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Multiple barriers to participation for people with psychosocial disability in Dehradun district, North India – a cross-sectional study

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Text – 3206 words (excluding title page, abstract, references, figures and tables)

Abstract –

OBJECTIVES

This study used a population-based cross-sectional survey to describe the prevalence of psycho-social disability and unmet need for access to services in North India

SETTING

This study was conducted in Dehradun district, Uttarakhand in 2014.

PARTICIPANTS

A population-based sample of 2441 people over the age of 18 years

PRIMARY OUTCOME MEASURES

The Rapid Assessment of Disability (RAD) survey tool identified people with disability and used an adapted version of the Kessler scale to identify those with psycho-social disability. It additionally collected information on socio-economic variables, access to community services and barriers to participation. Prevalence of psycho-social disability and unmet needs, and descriptions of barriers to services were calculated, and multi-variable logistic regression were used to assess associations between risk factors and psycho-social disability.

RESULTS

Prevalence of psycho-social disability was 4.8 % and 75% of participants with psychological distress also reported comorbid functional impairments. Adjusted odds-ratios for depression of more than 2 were found for people who were unschooled, unemployed and of moderate or poor socio-economic status. The unmet need for access to services was significantly higher in every domain for people with psycho-social disability and was more than 25% in the areas of employment, health service access and community consultation. People with psycho-social disability encountered greater barriers in each domain compared to controls.

CONCLUSIONS

People who are poor, uneducated and unemployed are two to four times more likely to have psycho-social disability in Dehradun district. They face unmet needs in accessing community services and perceive negative social attitudes, lack of physical accessibility and lack of information as barriers limiting their participation. Social policy must increase access to education and reduce poverty but additionally ensure action is taken in all community services to increase information, physical accessibility and social inclusion of people with psycho-social and other forms of disability.

KEY WORDS

Depression

Anxiety

Mental health

Epidemiology

STRENGTHS AND LIMITATIONS

- This study uses a community-based randomly selected sample of adults to assess prevalence of psycho-social disability and barriers to participation
- This study presents one of the first assessments of barriers to community participation for people with psycho-social disability in India
- A limitation of this study is that it uses an adapted Kessler - 6 scale as screening tool to assess psycho-social disability rather than a definitive clinical assessment
- The cross-sectional design cannot indicate causation and the survey covered only one block in one district of Uttarakhand state, which may limit generalisability.

CONTRIBUTORSHIP STATEMENT

NG, GVS and MM conceived of the study and the overall design, HP and KM performed data analysis, and KM wrote the first and subsequent drafts. LS supported data collection and NG and MM supported study design, analysis and overview of the whole paper. All authors provided input into drafts of the paper.

FUNDING STATEMENT

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INTRODUCTION

Mental illness was the leading cause of years lived with disability in the 2010 Global Burden of Disease study, with the majority of people affected living in low and middle income countries (LMIC). Psycho-social disability is a term increasingly preferred by people who use mental health services, and includes related negative social impacts of psychological or social disability including discrimination, and exclusion. We use this term to support our stance that many barriers are related to the way society limits the personal, social, political and economic power of people with disability [1] [2].

To allow people with disabilities to fully enjoy all human rights and fundamental freedoms, the United Nations Convention on the Rights of Persons with Disability (UNCRPD) acknowledges “the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication” [3]. Yet this accessibility is significantly limited for many people with disabilities due to lack of regulation of law and policies, social attitudes, lack of financial resources and a lack of evidence-based research to quantify and implement solutions.

While many people with psycho-social disability are physically able to access services, barriers include real and perceived negative attitudes, limited motivation and self-belief and limited social role functioning. Policy guidance on social inclusion and community participation in the sphere of global mental health has been broad, with few specifics on what to measure and how to operationalise or measure participation by affected individuals [4]. In a paper describing the top 40 challenges for Global Mental health in 2011, *‘ to develop culturally informed methods to eliminate the stigma, discrimination and social exclusion of patients and families across cultural settings’* was ranked as the second most important challenge [5]. To engage and respond to the real challenges for psycho-social disability, we also need to conceptualise what community participation and social inclusion ‘look like’ and generate data to understand access to services, and barriers limiting participation[4].

Social inclusion has been identified as key to reducing health inequalities by increasing health-related knowledge [6], improving people’s control of their health and promoting healthy behaviours [7]. Participation can impact directly and indirectly on health. Opportunity to participate in accessing sanitation, clean water, health and education services can directly improve health. However participation in domains of life such as community consultations, religious gatherings and disabled persons groups can also indirectly impact health through strengthened social capital, social inclusion and a sense of belonging [6 8]. Within a broader study of diability[9] the aim of this study was to describe the prevalence of psycho-social disability and its association with social determinants of health and to examine barriers to participation between people with and without psycho-social disability.

METHODS

A cross sectional population based survey was completed in 2015 in Sahaspur block, Dehradun District in the northern Indian state of Uttarakhand using the Rapid Assessment of Disability (RAD) survey. The RAD survey was developed by the Nossal Institute for Global Health and the Centre for Eye Research Australia at The University of Melbourne, and was validated in Bangladesh and Fiji [10]. Greater detail on the methods used in this study are provided in another paper which examined the prevalence of all types of disability and its’ associations with health determinants and access and barriers to community services [9].

Sampling

The main study was conducted on a sample of 2441 individuals aged 18 years and over from Sahaspur block in Dehradun District. This study used a two-stage cluster random sampling where 50 clusters from 114 villages in Sahaspur block using probability proportion to size sampling. The second stage involved dividing each selected cluster into five distinct segments from which 10 people aged 18 years and above were selected from each segment to reach a total of 50 participants. Finally, for each person identified to be at risk of disability, an age (+/- 2 years) and gender matched control was recruited from an adjacent household.

Data collection and the survey tool

After forming ten data collection teams (which included people with disability), a four-day data-collection training was conducted. The RAD provides the ability to measure disability in a population and understand the barriers to participation across a range of life domains [10]. The RAD included an interviewer-administered household questionnaire conducted with the household head, and an individual questionnaire. The household questionnaire assessed the household demographics, characteristics and assets.

The individual questionnaire had four sections. Demographic information including age, gender, ethnicity, religion, marital status, education level and occupation as Section One. The second section was self-assessment of functioning designed to capture functional limitations on activities related to vision, hearing, communication, mobility, gross and fine motor skills, cognition, appearance and psychological distress. This study reports on the psychological distress component, which is a modified version of the Kessler-6 (K-6) scale which assesses anxiety and depression [11]. The response categories for the modified K-6 used in RAD were 'none', 'some of the time', 'most of the time,' and 'all of the time'. Participants were considered to have a disability if they had difficulties "most of the time" or "all of the time" in at least two domains in the items on Kessler's scale. Section three of the RAD comprised 16 questions related to general health, relationships, respect and taking of one's self and assessed the individual's perception of well-being. Questions were reported on a four-point Likert scale ranging from 'never' to 'all of the time'. Section four assessed the level of access to different services and participation in the community under domains such as health, education, work, rehabilitation, and social and religious activities. If a participant reported more than one barrier, they were asked to report the most limiting barrier. In this paper, the most limiting barriers were reported.

Statistical analysis

Statistical analysis used Stata 14.0 [12]. Odds ratios, both crude and adjusted were calculated using logistic regression to assess the association between psycho-social disability, marital status, age, gender, socio-economic status, employment and schooling. Chi square and Fisher's exact tests were performed.

Any form of school attendance was classified as 'schooled' and the five age categories were used (18-24, 25-34, 35-44, 45-54 and ≥ 55 years). Employment categories used were employed, not employed and home maker. The reference group characteristics were: male, 18-24 years, any schooling, not married, employed and of high socioeconomic status. To calculate the asset index, principal component analysis was used (rescaled to 0-1) as a proxy for socioeconomic status [16] using categorisations of poor (between 0 and 0.4), middle class (between 0.4 and 0.8) and rich (between 0.8 and 1). Persons with psychosocial disabilities (cases) and persons without psychosocial disability (controls) were matched for age and sex to understand barriers of service utilisation and participation and compared.

The ethics committee at the Indian Institute of Public Health - Hyderabad and the ethics committee of the CHGN Uttarakhand Cluster granted ethics approval. Written informed consent was obtained in ways appropriate for specific disabilities and people who were not literate gave witnessed verbal consent. A plain language statement was provided to each participant.

RESULTS

Out of 2500 people invited to undertake the survey, 2441 (97.6%) surveys were completed. The mean age of the participants was 40.4 ± 15.2 years and 51.6% (n=1260) were male. Socio-demographic profile of the participants is presented in Table 1.

Table 1. Profile of socio-demographic characteristics of survey participants

	Categories	Total sample n (%)	People without psychosocial disability n (%)	People with psychosocial disability n (%)
Total		2441 (100)	2326 (95.2)	117 (4.8)
Age	18-24 years	410 (16.8)	397 (17.1)	13 (11.0)
	25-34 years	544 (22.3)	522 (22.5)	22 (18.6)
	35-44 years	586 (24.0)	565 (24.3)	21 (17.8)
	45-54 years	396 (16.2)	381 (16.4)	15 (12.7)
	≥ 55 years	505 (20.7)	458 (19.7)	46 (39.8)
Gender	Male	1,260 (51.6)	1,196 (51.5)	64 (54.2)
	Female	1,181 (48.4)	1,127 (48.5)	53 (45.8)

The prevalence of psycho- social disability according to the study definition was 4.8%. with the prevalence of other types of disability self-reported at less than 2%. Of note, the prevalence of psychological distress, with no functional impairment, was only 1.2% meaning 75% of participants with psycho-social disability also reported comorbid functional impairments. Table 2 represents a model for the prevalence of psycho-social disability, adjusting for age, gender, marital status, occupation, and education.

Table 2: Association between socio-demographic factors and psycho-social disability

Schooling	Yes	1,888 (77.4)	1,828 (78.7)	60 (50.9)
	No	553 (22.7)	495 (21.3)	57 (49.2)
Socio-economic status	Poor	998 (40.9)	933 (40.2)	65 (55.1)
	Middle	983 (40.3)	939 (40.4)	43 (37.3)
	Rich	460 (18.8)	451 (19.4)	9 (7.6)
Marital status	Single	409 (16.8)	389 (16.8)	20 (17.0)
	Married	1,866 (76.4)	1,789 (77.0)	76 (65.3)
	Separated/Divorced/ Widowed	166 (6.8)	145 (6.2)	21 (17.8)
Occupation	Employed	1,222 (52.2)	1,175 (52.9)	47 (40.2)
	Homemaker	834 (35.7)	796 (35.8)	38 (32.5)
	None	283 (12.1)	251 (11.3)	32 (27.4)

	Categories	**Prevalence of psychosocial disability (%) Sample *n*=2411**	**Unadjusted OR (95%CI) *n*=117**	**Adjusted OR (95%CI) *n*=117**	**Psychosocial disability alone (excluding those with functional impairment) Adjusted OR (95% CI) *n*=29**
Age	18-24 years	3.17 (1.7-5.36)	-	-	-
	25-34 years	4.04 (2.55-6.06)	1.3 (0.64-2.59)	2.93 (1.0-8.78)	5.58 (0.52 -59.01)
	35-44 years	3.58 (2.22-5.43)	1.2 (0.56-2.29)	1.62 (0.31-8.41)	2.86 (0.24 – 34.73)
	45-54 years	3.79 (2.14-6.17)	1.2 (0.56-2.56)	1.41 (0.23-8.63)	5.77 (0.48 – 69.91)
	≥ 55 years	9.11 (6.75-11.96)	3.13 (1.66-5.91)	2.2 (0.59-8.22)	9.86 (0.91 – 109.63)
Gender	Female	4.49 (3.38-5.82)			2.89 (0.9 – 9.09)
	Male	5.07 (3.93-5.44)	1.12 (0.77-1.62)	1.27 (0.72-2.21)	
Schooling	Yes	3.18 (2.43-4.07)			
	No	10.31 (7.90 -13.15)	3.6 (2.44-5.21)	2.3 (1.25-3.85)*	2.29 (0.95 – 5.53)
Marital status	Married	4.89(3.01-7.45)			
	Single	4.07(3.22-5.07)	0.81 (0.51-1.39)	0.43 (0.20-0.95)*	1.39 (0.33 – 5.95)
	Separate/ widowed/ divorced	12.65 (8.0-18.68)	2.82 (1.47-5.39)	3.25 (0.56-8.96)	2.05 (0.38 – 11.13)
Occupation	Employed	3.84 (2.89-5.08)			
	Homemaker	4.43 (3.14-6.06)	1.19 (0.77-1.85)	1.07 (0.58-2.0)	3.13 (1.0 - 10.81)*
	Unemployed	11.31 (7.86-15.58)	3.19 (1.98-5.12)	2.90 (1.60-5.26)*	1.09 (0.40 – 2.95)
Socio-economic status	Rich	1.96(0.9-3.68)			
	Middle	4.37 (3.18-5.85)	2.35 (1.13-4.86)	3.90 (1.57-9.67) *	0.53 (0.12 – 2.3)
	Poor	6.41 (5.06-8.22)	3.49 (1.72-7.1)	4.63 (1.88-11.43)*	1.13(0.27 – 4.02)

An * denotes a statistically significant association.

Table 2 demonstrates that the odds of having psycho-social disability were significantly higher in those with no schooling (2.3 times higher than those with schooling), unemployed people (2.9 times higher than those employed) and people in both the middle and poorer levels of socio-economic status (3.9 and 4.6 times high respectively than those of rich socio-economic status). The adjusted odds for psycho-social disability without functional impairment however finds almost no statistically significant associations with these socio-demographic variables which show wide confidence intervals. This suggests that for these study participants, co-morbid functional impairment is a significant risk factor for psycho-social disability. Table 3 explores unmet need among people with and without psycho-social disability.

Table 3. Unmet need in those with psychosocial disability versus those without psycho-social disability (selected domains)

Domain	Need (In the last 6 months, to what extent have you been able to access...?)	People with PSD (*n* = 117)	%	People without PSD (*n = 2326*)	%	P-Value
Work	MET NEED	43	36.75	106	56.08	<0.001
	UNMET NEED	45	38.46	27	14.29	
	Have not wanted to work for a living	29	24.79	56	29.63	
Health Services	MET NEED	66	56.41	108	57.41	<0.001
	UNMET NEED	33	28.21	25	13.23	
	Have not needed health services access	18	15.38	56	29.63	
Community Consultations	MET NEED	31	25.5	95	50.26	<0.001
	UNMET NEED	36	30.77	28	14.81	
	Have not wanted to participate	50	42.74	66	34.92	
Disabled Persons' Organisations (DPOs)	MET NEED	7	5.98	7	3.7	<0.001
	UNMET NEED	13	11.11	10	5.29	
	Have not wanted to access DPOs	6	5.13	60	31.75	
	Do not know what DPOs are	91	77.78	112	59.26	
Social Activities	MET NEED	52	44.44	119	62.96	<0.001
	UNMET NEED	28	23.93	10	5.29	
	Have not wanted to participate	37	31.62	60	31.75	
Sanitation	MET NEED	100	85.47	187	98.94	<0.001
	UNMET NEED	17	14.53	2	1.06	
Safe Drinking Water	MET NEED	91	77.78	176	93.12	<0.001
	UNMET NEED	26	22.22	13	6.88	
Religion	MET NEED	73	62.39	139	73.54	0.001
	UNMET NEED	24	20.51	12	6.35	
	Have not wanted to participate in religion	20	17.09	38	20.11	

NB Domains measured but not listed above also addressed assistive devices and disaster management.

In Table 3, across different access domains the unmet need was significantly higher in every domain for people with psycho-social disability. More than a quarter of surveyed people with psycho-social disability described unmet need in relation to work (38%), health services (28%) and community consultation (30%). However, the unmet need was lower in some other domains as either the participants were not familiar with the service (e.g. nearly 80% of respondents did not know what a DPO was) or did not want to participate. Barriers faced in different domains of daily life were assessed and are summarised in Table 4 below.

Table 4. Summary of barriers experienced to access community services

Barriers	People with PSD (*n* = 117)	Average %	People without PSD (*n = 2326*)	Average %	P-value
Lack of information	155	50.7	104	34.0	<0.0001
Difficulty getting to services from home	103	33.7	70	22.9	0.01
Physical inaccessibility	38	12.4	119	38.9	<0.0001
Absence of reasonable accommodation	94	30.7	75	24.5	0.06
Cost	67	21.9	55	18.0	0.17
Absence of personal assistance to visit	75	24.5	49	16.0	0.03
Not available	41	13.4	56	18.3	0.02
Negative attitudes	54	17.6	35	11.4	0.03
Family has difficulty assisting access	38	12.4	25	8.2	0.02
Family did not want me to access	23	7.5	25	8.2	0.1

In assessing the barriers faced by people with psycho-social disability compared to controls, they encountered greater barriers in each domain. Those related to lack of information, physical inaccessibility of services and lack of accompanying assistance accessing services and perceived negative attitudes were significantly higher. Table 5 describes the types of barriers encountered under selected access domains. We present only the domains which demonstrated a consistent difference for people with and without psycho-social disability.

Table 5. Barriers faced by people with psycho-social disability vs those without (selected access domains)

Barriers	People with PSD n = 117	%	People without PSD	%	P-value
Place of work					
Lack of information about work	12	100	10	100	0.10
Negative attitudes towards me at work	11	9.4	4	2.1	<0.001*
Difficulty getting to work from home	17	14.5	11	5.8	0.01*
Health					
Lack of information about health services	18	15.4	12	6.4	0.01*
Negative attitudes towards me	8	6.8	4	2.1	0.04*
Difficulty getting to health services	13	11.1	8	4.2	0.02*
Community Consultations					
Lack of information about community consultations	14	12.0	18	9.5	0.50
Negative attitudes towards me	12	10.3	2	1.1	<0.001*
Difficulty getting to community meetings from home	16	13.7	7	3.7	<0.001*
Rehabilitation Services					

Lack of information about rehabilitation services	19	16.2	12	6.4	0.01*
Negative attitudes towards you from rehab services	4	3.4	0	0	0.01*
Difficulty getting to rehabilitation services from home	9	7.7	8	4.2	0.20
Safe drinking water					
Lack of information about accessible safe water	5	4.3	1	0.5	0.02*
Negative attitudes towards me	6	5.1	1	0.5	0.01*
Difficulty getting to safe water supplies (e.g. pumps, wells) from home	8	6.8	3	1.6	0.02*
Social Activities					
Lack of information about social activities	5	4.3	3	1.6	0.15
Negative attitudes towards me	5	4.3	2	1.1	0.07
Difficulty getting to social venues from home	13	11.1	1	0.5	<0.001*
Religion					
Lack of information about religious activities	5	4.3	3	1.6	0.15
Negative attitudes towards me	5	4.3	2	1.1	0.07
Difficulty getting to religious venues from home	11	9.4	3	1.6	<0.001*
Government Social Welfare Services					
Lack of information about Government social services	12	10.3	6	3.2	0.01**
Negative attitudes towards me	9	7.7	0	0.00	<0.001*
Difficulty getting to social welfare services	5	4.3	1	0.5	0.02*
Disabled Persons' Organisations					
Lack of information about DPO services[1]	11	9.4	3	1.6	<0.001*
Negative attitudes towards me	1	0.9	1	0.5	0.73
Difficulty getting to DPO venue from home	5	4.3	3	1.6	0.152
Education					
Lack of information about education or training	14	12.0	11	5.82	0.06
Negative attitudes towards you	4	3.4	1	0.53	0.05
Difficulty getting to education or training facilities	7	6.0	2	1.06	0.01*

NB Domains measured but not listed above also addressed assistive devices, disaster management and sanitation.

Lack of information about services as a barrier to access was significantly higher for people with psycho-social disability compared to matched controls in the domains of health services, rehabilitation services, safe drinking water, Government social services and DPOs i.e. in half of the domains described. There was also a significant difference in negative attitudes perceived by people with psycho-social disability compared to controls in over half of the domains i.e. in domains of workplace, health, community consultations, rehabilitation services, safe drinking water and Government social welfare services. Surprisingly perhaps, physical accessibility was also a barrier that was significantly greater for people with psycho-social disability compared to controls (described in eight of ten domains).

DISCUSSION

This cross-sectional survey in Sahaspur Block of Dehradun district revealed a prevalence of psycho-social disability of 4.8%, considerably higher than 0.06% prevalence rate for psychosocial disability described in the 2011 census in Uttarakhand [13]. The broad definition of PSD used in this survey as well as the use of non-stigmatising language is likely to have led to a higher number of people identified and may explain part of this difference in prevalence [9]. The prevalence identified in this study aligns with the prevalence of mental illness in India ranging from 3.4% to 8.9% described in meta-analytic studies, using a range of tools and definitions [14 15] and also aligns fairly closely with a recent cross-sectional population survey conducted in the district of Dehradun conducted by the

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[1] Other aspects of the DPO domain had too few numbers for useful analysis

same lead author, that described the prevalence of depression as 6.0%, using a depression screening tool [16].

This study finds risks of psycho-social disability are two to four times higher among people who have low education, unemployment and middle or low socio-economic status. Given that three-quarters of those who identified themselves as having psycho-social disability also described a co-morbid functional impairment it seems likely that functional impairment itself is a factor increasing mental distress. This significant contribution of social determinants of health was also found in the cross-sectional study of depression described above where the risk of depression was two to four times higher among people with limited schooling, poor housing, indebtedness and membership of oppressed castes [16]. The mechanisms by which social health determinants lead to increased psycho-social disability are likely to be complex with multiple mediating factors [17]. In this study we cannot determine the direction of causation however a systematic review that assessed links between common mental disorders and poverty similarly found strong relationships between education, housing, SES and common mental disorders and suggests that poverty and common mental disorders interact in a 'vicious cycle' [17]. Figure 1 shows a possible model for the two-way interaction of poverty and psycho-social disability and we propose that disability and other functional limitations can be located under the title of 'social causation'. We propose that "Disability/ functional limitation" should be added under the title 'Social causation'.

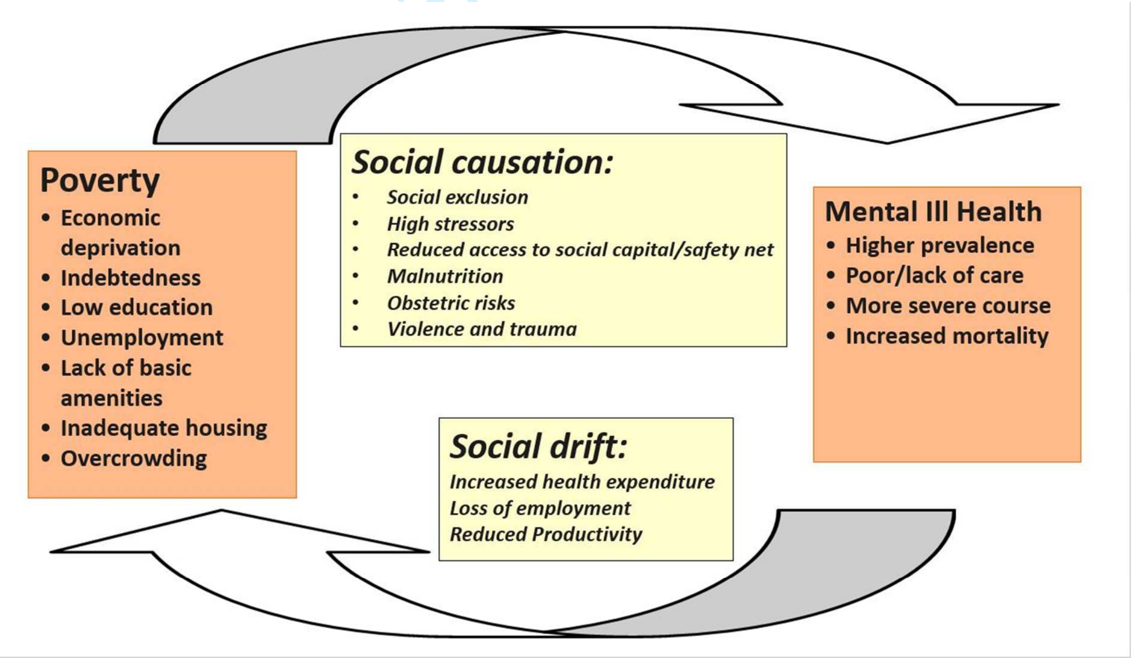

Figure 1. Diagram developed by Crick et al, proposing a two-way interaction between poverty and mental ill-health [17]

The high rate of co-morbid functional impairment reported in this study suggests a high rate of other forms of disability mixed with psycho-social disability although this cross-sectional study cannot ascertain directionality and causation (it is likely that those with functional impairment are also at higher risk of psycho-social distress). This finding is supported by this study's assessment of barriers to community services where there is a high rate of reporting of physical barriers to services and in particular, identification of the lack of physical access/ transport difficulties for people with psycho-social disability. It clearly points to the need for policies and programmes to promote mental health knowledge and skills for all people with disabilities. Additionally, mental health policies and programmes must ensure inclusion of all people with disabilities, and seek to reduce the multiple types of barriers that limit access to care and community participation.

This study presents one of the first accounts of barriers experienced by people with psycho-social disability for access to services in India. While the UNCRPD makes it clear that disability is influenced by both medical limitations and social prejudice, the ways that this plays out for people who suffer from psycho-social disability to limit their community participation is rarely assessed. The three key barriers to participation most frequently identified by participants with psycho-social disability in this study are related to attitudes (negative attitudes towards me), practices (lack of accommodation to support access to services) and structures (e.g. making it difficult to get to services), which are similar to findings in a study examining participation of people with psycho-social disability in mental health policy development in South Africa [2]. Our study shows that people with psycho-social disability describe stigma (negative attitudes) as a significant barrier in nearly half of the domains of services described here. A number of papers have described experiences of stigma of people with psycho-social disability in India and in particular how this can negatively impact access to mental health services [18-20] however this study is likely the first paper to demonstrate how perceived negative attitude interact with domains of community participation. The impact of multiple marginalities such as membership of an excluded social group or having female gender and low education status adding to the disadvantage of disability has been identified as a basis for additional exclusion of those with PSD [21 22].

In the multiple domains assessed in this study lack of information and physical accessibility were also frequently perceived as barriers to participation by people with psycho-social disability. The contribution of co-existing functional impairment is likely to explain the barriers related to physical accessibility and transport. While lack of access to information is high (34%) in the general community, it is even higher for people with PSD (50%). Possible reasons why lack of information appears to be a greater barrier for people with psycho-social disability could be that this group has lower literacy and fewer social contacts and networks (so less information comes their way), and that they are less motivated in seeking out information. Perhaps this group also has reduced access to mass media such as television or radio.

There are ample policies and legal structures to promote access and participation for people with disabilities in India including those with PSD. India was one of the first countries to sign the UNCRPD and recently passed the Mental Health Care Act (2017) both documents of which include components to support participation and access to services. The new Rights of Persons with disabilities act (2016) clearly includes people with mental illness, and builds on the Persons with disabilities act (1995) to push for a more disabled inclusive and accessible environment [23]. At the same time, we join with others to observe that access to services and participation for people with PSD remains limited, and implementation and regulation are very weak links in the chain in relation to health services and policies in India [23 24].

Programmatic implementation at all levels must intentionally seek to include people with psycho-social disability. This demands attention to increasing the accessibility of community level structures such as transport and dissemination of information related to services and entitlements so that they reach people with psycho-social disability. This will require using mediums that are accessible to those who have low literacy and who have limited social networks such as loudspeaker announcements which are used widely and effectively by campaigning political parties in India. It also requires changes in attitudes at all levels in the community and among service providers. A number of steps can be taken to reduce stigma and increase social inclusion in programmes related to health, education and sanitation which include increasing awareness in the community, educating service providers and increasing direct contact between people with psycho-social disability and others [25].

This study indicates that psycho-social disability is significantly associated with macro-economic health determinants that are outside the health service sector, including disability and functional impairment. Macro-policies that address education and unemployment, with a focus on those who are socially excluded, as well as policy action to reduce poverty and socio-economic deprivation may well also reduce the disease burden related to psycho-social disability [26].

Methodological limitations

The Kessler tool is a screening rather than diagnostic tool, and excluded two key risk factors for psycho-social disability: stressful life events and chronic illness. While the Kessler-6 scale has been found to have moderate- to- high discriminating ability when used by lay workers in identifying common mental disorders in India [27 28], it did not screen for the whole spectrum of psychosocial disability. A limitation of the findings presented in Table 3 and 5 particularly is that the numbers are small reducing the reliability of the findings and meaning that some findings that may well have been significant with a larger sample, were not elucidated. The study is limited to adults of over 18 years of age, and so cannot assess the prevalence of psycho-social disability or barriers they face, among children. As the RAD survey tool used self-reported data there may be a risk of social desirability or recall bias. As a cross-sectional survey, it cannot attribute causality to apparent risk factors. A major strength of this study is that its data are from a randomly selected population covering rural, semi-urban and urban populations in North India. Multivariable analysis ensured that potentially confounding factors were considered.

CONCLUSIONS

Psycho-social disability in Dehradun district, Uttarakhand, with a prevalence of at least 4.8% is two or three times more common among people with co-morbid functional impairment who are economically deprived, who have had little education and who are unemployed. People with psycho-social disability face significant unmet needs related to community services and perceive negative social attitudes as a significant barrier limiting their participation in multiple domains. Social policy and programmes in India must take active steps to address social determinants of psycho-social disability such as increasing access to education and reduce economic deprivation. Additionally, action is needed at all levels of community programmes and services to increase social inclusion of people with psycho-social disability.

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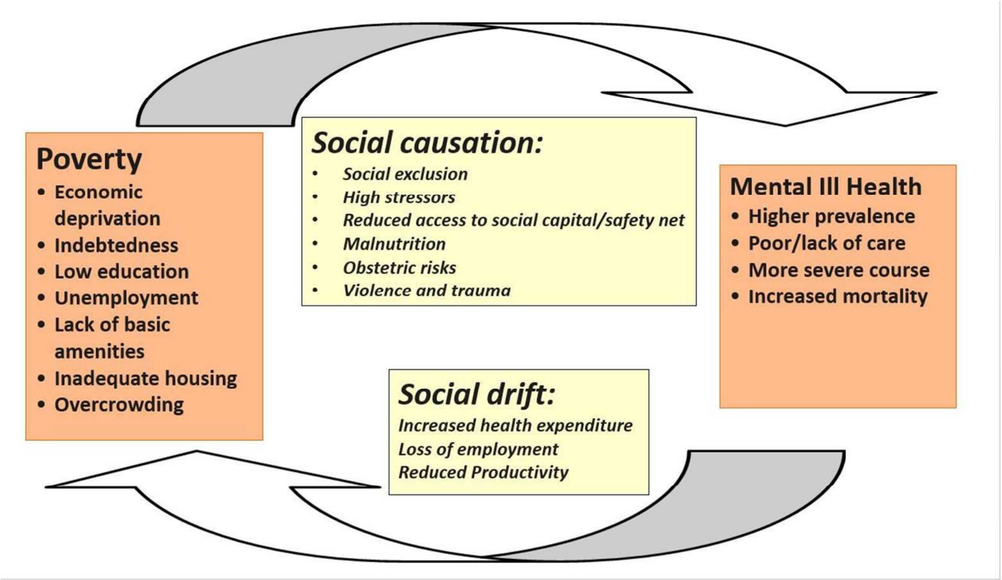

Figure 1. Diagram developed by Crick et al, proposing a two-way interaction between poverty and mental ill-health 17

230x134mm (144 x 144 DPI)

STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*

Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	Y
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	Y
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Y
Objectives	3	State specific objectives, including any pre-specified hypotheses	Y
Methods			
Study design	4	Present key elements of study design early in the paper	Y
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Y
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	Cross sectional – eligibility sources and methods - Y
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Y
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Y
Bias	9	Describe any efforts to address potential sources of bias	Y
Study size	10	Explain how the study size was arrived at	Y
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Y
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	Y
		(*b*) Describe any methods used to examine subgroups and interactions	Y
		(*c*) Explain how missing data were addressed	NA
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	Y

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	NA
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Y
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	Y
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Y
		(b) Indicate number of participants with missing data for each variable of interest	NA
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—Report numbers of outcome events or summary measures	Y
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	YY
		(*b*) Report category boundaries when continuous variables were categorized	Y
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Y
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Y
Discussion			
Key results	18	Summarise key results with reference to study objectives	Y
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	*Y*
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Y
Generalisability	21	Discuss the generalisability (external validity) of the study results	Y
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Y

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Multiple barriers to participation for people with psychosocial disability in Dehradun district, North India – a cross-sectional study

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Multiple barriers to participation for people with psychosocial disability in Dehradun district, North India – a cross-sectional study

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Abstract –

OBJECTIVES

This study used a population-based cross-sectional survey to describe the prevalence of psycho-social disability and unmet need for access to services in North India

SETTING

This study was conducted in Dehradun district, Uttarakhand in 2014.

PARTICIPANTS

A population-based sample of 2441 people over the age of 18 years

PRIMARY OUTCOME MEASURES

The Rapid Assessment of Disability (RAD) survey tool identified people with disability and used an adapted version of the Kessler scale to identify those with psycho-social disability. It additionally collected information on socio-economic variables, access to community services and barriers to participation. Prevalence of psycho-social disability and unmet needs, and descriptions of barriers to services were calculated, and multi-variable logistic regression were used to assess associations between risk factors and psycho-social disability.

RESULTS

Prevalence of psycho-social disability was 4.8 % and 75% of participants with psychological distress also reported comorbid functional impairments. Adjusted odds-ratios for depression of more than 2 were found for people who were unschooled, unemployed and of moderate or poor socio-economic status. The unmet need for access to services was significantly higher in every domain for people with psycho-social disability and was more than 25% in the areas of employment, health service access and community consultation. People with psycho-social disability encountered greater barriers in each domain compared to controls.

CONCLUSIONS

People who are poor, uneducated and unemployed are two to four times more likely to have psycho-social disability in Dehradun district. They face unmet needs in accessing community services and perceive negative social attitudes, lack of physical accessibility and lack of information as barriers limiting their participation. Social policy must increase access to education and reduce poverty but additionally ensure action is taken in all community services to increase information, physical accessibility and social inclusion of people with psycho-social and other forms of disability.

KEY WORDS

Depression

Anxiety

Mental health

Epidemiology

STRENGTHS AND LIMITATIONS

- This study uses a community-based randomly selected sample of adults to assess prevalence of psycho-social disability and barriers to participation
- This study presents one of the first assessments of barriers to community participation for people with psycho-social disability in India
- A limitation of this study is that it uses an adapted Kessler - 6 scale as screening tool to assess psycho-social disability rather than a definitive clinical assessment
- The cross-sectional design cannot indicate causation and the survey covered only one block in one district of Uttarakhand state, which may limit generalisability.

CONTRIBUTORSHIP STATEMENT

NG, GVS and MM conceived of the study and the overall design, HP and KM performed data analysis, and KM wrote the first and subsequent drafts. LS supported data collection and NG and MM supported study design, analysis and overview of the whole paper. All authors provided input into drafts of the paper.

FUNDING STATEMENT

CBM (an international development organisation with a focus on disability) funded this research. As they are not a research council they do not use grant numbers.

DATA SHARING STATEMENT

There is no additional unpublished data from this study available.

INTRODUCTION

Mental illness was the leading cause of years lived with disability in the 2010 Global Burden of Disease study, with the majority of people affected living in low and middle-income countries (LMIC). Psycho-social disability as a term refers to people who have either received a mental health diagnosis or who have identified that they experience limitations in functioning in basic psychological and social activities, and who have experienced the negative social impacts of psychological or social disability including discrimination, and exclusion[1]. We use this term to support our stance of a social model of disability that recognises that many barriers experienced are related to the way society limits the personal, social, political and economic power of people with disability [1] [2], can be constant or episodic and can be understood assessing activities of daily living and functional ranges[3]

To allow people with disabilities to fully enjoy all human, political and civil rights and fundamental freedoms, the United Nations Convention on the Rights of Persons with Disability (UNCRPD) acknowledges "the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication" [4]. Yet in India, and beyond, at national and state levels, this accessibility is significantly limited for many people with disabilities due to lack of implementation and regulation of law and policies. Further barriers include stigma, lack of financial resources and a lack of evidence-based research to quantify and implement solutions.

While people with psycho-social disability are often physically able to access services, barriers for utilisation include real and perceived stigma, limited motivation and self-belief and limited social role functioning. Stigma and discrimination is a prevalent experience for PPSD in all parts of the world, and limits access to health care, opportunity and capacity for community participation[5] It results in unequal access to resources, capabilities and rights which leads to health inequalities and social exclusion[6]. Policy guidance on social inclusion and community participation in the sphere of global mental health has been broad, with few specifics on what to measure and how to operationalise or measure participation by affected individuals [7]. In a paper describing the top 40 challenges for Global Mental health in 2011, *' to develop culturally informed methods to eliminate the stigma, discrimination and social exclusion of patients and families across cultural settings'* was ranked as the second most important challenge [8]. To engage and respond to the real challenges for social exclusion and psycho-social disability, we recognise the contribution of the larger social, economic, cultural and political environment to the prevalence and experience of psycho-social disability. It is clear that people with greater social and economic disadvantage are at greater risk of common mental illnesses[9] and that this is particularly evident in LMIC[10].

The importance of social inclusion for access to services has become more evident, and it has been identified as key to reducing health inequalities by increasing health-related knowledge [11], improving people's control of their health and promoting healthy behaviours [12]. Participation can impact directly and indirectly on health. Opportunity to participate in accessing sanitation, clean water, health and education services can directly improve health. However participation in domains of life such as community consultations, religious gatherings and disabled persons groups can also indirectly impact health through strengthened social capital, social inclusion and a sense of belonging [11 13].

There is limited research in LMIC, and particularly little evidence from setting of North India, to understand the ways that social exclusion and disability interact for PPSD in access to services and community participation [7 8 14]. Within a broader study of diability[15] the aim of this study was to describe the prevalence of psycho-social disability and its association with social determinants of health and to examine barriers to participation among people with and without psycho-social disability.

METHODS

Setting

Publicly funded human resources and infra-structure for disability in Dehradun district, Uttarakhand, are limited, and although the state provides some residential institutional care for people with intellectual disability, and runs a disability resource centre, most PPSD do not access government services, with a recent study showing that as many as 96% of people screened as having depression did not have access to care[16].

A cross sectional population based survey was completed in 2015 in Sahaspur block, Dehradun District in the northern Indian state of Uttarakhand using the Rapid Assessment of Disability (RAD) survey. The RAD survey was developed by the Nossal Institute for Global Health and the Centre for Eye Research Australia at The University of Melbourne, and was validated in Bangladesh and Fiji, and underwent rigorous pre-testing and piloting in India to ensure content validity, prior to the actual survey[17]. Greater detail on the methods used in this study are provided in another paper which examined the prevalence of all types of disability and its' associations with health determinants and access and barriers to community services [15].

Sampling

The main study was conducted on a sample of 2441 individuals aged 15 years and over from Sahaspur block in Dehradun District. This study used a two-stage cluster random sampling where 50 clusters from 114 villages in Sahaspur block using probability proportion to size sampling, an approach that is useful when the units are of unequal sizes, and ensures the likelihood of a unit being selected is proportionate to the size of the represented population. The second stage involved dividing each selected cluster into five distinct segments from which 10 people aged 18 years and above were selected from each segment to reach a total of 50 participants. Finally, for each person identified to be at risk of disability, an age (+/- 2 years) and gender matched control was recruited from an adjacent household.

Data collection and the survey tool

Eleven data collectors, three of whom had a disability were identified: 8 females and 3 males aged between 19 and 53 years, and given a four-day training in data collection. The RAD provides the ability to measure disability in a population and understand the barriers to participation across a range of life domains [17]. The RAD included an interviewer-administered household questionnaire conducted with the household head, and an individual questionnaire. The household questionnaire assessed the household demographics, characteristics and assets.

The individual questionnaire had four sections. Demographic information including age, gender, ethnicity, religion, marital status, education level and occupation as Section One. The second section was self-assessment of functioning designed to capture functional limitations on activities related to vision, hearing, communication, mobility, gross and fine motor skills, cognition, appearance and psychological distress. This study reports on the psychological distress component, which is a modified version of the Kessler-6 (K-6) scale which is a tool validated to screen for both severe and common mental illness, although scoring of K-6 does not recommend a single-parameter cut-off score[18 19]. The response categories for the modified K-6 used in RAD were 'none', 'some of the time', 'most of the time,' and 'all of the time'. As this study was focusing on subjective experiences of limited functioning, participants were considered to have a disability if they had difficulties "most of the time" or "all of the time" in at least two domains in the items on Kessler's scale. Section three of the RAD comprised 16 questions related to general health, relationships, respect and taking of one's self and assessed the individual's perception of well-being. Questions were reported on a four-point Likert scale ranging from 'never' to 'all of the time'. Section four assessed the level of access to different services and participation in the community under domains of employment, health services, community consultations, disabled persons' organisations, social activities, sanitation, safe drinking water and religion. If a participant reported more than one barrier, they were asked to report the most limiting barrier. In this paper, only the most limiting barriers were reported.

Statistical analysis

Statistical analysis used Stata 14.0 [20]. Odds ratios, both crude and adjusted were calculated using logistic regression to assess the association between psycho-social disability, marital status, age, gender, socio-economic status, employment and schooling. Chi square and Fisher's exact tests were performed.

Any form of school attendance was classified as 'schooled' and the five age categories were used (18-24, 25-34, 35-44, 45-54 and ≥ 55 years). Employment categories used were employed, not employed and home maker. The reference group characteristics were: male, 18-24 years, any schooling, not married, employed and of high socioeconomic status. To calculate the asset index, principal component analysis was used (rescaled to 0-1) as a proxy for socioeconomic status [16] using categorisations of poor (between 0 and 0.4), middle class (between 0.4 and 0.8) and rich (between 0.8 and 1). Persons with psychosocial disabilities (cases) and persons without psychosocial disability (controls) were matched for age and sex to understand barriers of service utilisation and participation and compared.

The ethics committee at the Indian Institute of Public Health - Hyderabad and the ethics committee of the CHGN Uttarakhand Cluster granted ethics approval. Written informed consent was obtained in ways appropriate for specific disabilities and people who were not literate gave witnessed verbal consent. A plain language statement was provided to each participant.

RESULTS

Out of 2500 people invited to undertake the survey, 2441 (97.6%) surveys were completed. The mean age of the participants was 40.4 ± 15.2 years and 51.6% (n=1260) were male. Socio-demographic profile of the participants is presented in Table 1.

Table 1. Profile of socio-demographic characteristics of survey participants

	Categories	Total sample n (%)	People without psychosocial disability n (%)	People with psychosocial disability n (%)
Total		2441 (100)	2326 (95.2)	117 (4.8)
Age	18-24 years	410 (16.8)	397 (17.1)	13 (11.0)
	25-34 years	544 (22.3)	522 (22.5)	22 (18.6)
	35-44 years	586 (24.0)	565 (24.3)	21 (17.8)
	45-54 years	396 (16.2)	381 (16.4)	15 (12.7)

The prevalence of psycho- social disability according to the study definition was 4.8%. with the prevalence of other types of disability self-reported at less than 2%. Of note, the prevalence of psychological distress, with no functional impairment, was only 1.2% meaning 75% of participants with psycho-social disability also reported comorbid functional impairments such as difficulties with mobility or eye-sight. Table 2 represents a model for the prevalence of psycho-social disability, adjusting for age, gender, marital status, occupation, and education.

Table 2: Association between socio-demographic factors and psycho-social disability

	≥ 55 years	505 (20.7)	458 (19.7)	46 (39.8)
Gender	Male	1,260 (51.6)	1,196 (51.5)	64 (54.2)
	Female	1,181 (48.4)	1,127 (48.5)	53 (45.8)
Schooling	Yes	1,888 (77.4)	1,828 (78.7)	60 (50.9)
	No	553 (22.7)	495 (21.3)	57 (49.2)
Socio-economic status	Poor	998 (40.9)	933 (40.2)	65 (55.1)
	Middle	983 (40.3)	939 (40.4)	43 (37.3)
	Rich	460 (18.8)	451 (19.4)	9 (7.6)
Marital status	Single	409 (16.8)	389 (16.8)	20 (17.0)
	Married	1,866 (76.4)	1,789 (77.0)	76 (65.3)
	Separated/Divorced/ Widowed	166 (6.8)	145 (6.2)	21 (17.8)
Occupation	Employed	1,222 (52.2)	1,175 (52.9)	47 (40.2)
	Homemaker	834 (35.7)	796 (35.8)	38 (32.5)
	None	283 (12.1)	251 (11.3)	32 (27.4)

	Categories	**Prevalence of psychosocial disability using Kessler screening tool (%) Sample *n*=2411**	**Unadjusted OR (95%CI) *n*=117**	**Adjusted OR (95%CI) *n*=117**
Age	18-24 years	3.17 (1.7-5.36)	-	-
	25-34 years	4.04 (2.55-6.06)	1.3 (0.64-2.59)	2.93 (1.0-8.78)
	35-44 years	3.58 (2.22-5.43)	1.2 (0.56-2.29)	1.62 (0.31-8.41)
	45-54 years	3.79 (2.14-6.17)	1.2 (0.56-2.56)	1.41 (0.23-8.63)
	≥ 55 years	9.11 (6.75-11.96)	3.13 (1.66-5.91)	2.2 (0.59-8.22)
Gender	Female	4.49 (3.38-5.82)		
	Male	5.07 (3.93-5.44)	1.12 (0.77-1.62)	1.27 (0.72-2.21)
School-ing	Yes	3.18 (2.43-4.07)		
	No	10.31 (7.90 -13.15)	3.6 (2.44-5.21)	2.3 (1.25-3.85)*
Marital status	Married	4.89(3.01-7.45)		
	Single	4.07(3.22-5.07)	0.81 (0.51-1.39)	0.43 (0.20-0.95)*
	Separate/ widowed/ divorced	12.65 (8.0-18.68)	2.82 (1.47-5.39)	3.25 (0.56-8.96)
Occupation	Employed	3.84 (2.89-5.08)		
	Homemaker	4.43 (3.14-6.06)	1.19 (0.77-1.85)	1.07 (0.58-2.0)
	Unemployed	11.31 (7.86-15.58)	3.19 (1.98-5.12)	2.90 (1.60-5.26)*
Socio-economic status	Rich	1.96(0.9-3.68)		
	Middle	4.37 (3.18-5.85)	2.35 (1.13-4.86)	3.90 (1.57-9.67) *
	Poor	6.41 (5.06-8.22)	3.49 (1.72-7.1)	4.63 (1.88-11.43)*

An * denotes a statistically significant association.

Table 2 demonstrates that the odds of having psycho-social disability were significantly higher in those with no schooling (2.3 times higher than those with schooling), unemployed people (2.9 times higher than those employed) and people in both the middle and poorer levels of socio-economic status (3.9 and 4.6 times high respectively than those of rich socio-economic status). Table 3 explores unmet need among people with and without psycho-social disability.

Table 3. Unmet need in those with psychosocial disability versus those without psycho-social disability (selected domains)

Domain	Need (In the last 6 months, to what extent have you been able to access...?)	People with PSD (*n* = 117)	%	People without PSD (*n = 2326*)	%	P-Value
Work	MET NEED	43	36.75	106	56.08	<0.001
	UNMET NEED	45	38.46	27	14.29	
Health Services	MET NEED	66	56.41	108	57.41	<0.001
	UNMET NEED	33	28.21	25	13.23	
Community Consultations	MET NEED	31	25.5	95	50.26	<0.001
	UNMET NEED	36	30.77	28	14.81	
Disabled Persons' Organisations (DPOs)	MET NEED	7	5.98	7	3.7	<0.001
	UNMET NEED	13	11.11	10	5.29	
Social Activities	MET NEED	52	44.44	119	62.96	<0.001
	UNMET NEED	28	23.93	10	5.29	
Sanitation	MET NEED	100	85.47	187	98.94	<0.001
	UNMET NEED	17	14.53	2	1.06	
Safe Drinking Water	MET NEED	91	77.78	176	93.12	<0.001
	UNMET NEED	26	22.22	13	6.88	
Religion	MET NEED	73	62.39	139	73.54	0.001
	UNMET NEED	24	20.51	12	6.35	

NB Domains measured but not listed above also addressed rehabilitation services, legal assistance, assistive devices and disaster management.

In Table 3, across different access domains the unmet need was significantly higher in every domain for people with psycho-social disability, however when we removed the group who described that they did not want to participate, the difference between met and unmet need was not significant for Disabled Persons Organisations. More than a quarter of surveyed people with psycho-social disability described unmet need in relation to work (38%), health services (28%) and community consultation (30%). However, the unmet need was lower in some other domains as either the participants were not familiar with the service (e.g. nearly 80% of respondents did not know what a DPO was) or did not want to participate. Barriers faced in the different domains of daily life described above were assessed and are summarised in Table 4 below.

Table 4. Summary of barriers experienced to access domains of community services

Barriers	People with PSD	Average	People without PSD	Average	P- value

	(*n* = 117)	%	(*n = 2326*)	%	
Lack of information	146	47.7	104	30.7	<0.0001*
Difficulty getting to services from home	113	36.9	64	20.9	0.01*
Physical inaccessibility	128	41.8	31	10.1	<0.0001*
Absence of reasonable accommodation	100	32.6	73	23.8	0.01*
Cost	75	24.5	51	16.6	0.06
Absence of personal assistance to visit	79	25.8	49	16.0	0.03*
Not available	41	13.4	56	18.3	0.01*
Negative attitudes	59	19.3	34	11.1	0.01*
Family has difficulty assisting access	26	8.4	26	8.4	0.15
Family did not want me to access	23	7.5	25	8.2	0.1

People with psycho-social disability encountered greater barriers in each domain than controls and Table 4 shows that barriers related to lack of information, difficulty getting to services, physical inaccessibility of services, unavailability of services, lack of reasonable accommodation, lack of accompanying assistance accessing services and perceived negative attitudes were significantly higher for PPSD. Table 5 describes the types of barriers encountered under selected access domains. We present only the domains which demonstrated a consistent difference for people with and without psycho-social disability.

Table 5. Barriers faced by people with psycho-social disability vs those without (selected access domains)

Barriers	**People with PSD n = 117**	**%**	**People without PSD**	**%**	**P-value**
Place of work					
Lack of information about work	12	10.26	10	5.29	0.10
Negative attitudes towards me at work	11	9.4	4	2.1	<0.001*
Difficulty getting to work from home	17	14.5	11	5.8	0.01*
Health					
Lack of information about health services	18	15.4	12	6.4	0.01*
Negative attitudes towards me	8	6.8	4	2.1	0.04*
Difficulty getting to health services	13	11.1	8	4.2	0.02*
Community Consultations					
Lack of information about community consultations	14	12.0	18	9.5	0.50
Negative attitudes towards me	12	10.3	2	1.1	<0.001*
Difficulty getting to community meetings from home	16	13.7	7	3.7	<0.001*
Rehabilitation Services					
Lack of information about rehabilitation services	19	16.2	12	6.4	0.01*
Negative attitudes towards you from rehab services	4	3.4	0	0	0.01*
Difficulty getting to rehabilitation services from home	9	7.7	8	4.2	0.20

Safe drinking water					
Lack of information about accessible safe water	5	4.3	1	0.5	0.02*
Negative attitudes towards me	6	5.1	1	0.5	0.01*
Difficulty getting to safe water supplies (e.g. pumps, wells) from home	8	6.8	3	1.6	0.02*
Social Activities					
Lack of information about social activities	5	4.3	3	1.6	0.15
Negative attitudes towards me	5	4.3	2	1.1	0.07
Difficulty getting to social venues from home	13	11.1	1	0.5	<0.001*
Religion					
Lack of information about religious activities	5	4.3	3	1.6	0.15
Negative attitudes towards me	5	4.3	2	1.1	0.07
Difficulty getting to religious venues from home	11	9.4	3	1.6	<0.001*
Government Social Welfare Services					
Lack of information about Government social services	12	10.3	6	3.2	0.01**
Negative attitudes towards me	9	7.7	0	0.00	<0.001*
Difficulty getting to social welfare services	5	4.3	1	0.5	0.02*
Disabled Persons' Organisations					
Lack of information about DPO services[1]	11	9.4	3	1.6	<0.001*
Negative attitudes towards me	1	0.9	1	0.5	0.73
Difficulty getting to DPO venue from home	5	4.3	3	1.6	0.152
Education					
Lack of information about education or training	14	12.0	11	5.82	0.06
Negative attitudes towards you	4	3.4	1	0.53	0.05
Difficulty getting to education or training facilities	7	6.0	2	1.06	0.01*

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Lack of information about services as a barrier to access was significantly higher for people with psycho-social disability compared to matched controls in the domains of health services, rehabilitation services, safe drinking water, Government social services and DPOs i.e. in half of the domains described. 'Negative attitudes towards you' was identified as a significant barrier to services for PPSD compared to controls in 6 of the 10 services described above. There was also a significant difference in negative attitudes perceived by people with psycho-social disability compared to controls in over half of the domains i.e. in domains of workplace, health, community consultations, rehabilitation services, safe drinking water and Government social welfare services. Surprisingly perhaps, physical accessibility was also a barrier that was significantly greater for people with psycho-social disability compared to controls (described in eight of ten domains).

DISCUSSION

This cross-sectional survey in Sahaspur Block of Dehradun district revealed a prevalence of psycho-social disability of 4.8%, considerably higher than 0.06% prevalence rate for psychosocial disability described in the 2011 census in Uttarakhand [21]. The broad definition of PSD used in this survey as well as the use of non-stigmatising language is likely to have led to a higher number of people identified and may explain part of this difference in prevalence [15]. The prevalence identified in this study aligns with the prevalence of mental illness in India ranging from 3.4% to 8.9% described in

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[1] Other aspects of the DPO domain had too few numbers for useful analysis

meta-analytic studies, using a range of tools and definitions [22 23] and also aligns fairly closely with a recent cross-sectional population survey conducted in the district of Dehradun conducted by the same lead author, that described the prevalence of depression as 6.0%, using a depression screening tool [16].

This study finds risks of psycho-social disability are two to four times higher among people who have low education, unemployment and middle or low socio-economic status. Given that three-quarters of those who identified themselves as having psycho-social disability also described a co-morbid functional impairment it seems likely that functional impairment itself may increase mental distress. This significant contribution of social determinants of health was also found in the cross-sectional study of depression described above where the risk of depression was two to four times higher among people with limited schooling, poor housing, indebtedness and membership of oppressed castes [16]. The mechanisms by which social health determinants lead to increased psycho-social disability are likely to be complex with multiple mediating factors [10]. In this study, we cannot determine the direction of causation however a systematic review that assessed links between common mental disorders and poverty similarly found strong relationships between education, housing, socio-economic status and common mental disorders, a finding supported by other key publications on social determinants of mental health. [9 24]. Figure 1 shows a possible model for the two-way interaction of poverty and common psycho-social disability in a vicious cycle. We propose that with a social model of disability, disability itself, and other functional limitations can be located under the title of ‘social causation’.

Figure 1. Diagram developed by Crick et al, proposing a two-way interaction between poverty and mental ill-health [10]

The high rate of co-morbid functional impairment reported in this study suggests a high rate of other forms of disability mixed with psycho-social disability although this cross-sectional study cannot ascertain directionality and causation (it is likely that those with functional impairment are also at higher risk of psycho-social distress). This finding is supported by this study’s assessment of barriers to community services where there is a high rate of reporting of physical barriers to services and in particular, identification of the lack of physical access/ transport difficulties for people with psycho-social disability. It clearly points to the need for policies and programmes to promote mental health knowledge and skills for all people with disabilities. Additionally, mental health policies and programmes must ensure inclusion of all people with disabilities, and seek to reduce the multiple types of barriers that limit access to care and community participation.

This study presents one of the first accounts of barriers experienced by people with psycho-social disability for access to services in India. While the total percentage numbers of PPSD who identify barriers to access community services are lower than expected, it is notable that PPSD are significantly more likely to describe barriers in multiple domains of life, when compared to matched controls. While the UNCRPD makes it clear that disability is influenced by both medical limitations and social prejudice, the ways that this plays out for people who suffer from psycho-social disability to limit their community participation is rarely assessed. The three key barriers to participation most frequently identified by participants with psycho-social disability in this study are related to attitudes (negative attitudes towards me), practices (lack of accommodation to support access to services) and structures (e.g. making it difficult to get to services), which are similar to findings in a study examining participation of people with psycho-social disability in mental health policy development in South Africa [2]. Our study shows that people with psycho-social disability describe stigma (negative attitudes) as a significant barrier in nearly half of the domains of services described here. A number of papers have described experiences of stigma of people with psycho-social disability in India and in particular how this can negatively impact access to mental health services [25-27] however this study is likely the first paper to demonstrate how perceived negative attitude interact with domains of community services and participation. Reasons why negative attitudes were not identified as limiting access to some community services is not clear and this is an area that requires further research. The impact of multiple marginalities such as membership of an excluded social group or having female gender and low education status adding to the disadvantage of disability has been identified as a basis for additional exclusion of those with PSD [28 29].

In the multiple domains assessed in this study lack of information and physical accessibility were also frequently perceived as barriers to participation by people with psycho-social disability. The contribution of co-existing functional impairment is likely to explain the barriers related to physical accessibility and transport. While lack of access to information is high (34%) in the general community, it is even higher for people with PSD (50%). Possible reasons why lack of information appears to be a greater barrier for people with psycho-social disability could be that this group has lower literacy and fewer social contacts and networks (so less information comes their way), and that they are less motivated in seeking out information. Perhaps this group also has reduced access to mass media such as television or radio.

There are ample policies and legal structures to promote access and participation for people with disabilities in India including those with PSD. India was one of the first countries to sign the UNCRPD and recently passed the Mental Health Care Act (2017) both documents of which include components to support participation and access to services. The new Rights of Persons with disabilities act (2016) clearly includes people with mental illness, and builds on the Persons with disabilities act (1995) to push for a more disabled inclusive and accessible environment [30]. At the same time, we join with others to observe that access to services and participation for people with PSD remains limited, and implementation and regulation are very weak links in the chain in relation to health services and policies in India [30 31].

Programmatic implementation at all levels must intentionally seek to include people with psycho-social disability. This demands attention to increasing the accessibility of community level structures such as transport and dissemination of information related to services and entitlements so that they reach people with psycho-social disability. This will require using mediums that are accessible to those who have low literacy and who have limited social networks such as loudspeaker announcements which are used widely and effectively by campaigning political parties in India. It also requires changes in attitudes at all levels in the community and among service providers. A number of steps can be taken to reduce stigma and increase social inclusion in programmes related to health, education and sanitation which include increasing awareness in the community, educating service providers and increasing direct contact between people with psycho-social disability and others [32].

A further clear message from this study is that since risk and protective factors for mental health act at several different levels, and include macro-economic health determinants, responses to them need to be multi-layered and multi-sectoral. Macro-policies that address poverty, education, welfare, transport, housing and employment sectors are required, with a 'health in all policies' approach[9].and seems likely to to also reduce the disease burden related to psycho-social disability [33].

Methodological limitations

The Kessler tool is a screening rather than diagnostic tool, and excluded two key risk factors for psycho-social disability: stressful life events and chronic illness. While the Kessler-6 scale has been found to have moderate- to- high discriminating ability when used by lay workers in identifying common mental disorders in India [34 35], it did not screen for the whole spectrum of psychosocial disability. A limitation of the findings presented in Table 3 and 5 particularly is that the numbers are small reducing the reliability of the findings and meaning that some findings that may well have been significant with a larger sample, were not elucidated. The study is limited to adults of over 18 years of age, and so cannot assess the prevalence of psycho-social disability or barriers they face, among children. As the RAD survey tool used self-reported data there may be a risk of social desirability or recall bias. As a cross-sectional survey, it cannot attribute causality to apparent risk factors. A major strength of this study is that its data are from a randomly selected population covering rural, semi-urban and urban populations in North India. Multivariable analysis ensured that potentially confounding factors were considered.

CONCLUSIONS

Psycho-social disability in Dehradun district, Uttarakhand, with a prevalence of at least 4.8% is two or three times more common among people with co-morbid functional impairment who are economically deprived, who have had little education and who are unemployed. People with psycho-social disability face significant unmet needs related to community services and perceive negative social attitudes as a significant barrier limiting their participation in multiple domains. Social policy and programmes in India must take active steps to address social determinants of psycho-social disability such as increasing access to education and reduce economic deprivation. Additionally, action is needed at all levels of community programmes and services to increase social inclusion of people with psycho-social disability.

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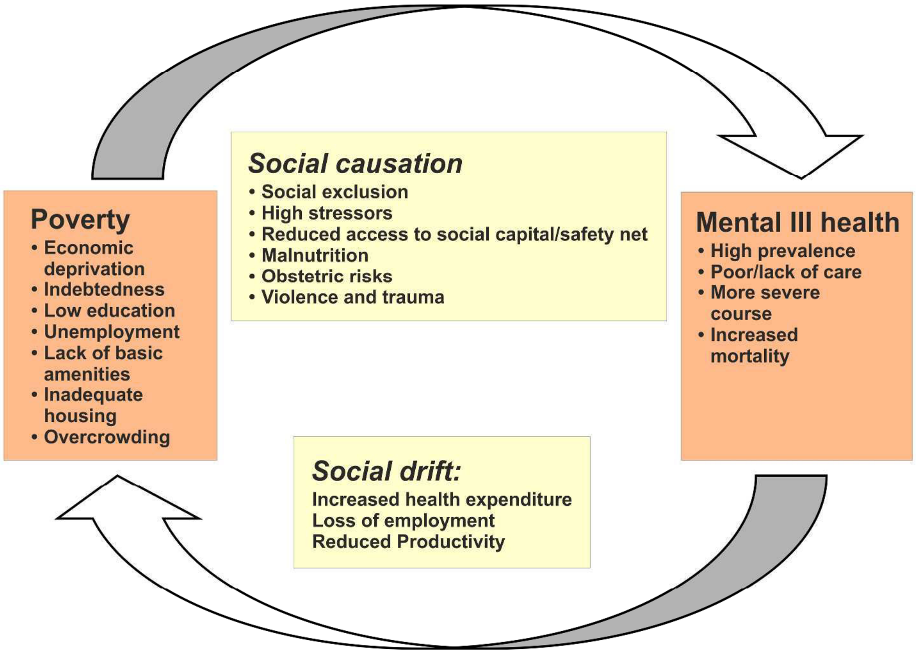

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STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*

Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	**Item #**	**Recommendation**	**Reported on page #**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	Y
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	Y
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Y
Objectives	3	State specific objectives, including any pre-specified hypotheses	Y
Methods			
Study design	4	Present key elements of study design early in the paper	Y
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Y
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	Cross sectional – eligibility sources and methods - Y
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Y
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Y
Bias	9	Describe any efforts to address potential sources of bias	Y
Study size	10	Explain how the study size was arrived at	Y
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Y
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	Y
		(*b*) Describe any methods used to examine subgroups and interactions	Y
		(*c*) Explain how missing data were addressed	NA
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	Y

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	NA
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Y
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	Y
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Y
		(b) Indicate number of participants with missing data for each variable of interest	NA
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—Report numbers of outcome events or summary measures	Y
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	YY
		(*b*) Report category boundaries when continuous variables were categorized	Y
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Y
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Y
Discussion			
Key results	18	Summarise key results with reference to study objectives	Y
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Y
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Y
Generalisability	21	Discuss the generalisability (external validity) of the study results	Y
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Y

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Multiple barriers to participation for people with psychosocial disability in Dehradun district, North India – a cross-sectional study

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Multiple barriers to participation for people with psychosocial disability in Dehradun district, North India – a cross-sectional study

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Abstract

OBJECTIVES

This study used a population-based cross-sectional survey to describe the prevalence of psycho-social disability and unmet need for access to services in North India

SETTING

This study was conducted in Dehradun district, Uttarakhand in 2014.

PARTICIPANTS

A population-based sample of 2441 people over the age of 18 years

PRIMARY OUTCOME MEASURES

The Rapid Assessment of Disability (RAD) survey tool identified people with disability and used an adapted version of the Kessler scale to identify those with psycho-social disability. It additionally collected information on socio-economic variables, access to community services and barriers to participation. Prevalence of psycho-social disability and unmet needs, and descriptions of barriers to services were calculated, and multi-variable logistic regression were used to assess associations between risk factors and psycho-social disability.

RESULTS

Prevalence of psycho-social disability was 4.8 % and 75% of participants with psychological distress also reported comorbid functional impairments. Adjusted odds-ratios for depression of more than 2 were found for people who were unschooled, unemployed and of moderate or poor socio-economic status. The unmet need for access to services was significantly higher in every domain for people with psycho-social disability and was more than 25% in the areas of employment, health service access and community consultation. People with psycho-social disability encountered greater barriers in each domain compared to controls.

CONCLUSIONS

People who are poor, uneducated and unemployed are two to four times more likely to have psycho-social disability in Dehradun district. They face unmet needs in accessing community services and perceive negative social attitudes, lack of physical accessibility and lack of information as barriers limiting their participation. Social policy must increase access to education and reduce poverty but additionally ensure action is taken in all community services to increase information, physical accessibility and social inclusion of people with psycho-social and other forms of disability.

KEY WORDS

Depression

Anxiety

Mental health

Epidemiology

STRENGTHS AND LIMITATIONS

- This study uses a community-based randomly selected sample of adults to assess prevalence of psycho-social disability and barriers to participation
- This study presents one of the first assessments of barriers to community participation for people with psycho-social disability in India
- A limitation of this study is that it uses an adapted Kessler - 6 scale as screening tool to assess psycho-social disability rather than a definitive clinical assessment
- The cross-sectional design cannot indicate causation

CONTRIBUTORSHIP STATEMENT

NG, GVS and MM conceived of the study and the overall design, HP and KM performed data analysis, and KM wrote the first and subsequent drafts. LS supported data collection and NG and MM supported study design, analysis and overview of the whole paper. All authors provided input into drafts of the paper.

FUNDING STATEMENT

CBM (an international development organisation with a focus on disability) funded this research. As they are not a research council they do not use grant numbers.

DATA SHARING STATEMENT

There is no additional unpublished data from this study available.

INTRODUCTION

Mental illness was the leading cause of years lived with disability in the 2010 Global Burden of Disease study, with the majority of people affected living in low and middle-income countries (LMIC). Psycho-social disability as a term refers to people who have either received a mental health diagnosis or who have identified that they experience limitations in functioning in basic psychological and social activities, and who have experienced the negative social impacts of psychological or social disability including discrimination, and exclusion[1]. We use this term to support our stance of a social model of disability that recognises that many barriers experienced are related to the way society limits the personal, social, political and economic power of people with disability [1 2], can be constant or episodic and can be understood assessing activities of daily living and functional ranges[3]

To allow people with disabilities to fully enjoy all human, political and civil rights and fundamental freedoms, the United Nations Convention on the Rights of Persons with Disability (UNCRPD) acknowledges “the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication” [4]. Yet in India, and beyond, at national and state levels, this accessibility is significantly limited for many people with disabilities due to lack of implementation and regulation of law and policies. Further barriers include stigma, lack of financial resources and a lack of evidence-based research to quantify and implement solutions.

While people with psycho-social disability are often physically able to access services, barriers for utilisation include real and perceived stigma, limited motivation and self-belief and limited social role functioning. Stigma and discrimination is a prevalent experience for PPSD in all parts of the world, and limits access to health care, opportunity and capacity for community participation[5] It results in unequal access to resources, capabilities and rights which leads to health inequalities and social exclusion[6]. Policy guidance on social inclusion and community participation in the sphere of global mental health has been broad, with few specifics on what to measure and how to operationalise or measure participation by affected individuals [7]. In a paper describing the top 40 challenges for Global Mental health in 2011, *‘ to develop culturally informed methods to eliminate the stigma, discrimination and social exclusion of patients and families across cultural settings’* was ranked as the second most important challenge [8]. To engage and respond to the real challenges for social exclusion and psycho-social disability, we recognise the contribution of the larger social, economic, cultural and political environment to the prevalence and experience of psycho-social disability. It is clear that people with greater social and economic disadvantage are at greater risk of common mental illnesses[9] and that this is particularly evident in LMIC[10].

The importance of social inclusion for access to services has become more evident, and it has been identified as key to reducing health inequalities by increasing health-related knowledge [11], improving people’s control of their health and promoting healthy behaviours [12]. Participation can impact directly and indirectly on health. Opportunity to participate in accessing sanitation, clean water, health and education services can directly improve health. However participation in domains of life such as community consultations, religious gatherings and disabled persons groups can also indirectly impact health through strengthened social capital, social inclusion and a sense of belonging [11 13].

There is limited research in LMIC, and particularly little evidence from setting of North India, to understand the ways that social exclusion and disability interact for PPSD in access to services and community participation [7 8 14]. Within a broader study of diability[15] the aim of this study was to describe the prevalence of psycho-social disability and its association with social determinants of health and to examine barriers to participation among people with and without psycho-social disability.

METHODS

Setting

Publicly funded human resources and infra-structure for disability in Dehradun district, Uttarakhand, are limited, and although the state provides some residential institutional care for people with intellectual disability, and runs a disability resource centre, most PPSD do not access government services, with a recent study showing that as many as 96% of people screened as having depression did not have access to care[16].

A cross sectional population based survey was completed in 2015 in Sahaspur block, Dehradun District in the northern Indian state of Uttarakhand using the Rapid Assessment of Disability (RAD) survey. The RAD survey was developed by the Nossal Institute for Global Health and the Centre for Eye Research Australia at The University of Melbourne, and was validated in Bangladesh and Fiji, and underwent rigorous pre-testing and piloting in India to ensure content validity, prior to the actual survey[17]. Greater detail on the methods used in this study are provided in another paper which examined the prevalence of all types of disability and its' associations with health determinants and access and barriers to community services [15].

Sampling

The main study was conducted on a sample of 2441 individuals aged 15 years and over from Sahaspur block in Dehradun District. This study used a two-stage cluster random sampling where 50 clusters from 114 villages in Sahaspur block using probability proportion to size sampling, an approach that is useful when the units are of unequal sizes, and ensures the likelihood of a unit being selected is proportionate to the size of the represented population. The second stage involved dividing each selected cluster into five distinct segments from which 10 people aged 18 years and above were selected from each segment to reach a total of 50 participants. Finally, for each person identified to be at risk of disability, an age (+/- 2 years) and gender matched control was recruited from an adjacent household to allow a comparison between persons with disabilities (cases) and persons without disability (controls) to understand the barriers of service utilisation and participation.

Data collection and the survey tool

Eleven data collectors, three of whom had a disability were identified: 8 females and 3 males aged between 19 and 53 years, and given a four-day training in data collection. The RAD provides the ability to measure disability in a population and understand the barriers to participation across a range of life domains [17]. The RAD included an interviewer-administered household questionnaire conducted with the household head, and an individual questionnaire. The household questionnaire assessed the household demographics, characteristics and assets.

The individual questionnaire had four sections. Demographic information including age, gender, ethnicity, religion, marital status, education level and occupation as Section One. The second section was self-assessment of functioning designed to capture functional limitations on activities related to vision, hearing, communication, mobility, gross and fine motor skills, cognition, appearance and psychological distress. All study participants (N = 2441) filled Sections One and Two of the survey. This study reports on the psychological distress component, which is a modified version of the Kessler-6 (K-6) scale which is a tool validated to screen for both severe and common mental illness, although scoring of K-6 does not recommend a single-parameter cut-off score[18 19]. The response categories for the modified K-6 used in RAD were 'none', 'some of the time', 'most of the time,' and 'all of the time'. As this study was focusing on subjective experiences of limited functioning, participants were considered to have a disability if they had difficulties "most of the time" or "all of the time" in at least two domains in the items on Kessler's scale. Section three of the RAD comprised 16 questions related to general health, relationships, respect and taking of one's self and assessed the individual's perception of well-being. Questions were reported on a four-point Likert scale ranging from 'never' to 'all of the time'. Section four assessed the level of access to different services and participation in the community under domains of employment, health services, community consultations, disabled persons' organisations, social activities, sanitation, safe drinking water and religion. If a participant reported more than one barrier, they were asked to report the most limiting barrier. In this paper, only the most limiting barriers were reported.From the total sample of participants selected for the study, only those identified to have disability and their age matched controls filled sections Three and Four (N = 306 people) were interviewed for sections 3 and 4 (which address well-being and adult access to community services), and of these, 117 had psycho-social disability and 189 (age and sex matched controls) did not have psycho-social disability.

Statistical analysis

Statistical analysis used Stata 14.0 [20]. Odds ratios, both crude and adjusted were calculated using logistic regression to assess the association between psycho-social disability, marital status, age, gender, socio-economic status, employment and schooling. Chi square and Fisher's exact tests were performed.

Any form of school attendance was classified as 'schooled' and the five age categories were used (18-24, 25-34, 35-44, 45-54 and ≥ 55 years). Employment categories used were employed, not employed and home maker. The reference group characteristics were: male, 18-24 years, any schooling, not married, employed and of high socioeconomic status. To calculate the asset index, principal component analysis was used (rescaled to 0-1) as a proxy for socioeconomic status [16] using categorisations of poor (between 0 and 0.4), middle class (between 0.4 and 0.8) and rich (between 0.8 and 1). Persons with psychosocial disabilities (cases) and persons without psychosocial disability (controls) were matched for age and sex to understand barriers of service utilisation and participation and compared.

The ethics committee at the Indian Institute of Public Health - Hyderabad and the ethics committee of the CHGN Uttarakhand Cluster granted ethics approval. Written informed consent was obtained in ways appropriate for specific disabilities and people who were not literate gave witnessed verbal consent. A plain language statement was provided to each participant.

RESULTS

Out of 2500 people invited to undertake the survey, 2441 (97.6%) surveys were completed. The mean age of the participants was 40.4 ± 15.2 years and 51.6% (n=1260) were male. Socio-demographic profile of the participants is presented in Table 1.

Table 1. Profile of socio-demographic characteristics of survey participants

	Categories	Total sample n (%)	People without psychosocial disability n (%)	People with psychosocial disability n (%)
Total		2441 (100)	2326 (95.2)	117 (4.8)

The prevalence of psycho- social disability according to the study definition was 4.8%. with the prevalence of other types of disability self-reported at less than 2%. Of note, the prevalence of psychological distress, with no functional impairment, was only 1.2% meaning 75% of participants with psycho-social disability also reported comorbid functional impairments such as difficulties with mobility or eye-sight. Table 2 represents a model for the prevalence of psycho-social disability, adjusting for age, gender, marital status, occupation, and education.

Table 2: Association between socio-demographic factors and psycho-social disability

Age	18-24 years	410 (16.8)	397 (17.1)	13 (11.0)
	25-34 years	544 (22.3)	522 (22.5)	22 (18.6)
	35-44 years	586 (24.0)	565 (24.3)	21 (17.8)
	45-54 years	396 (16.2)	381 (16.4)	15 (12.7)
	≥ 55 years	505 (20.7)	458 (19.7)	46 (39.8)
Gender	Male	1,260 (51.6)	1,196 (51.5)	64 (54.2)
	Female	1,181 (48.4)	1,127 (48.5)	53 (45.8)
Schooling	Yes	1,888 (77.4)	1,828 (78.7)	60 (50.9)
	No	553 (22.7)	495 (21.3)	57 (49.2)
Socio-economic status	Poor	998 (40.9)	933 (40.2)	65 (55.1)
	Middle	983 (40.3)	939 (40.4)	43 (37.3)
	Rich	460 (18.8)	451 (19.4)	9 (7.6)
Marital status	Single	409 (16.8)	389 (16.8)	20 (17.0)
	Married	1,866 (76.4)	1,789 (77.0)	76 (65.3)
	Separated/Divorced/ Widowed	166 (6.8)	145 (6.2)	21 (17.8)
Occupation	Employed	1,222 (52.2)	1,175 (52.9)	47 (40.2)
	Homemaker	834 (35.7)	796 (35.8)	38 (32.5)
	None	283 (12.1)	251 (11.3)	32 (27.4)

	Categories	**Prevalence of psychosocial disability using Kessler screening tool (%) Sample *n*=2411**	**Unadjusted OR (95%CI) *n*=117**	**Adjusted OR (95%CI) *n*=117**
Age	18-24 years	3.17 (1.7-5.36)	-	-
	25-34 years	4.04 (2.55-6.06)	1.3 (0.64-2.59)	2.93 (1.0-8.78)
	35-44 years	3.58 (2.22-5.43)	1.2 (0.56-2.29)	1.62 (0.31-8.41)
	45-54 years	3.79 (2.14-6.17)	1.2 (0.56-2.56)	1.41 (0.23-8.63)
	≥ 55 years	9.11 (6.75-11.96)	3.13 (1.66-5.91)	2.2 (0.59-8.22)
Gender	Female	4.49 (3.38-5.82)		
	Male	5.07 (3.93-5.44)	1.12 (0.77-1.62)	1.27 (0.72-2.21)
School-ing	Yes	3.18 (2.43-4.07)		
	No	10.31 (7.90 -13.15)	3.6 (2.44-5.21)	2.3 (1.25-3.85)*
Marital status	Married	4.89(3.01-7.45)		
	Single	4.07(3.22-5.07)	0.81 (0.51-1.39)	0.43 (0.20-0.95)*
	Separate/ widowed/ divorced	12.65 (8.0-18.68)	2.82 (1.47-5.39)	3.25 (0.56-8.96)
Occupation	Employed	3.84 (2.89-5.08)		
	Homemaker	4.43 (3.14-6.06)	1.19 (0.77-1.85)	1.07 (0.58-2.0)
	Unemployed	11.31 (7.86-15.58)	3.19 (1.98-5.12)	2.90 (1.60-5.26)*
Socio-economi	Rich	1.96(0.9-3.68)		
	Middle	4.37 (3.18-5.85)	2.35 (1.13-4.86)	3.90 (1.57-9.67) *

c status	Poor	6.41 (5.06-8.22)	3.49 (1.72-7.1)	4.63 (1.88-11.43)*

An * denotes a statistically significant association.

Table 2 demonstrates that the odds of having psycho-social disability were significantly higher in those with no schooling (2.3 times higher than those with schooling), unemployed people (2.9 times higher than those employed) and people in both the middle and poorer levels of socio-economic status (3.9 and 4.6 times high respectively than those of rich socio-economic status). Table 3 explores unmet need among people with and without psycho-social disability.

Table 3. Unmet need in those with psychosocial disability versus those without psycho-social disability (selected domains)

Domain	Need (In the last 6 months, to what extent have you been able to access...?)	People with PSD (*n* = 117)	%	People without PSD (*n = 189*)	%	P-Value
Work	MET NEED	43	36.75	106	56.08	<0.001
	UNMET NEED	45	38.46	27	14.29	
Health Services	MET NEED	66	56.41	108	57.41	<0.001
	UNMET NEED	33	28.21	25	13.23	
Community Consultations	MET NEED	31	25.5	95	50.26	<0.001
	UNMET NEED	36	30.77	28	14.81	
Social Activities	MET NEED	52	44.44	119	62.96	<0.001
	UNMET NEED	28	23.93	10	5.29	
Sanitation	MET NEED	100	85.47	187	98.94	<0.001
	UNMET NEED	17	14.53	2	1.06	
Safe Drinking Water	MET NEED	91	77.78	176	93.12	<0.001
	UNMET NEED	26	22.22	13	6.88	
Religion	MET NEED	73	62.39	139	73.54	0.001
	UNMET NEED	24	20.51	12	6.35	

NB Domains measured but not listed above also addressed rehabilitation services, legal assistance, assistive devices and disaster management.

In Table 3, across different access domains the unmet need was significantly higher in every domain for people with psycho-social disability, however when we removed the group who described that they did not want to participate, the difference between met and unmet need was not significant for Disabled Persons Organisations. More than a quarter of surveyed people with psycho-social disability described unmet need in relation to work (38%), health services (28%) and community consultation (30%). However, the unmet need was lower in some other domains as either the participants were not familiar with the service (e.g. nearly 80% of respondents did not know what a DPO was) or did not want to participate. Barriers faced in the different domains of daily life described above were assessed and are summarised in Table 4 below.

Table 4. Summary of barriers experienced to access domains of community services

Barriers	**People with PSD (*n* = 117)**	**Average %**	**People without PSD (*n = 189*)**	**Average %**	**P- value**
Lack of information	54	46.15	30	15.87	<0.0001*
Difficulty getting to services from home	20	17.09	14	7.41	0.009*
Physical inaccessibility	24	20.51	10	5.29	<0.0001*
Absence of reasonable accommodation	22	18.80	16	8.47	0.008*
Cost	23	19.66	16	8.47	0.004*
Absence of personal assistance to visit	79	67.52	49	25.93	0.03*
Not available	41	35.04	56	29.63	0.01*
Negative attitudes	59	50.43	34	17.99	0.01*
Family has difficulty assisting access	26	22.22	26	13.76	0.15

People with psycho-social disability encountered greater barriers in every domain compared to matched controls and Table 4 shows that barriers related to lack of information, difficulty getting to services, physical inaccessibility of services, unavailability of services, lack of reasonable accommodation, lack of accompanying assistance accessing services and perceived negative attitudes were significantly higher for PPSD. Table 5 describes the types of barriers encountered under selected access domains. We present only the domains which demonstrated a consistent difference for people with and without psycho-social disability.

Table 5. Barriers faced by people with psycho-social disability vs those without (selected access domains)

Barriers	**People with PSD n = 117**	**%**	**People without PSD n = 189**	**%**	**P-value**
Place of work					
Lack of information about work	12	10.26	10	5.29	0.10
Negative attitudes towards me at work	11	9.4	4	2.1	<0.001*
Difficulty getting to work from home	17	14.5	11	5.8	0.01*
Health					
Lack of information about health services	18	15.4	12	6.4	0.01*
Negative attitudes towards me	8	6.8	4	2.1	0.04*
Difficulty getting to health services	13	11.1	8	4.2	0.02*
Community Consultations					
Lack of information about community consultations	14	12.0	18	9.5	0.50
Negative attitudes towards me	12	10.3	2	1.1	<0.001*
Difficulty getting to community meetings from home	16	13.7	7	3.7	<0.001*
Rehabilitation Services					
Lack of information about rehabilitation services	19	16.2	12	6.4	0.01*
Negative attitudes towards you from rehab services	4	3.4	0	0	0.01*
Difficulty getting to rehabilitation services from home	9	7.7	8	4.2	0.20
Safe drinking water					
Lack of information about accessible safe water	5	4.3	1	0.5	0.02*
Negative attitudes towards me	6	5.1	1	0.5	0.01*
Difficulty getting to safe water supplies (e.g. pumps, wells) from home	8	6.8	3	1.6	0.02*
Social Activities					
Lack of information about social activities	5	4.3	3	1.6	0.15
Negative attitudes towards me	5	4.3	2	1.1	0.07
Difficulty getting to social venues from home	13	11.1	1	0.5	<0.001*
Religion					
Lack of information about religious activities	5	4.3	3	1.6	0.15
Negative attitudes towards me	5	4.3	2	1.1	0.07
Difficulty getting to religious venues from home	11	9.4	3	1.6	<0.001*
Government Social Welfare Services					
Lack of information about Government social services	12	10.3	6	3.2	0.01**
Negative attitudes towards me	9	7.7	0	0.00	<0.001*
Difficulty getting to social welfare services	5	4.3	1	0.5	0.02*
Disabled Persons' Organisations					
Lack of information about DPO services[1]	11	9.4	3	1.6	<0.001*
Negative attitudes towards me	1	0.9	1	0.5	0.73
Difficulty getting to DPO venue from home	5	4.3	3	1.6	0.152
Education					
Lack of information about education or training	14	12.0	11	5.82	0.06

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[1] Other aspects of the DPO domain had too few numbers for useful analysis

Negative attitudes towards you	4	3.4	1	0.53	0.05
Difficulty getting to education or training facilities	7	6.0	2	1.06	0.01*

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Lack of information about services as a barrier to access was significantly higher for people with psycho-social disability compared to matched controls in the domains of health services, rehabilitation services, safe drinking water, Government social services and DPOs i.e. in half of the domains described. 'Negative attitudes towards you' was identified as a significant barrier to services for PPSD compared to controls in 6 of the 10 services described above. There was also a significant difference in negative attitudes perceived by people with psycho-social disability compared to controls in over half of the domains i.e. in domains of workplace, health, community consultations, rehabilitation services, safe drinking water and Government social welfare services. Surprisingly perhaps, physical accessibility was also a barrier that was significantly greater for people with psycho-social disability compared to controls (described in eight of ten domains).

DISCUSSION

This cross-sectional survey in Sahaspur Block of Dehradun district revealed a prevalence of psycho-social disability of 4.8%, considerably higher than 0.06% prevalence rate for psychosocial disability described in the 2011 census in Uttarakhand [21]. The broad definition of PSD used in this survey as well as the use of non-stigmatising language is likely to have led to a higher number of people identified and may explain part of this difference in prevalence [15]. The prevalence identified in this study aligns with the prevalence of mental illness in India ranging from 3.4% to 8.9% described in meta-analytic studies, using a range of tools and definitions [22 23] and also aligns fairly closely with a recent cross-sectional population survey conducted in the district of Dehradun conducted by the same lead author, that described the prevalence of depression as 6.0%, using a depression screening tool [16].

This study finds risks of psycho-social disability are two to four times higher among people who have low education, unemployment and middle or low socio-economic status. Given that three-quarters of those who identified themselves as having psycho-social disability also described a co-morbid functional impairment it seems likely that functional impairment itself may increase mental distress. This significant contribution of social determinants of health was also found in the cross-sectional study of depression described above where the risk of depression was two to four times higher among people with limited schooling, poor housing, indebtedness and membership of oppressed castes [16]. The mechanisms by which social health determinants lead to increased psycho-social disability are likely to be complex with multiple mediating factors [10]. In this study, we cannot determine the direction of causation however a systematic review that assessed links between common mental disorders and poverty similarly found strong relationships between education, housing, socio-economic status and common mental disorders, a finding supported by other key publications on social determinants of mental health. [9 24]. Figure 1 shows a possible model for the two-way interaction of poverty and common psycho-social disability in a vicious cycle. We propose that with a social model of disability, disability itself, and other functional limitations can be located under the title of 'social causation'.

Figure 1. Diagram developed by Crick et al, proposing a two-way interaction between poverty and mental ill-health [10]

The high rate of co-morbid functional impairment reported in this study suggests a high rate of other forms of disability mixed with psycho-social disability although this cross-sectional study cannot ascertain directionality and causation (it is likely that those with functional impairment are also at higher risk of psycho-social distress). This finding is supported by this study's assessment of barriers to community services where there is a high rate of reporting of physical barriers to services and in particular, identification of the lack of physical access/ transport difficulties for people with psycho-social disability. It clearly points to the need for policies and programmes to promote mental health knowledge and skills for all people with disabilities. Additionally, mental health policies and programmes must ensure inclusion of all people with disabilities, and seek to reduce the multiple types of barriers that limit access to care and community participation.

This study presents one of the first accounts of barriers experienced by people with psycho-social disability for access to services in India. While the total percentage numbers of PPSD who identify barriers to access community services are lower than expected, it is notable that PPSD are significantly more likely to describe barriers in multiple domains of life, when compared to matched controls. While the UNCRPD makes it clear that disability is influenced by both medical limitations and social prejudice, the ways that this plays out for people who suffer from psycho-social disability to limit their community participation is rarely assessed. The three key barriers to participation most frequently identified by participants with psycho-social disability in this study are related to attitudes (negative attitudes towards me), practices (lack of accommodation to support access to services) and structures (e.g. making it difficult to get to services), which are similar to findings in a study examining participation of people with psycho-social disability in mental health policy development in South Africa [2]. Our study shows that people with psycho-social disability describe stigma (negative attitudes) as a significant barrier in nearly half of the domains of services described here. A number of papers have described experiences of stigma of people with psycho-social disability in India and in particular how this can negatively impact access to mental health services [25-27] however this study is likely the first paper to demonstrate how perceived negative attitude interact with domains of community services and participation. Reasons why negative attitudes were not identified as limiting access to some community services is not clear and this is an area that requires further research. The impact of multiple marginalities such as membership of an excluded social group or having female gender and low education status adding to the disadvantage of disability has been identified as a basis for additional exclusion of those with PSD [28 29].

In the multiple domains assessed in this study lack of information and physical accessibility were also frequently perceived as barriers to participation by people with psycho-social disability. The contribution of co-existing functional impairment is likely to explain the barriers related to physical accessibility and transport. While lack of access to information is high (34%) in the general community, it is even higher for people with PSD (50%). Possible reasons why lack of information appears to be a greater barrier for people with psycho-social disability could be that this group has lower literacy and fewer social contacts and networks (so less information comes their way), and that they are less motivated in seeking out information. Perhaps this group also has reduced access to mass media such as television or radio.

There are ample policies and legal structures to promote access and participation for people with disabilities in India including those with PSD. India was one of the first countries to sign the UNCRPD and recently passed the Mental Health Care Act (2017) both documents of which include components to support participation and access to services. The new Rights of Persons with disabilities act (2016) clearly includes people with mental illness, and builds on the Persons with disabilities act (1995) to push for a more disabled inclusive and accessible environment [30]. At the same time, we join with others to observe that access to services and participation for people with PSD remains limited, and implementation and regulation are very weak links in the chain in relation to health services and policies in India [30 31].

Programmatic implementation at all levels must intentionally seek to include people with psycho-social disability. This demands attention to increasing the accessibility of community level structures such as transport and dissemination of information related to services and entitlements so that they reach people with psycho-social disability. This will require using mediums that are accessible to those who have low literacy and who have limited social networks such as loudspeaker announcements which are used widely and effectively by campaigning political parties in India. It also requires changes in attitudes at all levels in the community and among service providers. A number of steps can be taken to reduce stigma and increase social inclusion in programmes related to health, education and sanitation which include increasing awareness in the community, educating service providers and increasing direct contact between people with psycho-social disability and others [32].

A further clear message from this study is that since risk and protective factors for mental health act at several different levels, and include macro-economic health determinants, responses to them need to be multi-layered and multi-sectoral. Macro-policies that address poverty, education, welfare, transport, housing and employment sectors are required, with a 'health in all policies' approach[9].and seems likely to also reduce the disease burden related to psycho-social disability [33].

Methodological considerations

The Kessler tool is a screening rather than diagnostic tool, and excluded two key risk factors for psycho-social disability: stressful life events and chronic illness. While the Kessler-6 scale has been found to have moderate- to- high discriminating ability when used by lay workers in identifying common mental disorders in India [34 35], it did not screen for the whole spectrum of psychosocial disability. A limitation of the findings presented in Table 3 and 5 particularly is that the numbers are small reducing the reliability of the findings and meaning that some findings that may well have been significant with a larger sample, were not elucidated. The study is limited to adults of over 18 years of age, and so cannot assess the prevalence of psycho-social disability or barriers they face, among children. As the RAD survey tool used self-reported data there may be a risk of social desirability or recall bias. As a cross-sectional survey, it cannot attribute causality to apparent risk factors. A major strength of this study is that its data are from a randomly selected population covering rural, semi-urban and urban populations in North India which increases the generalisability of the findings, and suggests they may be applicable to other urban and rural settings in North India. Multivariable analysis ensured that potentially confounding factors were considered.

CONCLUSIONS

Psycho-social disability in Dehradun district, Uttarakhand, with a prevalence of at least 4.8% is two or three times more common among people with co-morbid functional impairment who are economically deprived, who have had little education and who are unemployed. People with psycho-social disability face significant unmet needs related to community services and perceive negative social attitudes as a significant barrier limiting their participation in multiple domains. Social policy and programmes in India must take active steps to address social determinants of psycho-social disability such as increasing access to education and reduce economic deprivation. Additionally, action is needed at all levels of community programmes and services to increase social inclusion of people with psycho-social disability.

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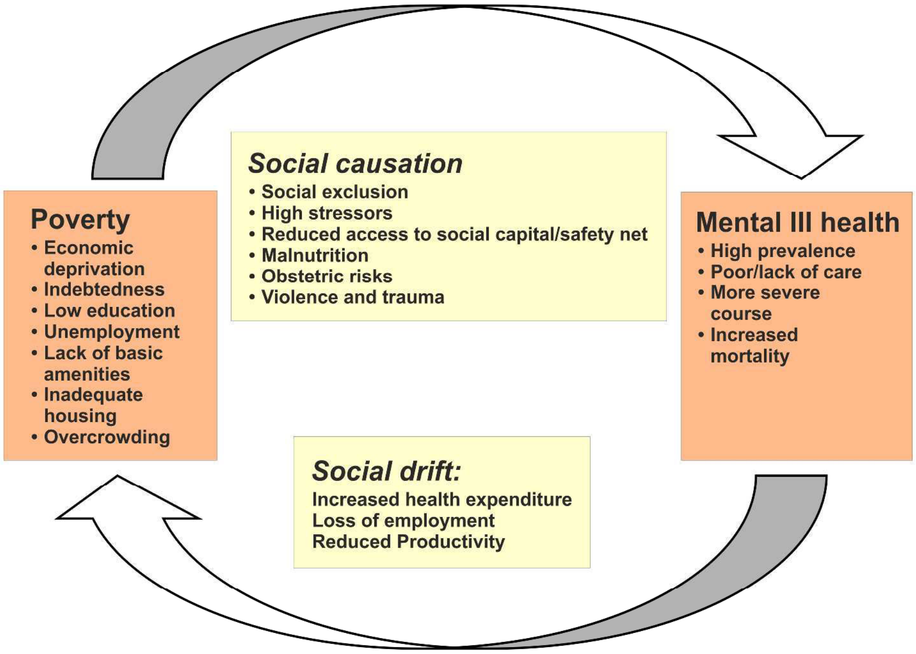

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STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*

Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	**Item #**	**Recommendation**	**Reported on page #**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	Y – p 1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	Y – p 1 and 2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Y – p 4 and 5
Objectives	3	State specific objectives, including any pre-specified hypotheses	Y – top of p 5 aim of study is outlined
Methods			
Study design	4	Present key elements of study design early in the paper	Y – in second paragraph of methods in p 5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Y – all of these are covered on p 5 and 6 in Methods section
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	Cross sectional – eligibility sources and methods – Y on p 5, 6
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Y – described within description of survey tool, p 5 last paragraph and top of p6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	*Y* – these are covered in description of the data collection tool in methods pages 5 and 6
Bias	9	Describe any efforts to address potential sources of bias	Y – methods in bottom of p 5 and 6 describe two-stage process for random selection of participants to

			reduce bias
Study size	10	Explain how the study size was arrived at	Y – p 5 – the linked study which has been published and was uploaded with this submission, describes the power calculation used to establish study size
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Y – the analysis used including how people with psychosocial disability were identified, and process for multi-variate regression is described in p 6
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	Y - process for multi-variate regression is described in p 6
		(*b*) Describe any methods used to examine subgroups and interactions	Y – analysis with PPSD compared to those without PSD is described in results and methods p 6
		(*c*) Explain how missing data were addressed	NA – there was not an issue of missing data
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	Y – the analysis process used described in p 6
		(*e*) Describe any sensitivity analyses	NA
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Y – the sampling process is described in p5 and Table 1 provides a summary of participants
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	Y – we considered but didn't believe it was required as once enrolled in the study, we did not lost participants.
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on	Y – these are provided in Table 1 on

		exposures and potential confounders	p 8
		(b) Indicate number of participants with missing data for each variable of interest	NA – data was complete
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—Report numbers of outcome events or summary measures	Y – these are reported in Tables 2 – 5 on pages 8 - 11
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Y – Table 2 provides crude and adjusted OR on p 8, and the confidence intervals – which variables included and why is described in Methods p 6
		(*b*) Report category boundaries when continuous variables were categorized	Y – for example age groups in Table 1 p 8
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NZ
Discussion			
Key results	18	Summarise key results with reference to study objectives	Y – these are summarised in para 2 of Discussion p 12
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	*Y* - discussed under methodological limitations p 14
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Y – these are discussed on p 12-14
Generalisability	21	Discuss the generalisability (external validity) of the study results	Y – see in Method considerations p 14
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Y – funders are discussed in acknowledgements section p 15

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.