Biohouse, Volume 1: Issue 4, Nov-Dec 2015
Biohouse Journal of Advanced Medical Research
ISSN 2470-6639

Percieved Stigma among Parents of Children with Mental Retardation

Manasa Godati
Dept of Nursing,
Sri Venkateswara Institute of Medical Sciences (SVIMS)
Tirupati, AP, INDIA
Email: godati.manasa@gmail.com

Prathyusha.N
Department of Nursing,
Sri Venkateswara Institute of Medical Sciences (SVIMS)
Tirupati, AP, INDIA
Email: prathyushaneigapula@gmail.com

Bhagyalakshmi. M
Dept of Nursing,
Sri Venkateswara Institute of Medical Sciences (SVIMS)
Tirupati, AP, INDIA
Email: bhagyaramana@gmail.com

Hemalatha. S
Department of Nursing,
Sri Venkateswara Institute of Medical Sciences (SVIMS)
Tirupati, AP, INDIA

Abstract: *This descriptive study assessed parent's stigma regarding mental retardation of their children. Fifty subjects were selected by convenience sampling. The study revealed that 38% reported mild stigma, 34% reported moderate stigma, and 28% of parents reported severe stigma. And there was a statistically (p=0.05) significant association between level of stigma and age of the child when at admission to in the rehabilitative center. There was no statistically significant association between perceived stigma and other demographic variables including age of, respondent, father education, mother education, monthly income, marital status, consanguineous marriage, number of siblings, type of family, age of the mother when child was born, gender of the child when MR has diagnosed, or age of the child at admission to the rehabilitative center.*

I. INTRODUCTION

"When mental illnesses are used as labels……. These labels can hurt.
Stigma is a mark that distinguishes a person as being deviant, flawed, spoiled or generally undesirable. Stigma is a characteristic that marks a person as different from others. It is selected by a social group to imply that an individual is flawed in some way. Any personal characteristic can be a basis for stigmatization or the development of stigma.

According to Goffman, (1993) most stigmas belong to one of the three broad classes:

- Physical differences (e.g. size, shape, cloths, hair)
- Blemishes of character (e.g. homelessness, unemployment)
- Tribal stigma (e.g. race, nationality, religion).

Stigma has been identified as a likely key factor in mental health services access and utilization, particularly under-utilization of existing services by some segments of society, most notably minority racial/ethnic children.
In child mental health services research, the role of stigma has not been well-conceptualized though it is presumed to be significant. Literature on caregiver strain and burden of care has explored processes and implications of coping with children's emotional and behavioral disorders.
Stigma has become a marker for adverse experiences.

- Shame
- Blame
- Secrecy
- The "black sheep of the family" role
- Isolation
- Social exclusion
- Stereotypes
- Discrimination

-Huxley, 1993

II. BACKGROUND

Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior is expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

-AAMR (2002)

Stigma leads others to avoid living, socializing, or working with, renting to or employing people with mental disorders – especially severe disorders, such as schizophrenia.

Before any research can be started whether it is a single study for an extended project, a literature review of previous studies and experiences related to the proposed investigations should be done.

One of the most satisfying aspect of the literature review is the contribution, it makes to the new knowledge, insight and general scholarship of the researches. Several textbooks, journal reports, articles circulations and website were referred to collect maximum information to lay foundation to study.

Literature related to perceived stigma:

Angela Parcesepe, MPH, MSW (2011), conducted a study regarding "stigma on children's Mental disorders" in the United States. They used probability U.S National samples of non-institutionalized adults or children and (2) reported findings relevant to stigma of mental disorders among children. Two reviewers working independently coded studies aims, sampling techniques, measures, results, and implications. Results were known to be nine articles met selection criteria. All studies were cross-sectional and most used vignette methodology, seven studies asked adults about perceptions of mental illness among children, two studies asked children about perception of mental illness among children, and one study compared adult's perceptions or mental illness among adults and children. Low levels of knowledge and reorganization of common mental disorders among children were reported. Finally she concluded that stigma and low levels of recognition and knowledge of children's mental disorders were widespread.

These findings can inform interventions to reduce stigma by increasing the public's knowledge of childhood mental disorders and enhancing positive social contact with people with mental illness.

Sharac J, Mc Crone P, Clement S et al. (2010), conducted study on "open The economic impact of mental health stigma and discrimination". Sample size is 130 between the age group of 25-40 years. Data was gathered through psychology history and perception of mental illness. Results were shown that medical illness stigma was found to impact negatively on employment, income, public views about resource allocation and health care costs. They concluded that stigma and discrimination regarding mental health problems leads to adverse economic effects for people with these conditions. Interventions that reduced stigma may therefore also be economically beneficial.

Elaine Brohan, Mike Slade, Sarah Clement et al. (2010), conducted study on "Experiences of mental illness stigma, prejudice and discrimination". Sample was 432 adolescents of same age, gender, socio-economic status selected through random sampling technique. Seven of the located measures addressed aspects of perceived stigma, 10 aspects of experienced stigma and 5 aspects of self-stigma. Results revealed that 72% had perceived stigma, 18% had experienced stigma, and 10% had self-stigma.

Abraham Mukolo, Craig Anne Hcflinger, K enneth. A. Wallston et al., (2009), conducted study on the "Stigma of Childhood Mental Disorders". Sample consists of 120 between the age group of 25-40 years by systematic sampling technique. They found 3 dimensions of stigma, (negative stereotypes, devaluation and dissemination), two contents of stigma (self, general, public). Results revealed that stigma experiences that were casually linked to how parent /care giver cope with children emotional behavioral problems such as seeking professional help.

Arthur H. Crisp, Michael G. Gelder, Susannah Rix, et al. (2004) conducted study on ("Stigmatization of mental illness"). Sample size is 1737 above the age group of 16 years, data collected by interview method. Results shown that negative opinions indiscriminately over emphasize social handicap that can accompany medical disorders. They contribute to social isolation, distress and difficulties in employment faced by suffers.

American Psychiatric Association, Luckasson, Radford & Park (2003), conducted study on "Assessment of stigma in care giver burden", a randomized controlled trials at America among 1214 care givers between age of 25-40 years was done by questionnaire with 7 items scale. Results revealed that 70% of care givers felt that most people devalued their children, while 29% felt that most people devalued them and 1% reflects presence of stigma.

Shannon M. Couture & David L. Penn (2003) conducted a study on "Interpersonal contact and the stigma of mental illness). Sample size was 130,, randomly selected between the age group of 20-40 years with schizophrenia , bipolar disorder and major depression, data collected through both retrospective and prospective contact. Results revealed that their experience of stigmatization or responsible for their feeling of discouragement, hurt, angry and for lowering self-esteem.

Micheal R. Phillips, MD, Veronica Pearson DPhil, Feifei LI, RN et al. (2002) conducted a study on "Stigma and expressed emotion". The sample consisted of 608 patient based on responses to 10 open-ended questions about stigma trained coders rated the effect of stigma on both patients and family members. Family members reported that stigma had a moderate to severe effect on the lives of patients over the previous 3 months in 60% of the interviews, and on the lives of other family members in 26% of the interviews.

Literature related to questionnaire:

Afia Ali, Andre Strydom, Angela Haniotis et al, (2008) conducted a study on a "Measure of perceived stigma in people with intellectual disability". Sample consists of 109 people. Items with limited variability in responses and kappa coefficients lower than 0.4 were dropped. Exploratory factor analysis revealed 2 factors – perceived discrimination (items and reaction to discrimination (4 items). Study concluded that this instrument further helps in understanding the impact of stigma in people with intellectual disabilities in clinical and research settings.

Micheal King, Societies Dinos …….. et al in 2007, conducted a study on "Development of standardized measure of stigma of mental illness". They used qualitative data from interviews with mental health service users to develop a pilot scale with 42 items. They recruited 193 service users in order to standardize the scale. The final 28 items stigma scale has a 3 factors structure. The first concern discrimination, the second disclosure, and third potential aspect of mental illness. Stigma scales scores were negatively correlated with global self esteem. Here to conclude, this self report questionnaire which can be completed in 5-10 min, may help to understand about the rule of stigma psychiatric illness in research and clinical setting.

Beown SA, conducted study (2007) on factors and measurements of mental illness stigma. Sample size was 774 college students, age group between 18-26 years were randomly selected and exploratory factor analysis was conducted. 20 items from the AQ space provide reliable and valid measurement of 4 important aspects of stigmatization attitudes/beliefs towards the mentally ill. Accurate measure of these attitudes/beliefs will be critical to more fully understanding the stigma process and developing effective strategies of address stigmas.

BRUCE G. Link, Lawrence H. Yang, Jo C. Phelan et al (2004) conducted a study on "Measuring Mental Illness Stigma". Sample consists of 204 between the age of 32-45 years adolescents. Data was collected by utilizing standardized instruments. Results showed that adolescent with mood disorder have fairly positive attitudes and illness perceptions were related to psychological openness and in difference to stigma.

III. METHODOLOGY

Using a convenience sampling data was collected from 50 parents with mentally retarded children, at a rehabilitative center in India Parents of children with mental retardation, who were willing to participate in the study and who could understand either Telugu and English languages were selected. Written consent was taken from the subjects and the purpose of the study was explained.

Tools used for the study were categorized into 2 sections.

Section 1: Demographic data

Section 2: A five point rating scale was used to assess the perceived stigma among parents of children with mental retardation. The scale adapted from one developed by Michel King in 2007, It consists of 20 questions based on physical,

ISSN 2470-6639

psychological, emotional, cognitive and social economic domains.

Options were strongly agree, agree, cannot say, disagree, strongly disagree, based on sum of the gained marks, students were categorized.

Numerical values were attached to answers and the resultant scores were categorized as follows:

Stigma
Mild stigma: 0– 26 (0-33%)
Moderate stigma: 27– 52 (34-66%)
Severe stigma: 53 – 80 (67-100%)

The pilot study was conducted and the findings of the study revealed that tool was reliable, and feasible for use in conduct the main study. The reliability score 'r'= 0.978. Formula used to calculate the reliability is:

$$r = \frac{N\sum XY \quad (\sum X)(\sum Y)}{\sqrt{[N\sum X^2 - (\sum X)^2][N\sum Y^2 - (\sum Y)^2]}}$$

The data was analyzed by using descriptive statistics such as frequency and percentage distribution and inferential statistics such as Chi-square test. Formula used for Chi-square is:

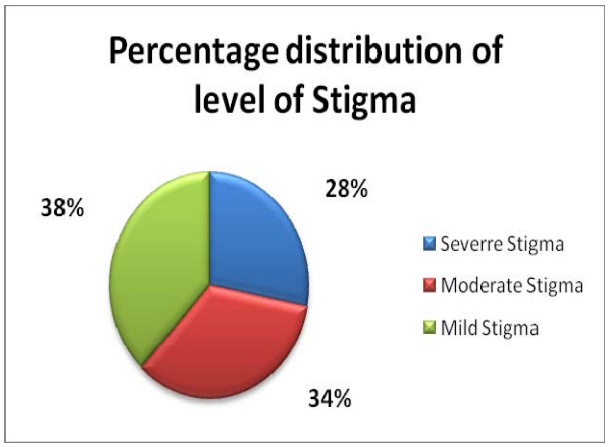
$$X^2 = \sum \frac{(o \quad e)}{e}$$

IV. Experiments And Results

The results of the study are as follows:

- Among 50 selected parents, 19 (38.0%) reported mild stigma, 17 (34.0%) reported moderate stigma, 14 (28.0%) reported severe stigma.

Level of Stigma					
Mild stigma (0-33%)		Moderate stigma (34-66%)		Severe stigma (67-100%)	
f	%	F	%	F	%
19	38%	17	34%	14	28%



V. Conclusions

The present study aimed to assess the perceived stigma among the parents of children with mental retardation in a rehabilitative center in India, our finding that greater perceptions of stigma towards parents suggests that in addition to posing a barrier to the recovery of people with mental illness, stigma erodes the morale of the family members who help care for them. The finding that social support and avoidance coping together largely explained the experience of stigma offers a plausible explanation for the severe stigmatized symptoms commonly reported by up to 28% of parents of children with mental retardation: parents may retreat from social support and adopt avoidance coping in order to fend off anticipated rejection and/or embarrassment. Because social support is a well-established buffer against recurrence of stigmatized symptoms, withdrawal from potential supporters as an adaptation to stigmatization illustrates the double jeopardy confronting parents of children with mental retardation, the study findings supported by study conducted to assess the stigma among parents with mentally retarded children conducted by David E. Gray. Results revealed that mental retardation has uniquely stigmatizing aspects because of the extremely disruptive nature of mental retardation symptoms, the normal physical appearance of MR children, and the lack of public knowledge and understanding regarding the nature of MR. Most parents perceived themselves to be stigmatized by their child's disorder.

The present study revealed,

- 19 (38%) had mild stigma,
- 17 (34%) had moderate stigma and
- 14 (28%) had severe stigma.

Recommendations or of the study:

1. There are efforts to educate individuals about the non-stigmatizing facts and why they should not stigmatize.
2. There are efforts to legislate against discrimination.

There are efforts to mobilize the participation of community members in anti-stigma efforts, to maximize the likelihood that the anti-stigma messages have relevance and effectiveness, according to local contexts

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Short Biodata for the Authors

Manasa Godati phd received M.Sc Nursing degree in Mental Health (Psychiatric) Nursing specialty from SVIMS University, AP, and India. She has 5 years of teaching experience. She is currently working as a Lecturer in Dept of Nursing, College of Arts and Science, King Khalid University, Khamis Mushyat – 1, Abha, Saudi Arabia.

Prathyusha Naigapula received M.Sc Nursing degree in Mental Health (Psychiatric) Nursing specialty from SVIMS University, AP, and India. She has 5 years of teaching experience. She is currently working as a Lecturer in Dept of Nursing, Swathanthra, College of Nursing, AP, India.

M. Bhagyalakshmi received PhD degree in Mental health (Psychiatric) Nursing from SVIMS University, AP, and India. She has 8 years of teaching experience. She is currently Assistant Professor in Dept of Nursing, , College of Nursing, SVIMS University, India

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Hemalatha. S received PhD degree in Mental health (Psychiatric) Nursing from SVIMS University, AP, and India. She has 7 years of teaching experience. Her area of interest in research is Psychiatric Nursing. She is currently Assistant Professor in Dept of Nursing, , College of Nursing, SVIMS University, India

ISSN 2470-6639