 9. Barriers in accessing care

SN	Barriers	Not at all	A little	Quite a lot	A lot	NA
1	Being unsure where to go for care (n=263)	183 (69.6)	31 (11.8)	29 (11)	20 (7.6)	-
2	Wanting to solve the problem on my own (n=263)	53 (20.2)	79 (30)	47 (17.9)	84 (31.9)	-
3	Concern that others might think me weak (n=262)	221 (84.4)	31 (11.8)	7 (2.7)	3 (1.1)	-
4	Fear of being put in hospital against my will (n=262)	246 (93.9)	11 (4.2)	3 (1.1)	2 (0.8)	-
5.	Thinking it might harm my chances of getting job (n=261)	242 (92.7)	3 (1.1)	4 (1.5)	2 (0.8)	10 (3.8)
6	Problem with transport (n=261)	229 (87.7)	16 (6.1)	7 (2.7)	8 (3.1)	1 (0.4)
7	Thinking the problem would get better by itself (n=263)	73 (27.8)	68 (25.9)	65 (24.7)	57 (21.7)	-
8	Thinking what my family would think/say/do/feel (n=260)	235 (90.4)	14 (5.4)	6 (2.3	5 (1.9)	-
9	Feeling embarrassed or ashamed (n=262)	231 (88.2)	26 (9.9)	1 (0.4)	4 (1.5)	-
10	Preferring to get alternative forms of care (n=262)	243 (92.7)	6 (2.3)	5 (1.9)	7 (2.7)	1 (0.4)
11	Not able to afford the financial cost (n=262)	188 (71.8)	28 (10.7)	16 (6.1)	30 (11.5)	-
12	Concerns that I might be seen as ‘crazy’ (n=262)	250 (95.4)	6 (2.3)	1 (0.4)	5 (1.9)	-
13	Thinking that professional care would not help (n=262)	219 (83.6)	21 (8.0)	12 (4.6)	10 (3.8)	-
14	Concern that I might be seen as a bad parent (n=261)	235 (90.0)	17 (6.5)	4 (1.5)	1 (0.4)	4 (1.5)
15	Professional from my ethnic group not available (n=261)	242 (92.7)	14 (5.4)	2 (0.8)	3 (1.1)	-
16	Being too unwell to ask for help (n=261)	247 (94.6)	7 (2.7)	3(1.1)	4 (1.5)	-
17	Concerns that people I know might find out (n=261)	242 (92.7)	13 (5.0)	2 (0.8)	4 (1.5)	-
18	Not like to talk about my feelings and emotions (n=261)	170 (65.1)	40 (15.3)	24 (9.2)	26 (10.0)	1 (0.4)
19	Concerns that people might not take me seriously (n=261)	248 (95.0)	7 (2.7)	4 (1.5)	2 (0.8)	-
20	Concerns about the side effects of treatment (n=261)	250 (95.8)	10 (3.8)	1 (0.4)	-	-
21	Didn’t want these problems to be recorded (n=261)	254 (97.3)	4 (1.5)	3 (1.1)	-	-
22	Bad experiences with mental health care (n=262)	247 (94.3)	9 (3.4)	4 (1.5)	2 (0.8)	-

23	Preferring to get help from family/friends (n=261)	215 (82.4)	26 (10.0)	12 (4.6)	8 (3.1)	-
24	Concerns about children (loosing custody etc.) (n=261)	240 (92.0)	12 (4.6)	5 (1.9)	3 (1.1)	1 (0.4)
25	Thinking I did not have problem (n=261)	96 (36.8)	65 (24.9)	26 (10.0)	74 (28.4)	-
26	Concerns about what friends might think/say/do (n=261)	244 (93.5)	9 (3.4)	3 (1.1)	5 (1.9)	-
27	Difficulty taking time off work (n=261)	225 (86.2)	26 (10.0)	3 (1.1)	7 (2.7)	-
28	Concerns about what people at work might think, say or do (n=261)	247 (94.6)	11 (4.2)	3 (1.1)	-	-
29	Problems with childcare while I receive care (n=261)	239 (91.6)	16 (6.1)	2 (0.8)	3 (1.1)	1 (0.4)
30	Having no one who could help me get care (n=261)	221 (84.7)	14 (5.4)	13 (5.0)	13 (5.0)	-

*the numbers in the parenthesis are percentages

3.9 Other experiences

The research team also collected different experiences from the field that could be helpful in successful conduction of national level survey. We also created a list of local names for some technical terms in the questionnaire that will be utilized in the national level survey. For example local terai name for 'atmahatya' (suicide) was identified as 'khudkhushi', 'nidra' (sleep) as 'neend', 'ausadhi' (medicine) as 'dabai', 'upachaar' (treatment) as 'ilaaj' etc. Questions that were difficult to administer to the participants were marked for revision. We also identified questioned that the particpants were not willing to answer. We also realized that some of the questions in the 30-item BACE module were found to be assessing the similar constructs and those may be removed in the final questionnaire. We also realized that for administering some disorders such as alcohol use disorder and substance use disorder due care should be taken so that the participant will not be affected by the external influencing factors such as presence of other members during the interview. This survey also enhanced the capacity of the field level enumerators in local level coordination, social mapping, rapport building with the participants and administering the tools.

Some of the management/administrative problems were: difficult geography and problem in transportation, difficulty in coordinating due to lack of mobile phone network, some participants had expectation of rewards (cash/kind) for being involved in the study etc. All these experiences helped the research team to gather insights regarding the technical and feasibility related aspects that need to be worked on further for the national level survey.

CHAPTER 4

CONCLUSION AND RECOMMENDATIONS

The analysis of data from 1647 participants (1371 adults above 17 years, 276 adolescents aged 13-17 years) showed the current prevalence of any form of mental disorders to be 12.9% which was 11.2% among 13-17-year-olds and 13.2% among those aged 17 years and above. A total of 21% of adult participants with mental disorders sought for the treatment of their disorders in last 12 months whereas around 18% received the complete treatment. Among those who did not seek any treatment for their mental disorders, majority wanted to solve their problem on their own. There were also knowledge related barriers that prevented the participants with mental disorders in receiving the appropriate treatment. The findings from the pilot survey on current prevalence of mental disorders can be utilized for estimating the sample size for the large-scale survey.

From the experiences of the pilot survey the research team has realized that the national level mental health survey is feasible. We also identified the technical and management related aspects that the research team needs to work on for the effective and successful conduction of the national mental health survey. For example, we realized the need of providing more comprehensive training to the FDCs and field supervisors. Similarly, the analysis of time required for the field level coordination, local level transportation, average time of completion of interview, non response rate etc in the pilot survey will help us to estimate the time, cost and human resource required for the national mental health survey. The pilot survey also helped us in refining our tools and making it fit more in the local context. For example we realized that, for making the interview effective we need to add the bridging sentences before transitioning from one module to another. Similarly, we could also prepare a list of local names for some terminology in the questionnaire. This will be included in the final questionnaire in the national level survey.

Based on the experiences from the pilot survey, we recommend that for the national mental health survey, the tools should be refined after incorporating the feedback received from the FDCs and supervisors in the pilot survey. Similarly, comprehensive practice based training, including interviews with the real patients should be provided to the FDCs and supervisors before moving to the field for data collection. There were some disorders for which we did not find any cases during the pilot survey. This should be further discussed among the experts and the possible reasons for the results should be analyzed. We also recommend that providing the participants with leaflet or pamphlets with basic information about mental disorders, common symptoms, and their management along with the contact details of the nearby mental health service provider will be helpful for the participants. We also recommend that adequate time should be given for the effective coordination in the local level including coordination with the female community health volunteers.

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ANNEX I: Photographs