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## Community management of intellectual disabilities in Pakistan: a mixed methods study

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### Abstract

**Background**—Pakistan has one of the highest reported rates of childhood intellectual disabilities in the world. Prevalence estimates vary from 19.1/1000 for serious intellectual disability to 65/1000 for mild intellectual disability

**Methods**—We surveyed carers of persons with intellectual disabilities (n=100) using quantitative and qualitative instruments. We conducted in-depth interviews of carers (n=16) and key primary health providers (n=10). We also carried out focus groups (n=7). Data was triangulated and interpreted in light of peer reviewed literature

**Results**—There was a delay of 2.92 (95% CI 1.9 to 3.94) to 4.17 (95% CI 2.34 to 6.01) years between detection and seeking of care. Parental stress associated with caring for these children was high (mean SRQ score 8.4; 95%CI 6.80 to 9.91). Home management consisted mainly of physical containment. Stigma associated with intellectual disability contributed to decreased opportunity for these children and families to participate in community activities. There was a lack of knowledge about causation and effective interventions for intellectual disabilities.

**Conclusions**—Our findings suggest that there is significant delay in detection of intellectual disabilities especially in rural setting where more than 70% of population of Pakistan resides. This missed opportunity for rehabilitation in early formative years is a cause of significant distress for the caregivers who rarely receive valid information about course, prognosis and what remedial action to take. There is a need to develop feasible, cost effective, community level interventions, which can be integrated into existing healthcare systems.

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## Introduction

Developmental disabilities in low and middle-income countries (LMIC) are a public health priority due to early age of onset and frequent lifetime disability (Jamison *et al*, 2006). Their increased prevalence rates in this context are also an impediment to future social and economic development (Institute of Medicine, 2001). Although estimates for disability adjusted life years are not available for many such disorders, it is estimated that they account for more than 10% of the Global Burden of Disease across the lifespan (Jamison, D. T, Breman, J. G, Measham, A. R, Alleyne, G, Claeson, M, Evans, D. B., Jha, P, Mills, A, and Musgrove, P, 2006). Intellectual disability or mental retardation is defined as “a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Intellectual disability can occur with or without any other mental or physical condition.” (WHO, 1993). The prevalence of intellectual disabilities is reported as two to eight times higher in low-income countries than in industrialized nations.

Pakistan with an estimated population of 160 million, 45% of which is below the age of 18, has higher than expected rates of intellectual disability. The prevalence estimates vary from 19.1/1000 for serious intellectual disability to 65/1000 for mild intellectual disability (Durkin *et al*, 1994) Services for such individuals are rudimentary and little research has been done to develop feasible, cost-effective community level interventions that can be integrated into existing health systems. Such research is necessary as it is not possible to extrapolate mental health interventions from the developed to the developing world due to major health care system and cultural differences (Patel, 2000; Lancet Global Mental Health Group, 2007). We conducted a mixed methods study to explore current community management of intellectual disability in Pakistan.

## Methods

In this study, *intellectual disability* was defined according to the ICD-10 criteria of mental retardation, following a clinical evaluation by a trained mental health practitioner of a grade of a consultant psychiatrist. *Carers* were defined as those individuals who are primarily and directly responsible for providing care to those with intellectual disability. These could be parents, siblings or a member of the extended family. *Care* includes both access to formal services and support for management at home.

## Research questions

We formulated the following research questions:

1. What are the pathways to care for those with intellectual disabilities?
2. What are the barriers to receiving care?
3. What is the experience of those caring for people with intellectual disabilities?
4. What are the beliefs about causation amongst carers and primary care providers?
5. What is the practice of management of intellectual disabilities?

## 6. What is the families' view of stigma associated with intellectual disabilities ?

### Measurements

We sought to minimize interviewer bias as well as response errors by using trained and experienced interviewers of both genders well versed in local languages.

*Pathways to care* questionnaire gathers information on socio-demographic characteristics of participants and sources of care before reaching the mental health service. A sample size of 50 is estimated to be sufficient for a meaningful analysis (Gater *et al*, 1991;Gater *et al*, 2005).

**Distress in the carer** was measured by *SRQ- 20* (WHO, 1994). This is a brief scale consisting of twenty items designed to identify 'mental distress'. It has been validated in Pakistan with probable caseness 8/9 for women and 5/6 for men, and found to have good psychometric properties (Husain *et al*, 2006;Rahman A *et al*, 2005).

**The Short Explanatory Model Interview (SEMI)** was used to study health beliefs and explanatory models of subjects about illnesses (Lloyd *et al*, 1998). Based on the Explanatory Model Interview, SEMI is non technical in language, easily translated and allows interviewers from any background to be readily trained in its use. An Urdu adaptation developed for Pakistani population was used in this study (Mirza *et al*, 2006).

*Qualitative data were collected through focus groups and in-depth interviews* conducted by IM and AT, both trained psychiatrists with experience of working both in Pakistan and the UK. The interviews were tape recorded, translated into English and back translated into Urdu by independent translators. Handwritten notes were made for focus groups and for interviews where the interviewees did not consent for their voice to be recorded.

### Setting

The study was conducted at three sites and levels of care. Rural *primary care* site was Gujar Khan, a rural sub-district (pop 493,000) of Rawalpindi district (pop 3.36 million) situated in Northern Punjab, Pakistan (Government of Pakistan, 1999). Primary health care is organized through a network of Basic Health Units (BHU), each providing care to about 15,000 – 20,000 population. A BHU is staffed by a doctor, midwife, vaccinator and 15–20 village-based community health workers called Lady Health Workers (LHWs). LHWs have completed secondary school, and are trained to provide mainly preventive maternal and child health care and education in the community. Each LHW is responsible for about 100 households in her village. The LHW programme is the focal point of Pakistan's national health strategy, and there are about 96,000 health workers providing coverage to over 80% of Pakistan's rural population (Ministry of Health, 2007). Urban *secondary care* site was the outpatients department at the Institute of Psychiatry, Rawalpindi General Hospital which provides secondary care services for mental health problems to Rawalpindi city and district. *Tertiary care* site was a special education school in Urban Lahore City district (pop 6.3 million) which provides institutional care and home based advice and intervention to families of children with intellectual disability.

## Sampling and recruitment

Data were collected from September 2006 to August 2007. Sampling sites, numbers recruited and sample characteristics are summarized in Table 1.

Sampling was done concurrently for **qualitative** (in-depth-interview for primary care & SEMI for secondary and tertiary care) and **quantitative** (Pathways to Care for secondary and tertiary care, and SRQ for carers at all three levels of care). In addition there was **concurrent qualitative** data-collection at primary (focus group & in-depth interview), and tertiary levels (focus group).

All consecutive attenders to secondary care and a simple random sample from tertiary care were approached. All attenders from the secondary centre agreed to take part in the study. Only 2/50 (1%) refused in the tertiary centre and the next two attenders from the random sampling list were recruited to complete the sample of 50. In-depth interviews and focus groups were conducted till information began to replicate themselves (*saturation*). Cases which did not fit the emerging model were sought (*theoretical purposive sampling*) in order to ensure representativeness.

## Analysis

**Quantitative**—Data were analyzed using fishers exact or chi square test for categorical variables and Rank Sum test and t-test for non-parametric and parametric data respectively.

**Qualitative**—Tape recorded interviews were transcribed after forward and back translation to ensure linguistic and conceptual equivalence (Rahman *et al*, 2003). Handwritten information was also transcribed. The descriptive data thus obtained was coded and subjected to content analysis using NUD IST (Non-numerical Unstructured Data Indexing Searching and Theorizing). Boolean and proximity searches for the coded text were done to identify themes. Findings were discussed regularly between AT, IM and AR which informed subsequent interviews. These were also discussed with the local community leaders. All authors were involved in the analysis and discussion of the findings following searches of the relevant world literature in order to develop a theory and model (theoretical framework) for a community based intervention.

## Ethical approval

Ethical approval was obtained from a local Institutional Review Board (submission 4349). The study conformed to good practice and to the Declaration of Helsinki. Approval was also obtained from community leaders for rural site. Carers were interviewed after obtaining written valid formal consent.

## Results

Population characteristics are summarised in table 1 for urban secondary care and tertiary care.

### Pathways to care: Delay in detection and help seeking

There was a delay of 2.92 (1.9 to 3.94) to 4.17 (2.34 to 6.01) years between detection and seeking of care from any health care provider. As this data was obtained retrospectively, it should be interpreted with caution due to the possibility of inaccurate recall.

Most carers regretted their lack of knowledge and the consequent delay in seeking help:

She was the first born and couldn't sit in 8 months. I wasn't wise enough to notice it.

(Int 12, woman carer, primary care, with 11 year old with ID)

Carers blamed themselves for not realizing that there was a problem at an earlier age of the child. This regret was associated with guilt at not seeking help.

He never used to have milk. If he had let me feed him, it (milk) would have had an effect (he might have been normal----We found out when he grew up [that he had a problem]). (Int 14, woman carer, primary care, son with ID)

### Barriers, support from health and social care system, expectations from treatment and stigma

As there was no overall difference in response between the secondary and tertiary samples of carers, the data were combined and summarized in table 3.

Carers described difficulty in accessing services. This occurred because the services were located mainly in major cities, which were far away and there was considerable financial and time costs involved in seeking help. It was especially problematic for women in a culture where it is not the norm to travel without a chaperone.

We visited the hospital 3-4 times----- it's far off and expensive too; we can't afford it. But she has improved a lot -----

(Int 12, woman carer, primary care, with 11 year old with ID)

There was limited information or knowledge in relation to developmental disorders available, not only for carers but also for health care providers. Parents described health-care shopping in order to find a cure for their children.

We have been taking her to those Junior MBBS Doctors. They have been saying it will happen/improve at this age and that age. It's been 4 years now. They said as she will grow old, her brain will also grow. But she is 4 years old now; Her brain didn't grow

(Int 11, woman carer, primary care, with 4 year old daughter with ID)

Parental concern about stigma associated with the condition and worry about abuse and neglect was evident during the interviews. Though they hoped for a complete cure, their main concern was that the child should be able to learn basic self care as they were worried about the child's future after the parents passed away. This is because there is no existing system of care from the local or federal government. Physical restraint such as tying with ropes or chains and locking in a room was commonly used for behavioural problems.

Parents expressed great concern about excessive use of force by next of kin and the community when they (the parents) were no longer around to check this.

-I get worried because nobody stands up for such children. People push them down in the streets.-----No, they don't say it, but I've seen it with my own eyes.-----  
We have seen people doing it. Had their siblings not taken care of the matter, they would be treated like that. (Int 6, mother of 3 children with ID)

They are harsh.----For example when either of the two girls go to someone's house -----, people turn them out. -----Then people say that we don't keep them at home and control them. ----- also that we should restrict their movement ---. tie their hands and feet.-----I do it sometimes.----- (Int 3, mother of two girls with ID).

Respondents believed that having such a child was the will of God (Allah) and it was a pious act of faith to look after a child with intellectual disability. They also believed that divine help could improve the condition.

The doctors at the hospital said that the girl was alright. We never went to a doctor after that.----- I took him to a Pir (spiritual healer) here. ----- You think like that in pain and anguish. -----I have faith in Allah. Allah says that he is beneficent

(Int 8, woman carer of 2 year old daughter with ID)

We ought to take care of him and Allah will reward us. We don't have to make him get better. We only have to feed him, wash his clothes and clean him overnight etc. this awareness is very important.

(Hakeem 1, man in his forties).

Thus, traditional healers were a source of guidance and solace for carers. Another source of advice were school-teachers, often seen as the most learned members of the community. In the absence of formal health and social support institutions, the support provided by these two existing community resources was valued by carers.

### Experience of caring: carer stress

In carers presenting to *secondary care*, both male and female carers had high levels of psychological stress measured by the SRQ-20 (mean score 8.4; 95% CI 6.80 to 9.91) but female carers experienced significantly more psychological stress than males (10.4 vs 4.4,  $z=-3.52$ ,  $p=0.0004$ ). The mean SRQ score for carers (all were women) in *tertiary care* setting was less than those in secondary care (mean 5.36, 95% CI 4.61 to 6.11). Carers of a female child had higher scores compared to those looking after a male child in secondary care but the difference was not statistically significant (8.5 vs. 5.6,  $z = -0.15$ ,  $p=0.87$ ).

Mean SRQ score for the 16 carers who were interviewed qualitatively at *primary care level* was 8.5 (95% CI 5.19 to 11.80).

The cut-off for probable mental illness on the SRQ in the Pakistani population is 7 or above (out of 20) for women and 4 or above for men. In the tertiary care setting, 13/50 (26%) and in the secondary care setting 19/50 (38%) scored above the cut-off which is higher than the rates reported for the general population (Mirza and Jenkins, 2004).

We asked carers what caused them greatest stress about their child's condition. Their most common concerns were about the child's future (53%) ("what will happen when we/I die; "who will look after her.") and fear of violence (30%) ("he might harm someone"; "is violent towards family members.").

### **Beliefs: Nomenclature and explanatory models**

The data from secondary and tertiary care is summarized in table 4.

In depth interviews revealed a number of deeply held traditional beliefs about the cause, explanation and management of these disorders. Inconsistent multiple explanations were offered by both health care providers and carers.

A few of these children develop a glitch in their brain. ----- They say a saint has been born.

(Hakeem 1, man in his forties).

-----that it's only because of weakness. ----- He couldn't sit; kept lying down,----...they call it weakness there.

(Lady health worker in her 40's)

.---- We don't know whether it's an evil possession or an illness..... a witch.

(int 10, woman carer with 4 year old son with intellectual disability)

It's just because of poverty. It happened because of poverty

(Int 8, woman carer of 2 year old daughter with ID)

I don't have anything in my mind. My maternal uncle's son has it.

(Int 12, woman carer, primary care, with 11 year old with ID)

It was customary to explain the condition as Allah's will. There was considerable reliance on supernatural explanations in the primary and secondary care population. This was not so for the tertiary care sample who were in a system of care.

It's God's will. ----- Allah knows.

(Int 4, woman carer, primary care, son with ID)

Allah knows why. He can do anything. -----Magic is very common in our Dhok (hamlet).

(Int 6, mother of 3 children with ID)

## **Discussion**

### **Main findings**

In this mixed-methods study of intellectual disabilities in a resource-poor setting, our qualitative and quantitative data indicates that: a) detection is delayed due to lack of an effective system of routine child health checks; b) there is significant time lag between identification of developmental concerns and presentation to a health care provider; c) a

fundamental barrier to treatment is the lack of awareness of effective interventions which are likely to improve outcome; d), management at home is mainly physical restraint and strict family supervision; e) there is significant stigma associated with intellectual disabilities resulting in decreased opportunity for these children and families to participate in community activities and high levels of stress in carers; and f) interviews of the health care providers inform us that there is lack of recognition and knowledge of basic management of such disorders at the primary care level.

### Strengths and limitations

A major strength of our study is that we obtained data from all levels of care for intellectual disabilities in Pakistan. However, all our sites were located in one out of four provinces of Pakistan (Punjab) and this could be a possible source of selection bias. Punjab is the largest and best-resourced of all 4 provinces, hence the community management of intellectual disabilities in the other provinces is unlikely to be better than Punjab. The nearest big city to our rural and secondary care field site is Islamabad (Federal Capital) which is arguably better resourced in terms of human and financial capital than the rest of the country. Similarly, our tertiary care site is situated in Lahore which has 2 of the 3 departments of child psychiatry in Pakistan.

We used a semi structured interview schedule, and worked in a field site where we have conducted previous studies. The researchers have also sought to be self-aware of conceptual issues as well as potential problems in communicating accurate and reliable information due to a social class difference between the participants and the interviewers. We acknowledge that it is difficult to control for these factors and we have sought to address it by using researchers who have knowledge of local culture and custom. There is a need to exercise caution whilst interpreting age in a rural population with variable literacy levels.

Denzin defined triangulation as the combination of methodologies in the study of the same phenomenon (Denzin, 1978). In this study we have used multiple data (from all levels of care, from carers and health care providers) and methodological (quantitative and qualitative methods) triangulation to identify main areas of concern for families of children with intellectual disabilities. We discuss these findings in the context of literature from other low-income countries.

The single most important issue raised by carers was training their children to care for themselves and successfully manage their environment. This has been reported in other studies. Sen and Goldbart, in their description of their work with families of children with disability in urban slums in India, reported that the greatest number of caregivers spoke about needs related to activities of daily living (Sen and Goldbart, 2005). Improving activities of daily living and thus increasing autonomy would be an essential outcome for any intervention (Vreede, 1993). To be most effective, these interventions need to begin early in life. Many interventions using culturally valid approaches focussing on early stimulation of young children have been tried successfully in developing countries (Grantham-McGregor *et al*, 2007; Engle *et al*, 2007). Islam and Begum describe successfully using adapted pictorial versions of the Portage Guide to Early Education in working with parents of children with intellectual disability in Bangladesh (Islam and Begum, 1994).



Russell and colleagues describe the development of a multi-modal adaptive behaviour programme for families of children with intellectual disability together with interactive group psychoeducation (Russell *et al*, 2004). WHO's Care For Development package is another simple tool (for normal children) that can be adapted for children with developmental delay (Guralnick, 2007). In our study, we found a number of everyday family routines and community settings providing a wide variety of experiences that could assist children in gaining developmental competencies.

Another major area of concern for carers in our sample was the behavioural problems displayed by their children, especially violent behaviour. This too has been a finding in other studies. Children with intellectual disabilities are more likely to engage in challenging behaviours than other children and this is a major source of distress for carers (Einfeld and Tonge, 1995). In neighbouring Bangladesh, Mobarak and colleagues in their work with mothers of children with cerebral palsy, described the strongest predictor of maternal stress was child behavior problems, and commented on the need to ensure practical help for mothers and advice on managing common behavior problems which may directly help to relieve stress on mothers of young disabled children in developing countries (Mobarak *et al*, 2000). The majority of carers in our sample managed behaviour problems by physically restraining the child.

We found high overall levels of stress in carers, especially mothers. Parents of children with intellectual disabilities universally report higher parenting stress and mental health problems than parents of normally developing children (Emerson, 2003). Similar carer stress is reported in other studies from low-resource settings (Mobarak, R, Khan, N. Z, and Munir, S, 2000). Poor carer mental health interferes with the optimal level of care that a carer can provide a child, especially in challenging circumstances (Rahman *et al*, 2002). Simple interventions based on cognitive behavioural principles to reduce stress such as the Thinking Healthy Program (Rahman, 2007; Rahman *et al*, 2008) have been used successfully by local health workers to support depressed mothers caring for young infants. Such approaches have a place in supporting distressed carers of the intellectually disabled.

It is important to consider that intervention programmes, without additional support, can themselves be a source of stress for carers. In a randomised control trial of alternative modes of service provision to children with cerebral palsy, it was found that maternal adaptation increased most in the group given health advice and minimal intervention, compared to more intensive interventions. The authors discussed how the more intensive intervention may have had paradoxical effects due to increased demands on the mother, compounded by problems of distance and transport, and suggested that a community based rehabilitation model with general support provided to mothers, might be the best approach (McConachie *et al*, 2000). In a study from India, where an outreach service was developed for families of children suffering from cerebral palsy, a support network developed among parents and parent-to-parent support was a highly rated aspect of the service (Goldbart and Mukherjee, 2001).

In our study, we found a significant delay in detection of the problem, and an even further delay before help was sought. Carers blamed themselves for not realizing that there was a

problem at an earlier age of the child. This regret was associated with guilt at not seeking help. It would thus be important to develop some form of a screening programme to assist parents identify children with intellectual disability. The Ten Question Screen (Durkin, M. S, Davidson, L. L, Desai, P, Hasan, Z. M, Khan, N, ShROUT, P, Thorburn, M. J, Wang, W, and Zaman, S. S, 1994) has proven to be an effective and efficient screening tool in identifying children with disabilities in countries with few professional resources available to evaluate children for neuro-developmental problems (Thorburn *et al*, 1992b; Thorburn *et al*, 1992a). It is delivered by community workers (who do not need to be trained in health and results in reducing the need for professionals (family doctors, pediatricians, psychologists) to assess children to less than 20% of the total number of children. It identified 100% of the seriously intellectually disabled, children with motor disorders or children with epilepsy in the original studies in Pakistan and has also been used successfully in a number of other Asian and African countries (Mung'ala-Odera *et al*, 2006).

Our findings suggest significant stigma associated with disabilities. In low-income countries, stigma and discrimination are important factors in the reluctance of many people worldwide to seek help, or even to accept that their difficulties relate to a mental disorder (Saxena *et al*, 2007). In Lesotho, community acceptance of disability was described as a priority need by parents (McConkey and Mphole, 2000). Thus, any community intervention must address stigma and discrimination. Community-based approaches to address stigma in low income settings could include a school-based approach where school-children (often the only educated members of the community) are trained to educate not only their peers but also parents and other community members. This approach has been used successfully in Pakistan and may be useful component of a health system level intervention (Rahman *et al*, 1998).

A recent review of childhood disability studies carried out in low and middle income countries, including screening, prevention, epidemiology and intervention studies highlighted the paucity of research on specific early childhood interventions and pointed towards the need for community-based, family-focussed programmes that are grounded in a sound epidemiologic and cultural framework (Maulik and Darmstadt, 2007). A model that has tried to meet these needs is the World Health Organization's community-based rehabilitation (CBR) model for disability. It provides a set of approaches to develop rehabilitation services for people with disabilities in developing countries (Institute of Medicine, 2001). The focus of intervention is shifted from city-based institutions to the community, involving people with disabilities, family members and volunteers, supported by local health professionals as well as having a system of consultation/referral to more specialized services (a 3 tier model). Apart from empowerment, this model is purported to provide local expertise in the community and also minimize the cost of rehabilitation.

Broader interpretations of the model call for a shift from being primarily a 'medical model' to a more 'social model' in recognition that a considerable contribution to disability is made by the attitude of other people (Turmusani *et al*, 2002). This has led to the move to minimize stigmatization and to support inclusive education and integration of people with disabilities. Turmusani and colleagues highlight that although community participation has been viewed as a key component of CBR from its inception, in practice, the participation has

mainly taken the form of delivering or receiving services, rather than a voice in the design and management of services.

Community-based approaches should not be seen as a cheap solution to a pressing health need in low-income countries. A criticism of CBR is that as the costs are shifted to family and volunteers the true cost of such interventions is not known. It has been suggested that these interventions may increase costs to the caregiver by time taken off work to care, and increased stress in the caregiver (Mobarak, R, Khan, N. Z, and Munir, S, 2000). The WHO Atlas on global resources for persons with intellectual disabilities highlights problems due to lack of public funding and difficulties the majority of the populations face in accessing any form of service (WHO, 2007). Community programmes must be supported by public funding to allow essential facilities, training, supervision and manpower resources to develop.

A society is defined by how it treats its most vulnerable. Efforts have been made to implement the community approaches, such as the CBR model in its various forms, in a number of countries. However, even after 25 years of work and an increasing amount of literature, a recent systematic review found the evidence base for such approaches is still fragmented with a large number of papers being descriptive (Finkenflugel *et al*, 2005).

In conclusion, our study supports the need to develop a feasible, cost effective, community level intervention, which can be up-scaled and integrated into existing healthcare systems. Such an intervention would need to have an educational component not only for the carers but also for the primary health care workers and school teachers. It should be community-based to ensure maximum population coverage, with an emphasis on solving problems that are prioritized by the carers, such as activities of daily living and improved adaptive behaviour. It should have a component of advocacy and local community mobilization but at the same time should be adequately supported by the health and social care systems. Finally, such interventions should be evaluated for their effectiveness through robust scientific designs such as the randomized controlled trial so that they have a sound evidence base.

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Table 1  
 Sampling sites, instruments, number of participants and sample characteristics for identical qualitative and quantitative secondary and tertiary care sample

Level of care/setting	N M:F ratio	Sample	Assessment	Carer's age (mean, 95% CI)	Patient's age (mean, 95% CI)	Persons per household/rooms per household (mean, 95% CI)
Tertiary Urban	50 0:50	Simple random sample of carers and patients	Pathways to Care; SEMI, SRQ.	42.10 (39.62 to 44.57)	15.26 (13.78 to 16.74)	7.1 (4.1 to 10.1)/ 2.0 (1.07 to 2.92)
Tertiary Urban	15 3:12	Purposive sample of carers	Focus group discussion	Age range 25–67		
Secondary Urban	50 17:33	Consecutive sample of carers and patients	Pathways to Care; SEMI, SRQ.	41.16 (37.72 to 44.60)	16.89 (14.59 to 19.19)	7.8 (6.72 to 9.07)/ 2.74 (2.34 to 3.17)
Primary Rural	16 1:15	Purposive sample	In-depth interviews; SRQ	Age range 20–50	Age range 1–28	6.64 (5.19 to 8.06)/3 (2.32 to 3.67)
Primary Rural	39 12: 27	Purposive sample	Focus group discussion	Age Range 22–73	N/A	N/A
Primary Rural	10 8:2	Purposive sample primary care physicians = 2 Hakeems* = 2 homeopaths = 2 faith healers = 2 community health workers = 2	In-depth interviews	Age Range 25–66	N/A	N/A

95% CI= 95% confidence interval

\* Hakeems practice ancient Greek medicine using herbs, spices and poultices

**Table 2**

Time lag between problem identification by the carer and first contact with any health care provider.

	Age when problem identified (years) Mean (95% CI)	Age at 1 <sup>st</sup> contact with health care provider (years) Mean (95% CI)	Delay in seeking care (years) Mean (95% CI)
<i>Secondary care (n=50)</i>	2.22 (1.60, 2.84)	6.40 ((4.28, 8.52)	4.17 (2.34, 6.01)
<i>Tertiary Care (n=50)</i>	2.17 (1.62, 2.71)	5.10 (4.07, 6.13)	2.92 (1.9, 3.94)

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**Table 3**

Barriers to care, expectations from treatment, stigma and impact on carer

Variable of interest	Summarized SEMI* response	Percentage (N=100)
Barriers	No social help available	69%
	No health care available	55%
	No help sought due to lack of money	12%
	No help sought due to lack of information	9%
Expectations from intervention	Improvement in self care	65%
	Improvement in behavior	20%
Reported benefits from previous interventions	No benefit	39%
	Some benefit	36%
Stigma	Taunts and teasing in public	40%
	Keep children locked up	16%
Impact on carer	Seriously affected mood	86%
	Seriously affected occupation	66%
	Seriously affected home environment	62%

\*The Short Explanatory Model Interview



**Table 4**

Summary of nomenclature and explanatory models

Variable of interest	Summarized qualitative response from SEMI	Secondary care (%)	Tertiary care (%)
What name do you give the condition	Developmental terms (weakness of the mind, mind not okay, brain half-sized according to age).	62%	74%
	Psychiatric terms (mental illness, madness, mentally upset).	38%	8%
	Neurological terms (has fits),	38%	4%
	Behavioral terms (stays on her own, runs away).	38%	4%
	Physical terms (muscle weakness, tension in muscles,	38%	4%
Explanatory models*	Social world (pressures of modern life, afghan war.)	28%	4%
	Natural world (fever, diarrhea, drought).	22%	50%
	Supernatural world (Allah's choice, Allah knows, evil eye)	26%	0%
	Internal world (fear, upset, fatigue);	26%	26%

\* These are explanations that carers assign to the cause and outcome of intellectual disability in their children. The terms social world relates to issues in the social environment; natural world relates to naturally occurring phenomenon; supernatural refers to divine and magical explanations while the internal world relates to causes which originate in the body or mind.