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Group differences on affiliate stigma experienced by family caregivers of psychiatric patients

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Abstract The present study aimed to study the effects of affiliate stigma among family caregivers of psychiatric patients. Total sample of 203 male and female caregivers of psychiatric patients were approached and administered the scales. The demographics and the item scores of the Affiliate Stigma Scale were analyzed using descriptive statistical analyses such as mean, standard deviation, and frequency. Moreover, *t* test was applied to explain group differences among demographics and affiliate stigma and its components. Results showed considerable differences between gender, marital status and employments status on affiliate stigma and its components with married, unemployed females experiencing more affiliate stigma while providing care for a family member with psychiatric illness.

Keywords Stigma · Affiliate stigma · Disability · Psychiatric patients · Caregivers · Family

1 Introduction

Nearly half of the world's population is affected by mental health related problems with an impact on their self-esteem, inter-personal relationships and ability to function in daily life (Storrie et al. 2010). Mental illnesses can also have negative impact on physical health which can lead to disturbance in different areas of life (Richards et al. 2012).

From last few decades rapid changes have occurred in mental health services in Pakistan, still the situation is not up-to-the-mark both due to lack of trained staff, patient's care and other mental health related facilities. Few numbers of mental health professionals including psychologists and social workers are present and almost all of them are in the

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large cities despite the fact that majority of our population lives in rural regions (Afridi 2009).

Proper epidemiological data regarding mental illnesses in Pakistan for proper mental health plan and implication system is by and large lacking. According to World Health Organization (WHO), 1% of the population suffers from severe and 10% from mild mental disorders in developing countries like Pakistan. According to the Global Burden of Disease (GBD) the mental health related problems constitute 10.5% of GBD, which may rise up to 15% in the year 2020. Among the top ten major causes of disability, five are mental illnesses, contributing 29% of the total disabilities while behavioral problems contribute an additional 34% to the GBD (WHO 2007).

Stigma about having a mental illness has a long history. The Latin word for it was *instigare* and in ancient Greece, the word *stizein* a physical mark or tattoo was cut or burned into the skin of criminals, slaves, or traitors and this marking lead to an action as to discriminate them as blemished or morally polluted persons. These psychiatric patients were to be avoided or shunned, particularly in public places. Today, stigma refers to discrimination in some undesirable way. It is a sign of shame, disgrace, or disapproval, rejected by others or by even the entire community (López-Ibor 2002).

Goffman argues that stigma "refers to an attribute that is deeply discrediting". People's stigma makes them different and puts them in a less desirable kind available (Goffman 1963). Goffman also defined stigma as 'the process by which the reaction of others spoils normal identity' (Nettleton 2006). He adopted the term stigma to describe the marked identity of individuals having traits that are different from what is considered normal or ideal (Goffman 1963). Stigma dehumanizes and devalues the stigmatized, reducing their identity to a single mark or flaw (Major and Brien 2005). The process of stigmatization starts when the individuals accept the label that makes them different and devalued from others (Goffman 1963).

Family caregiver is a spouse, adult, child, or relative who has a personal relationship with, and provides a broad range of unpaid assistance for another individual with chronic or disabling mental or physical condition (Wenberg 2011).

Caregiving at any stage of the life progression has been described as an "unexpected career" (Pearlin and Anashensel 1994). However, entering the caregiver role in midlife differs from caregiving as an older adult both in the specifics of the caregiving context and in the potential impact of caregiving on health and other psychosocial factors.

Mental Health is inseparably linked with the perception of society and culture; culture plays a significant role in how people conceptualize mental health, normality and healing (Kirmayer 1989). One important socio-cultural factor in the treatment of the mentally ill individual is their family or the person providing care. Patel (2008) in caring for the mentally ill said, "The core resource is humans". One of the main reasons of avoiding help for mental issues by patients or their caregivers is due to the stigma attached to psychological problems and its treatment in the society (Liegghio and Sdao-Jarvie 2012).

Studies have shown that 43–92% of caregivers of people with mental illness report feeling stigmatized (Struening et al. 2001), thus affecting the treatment process negatively. The recognition of the needs, in terms of support and services for individuals having mental illness, becomes the role of their caregivers; so it is very important to understand caregivers experiences; especially possible barriers to their care-giving experiences.

Caregivers are the ones to remind and encourage the patients to continue taking medications properly; avoid doing harm to him/her in extreme cases; responsible for making certain that the patient go to his/her follow-up appointments. But caring for the mentally ill can cause emotional and psychological stress; so sometimes, to avoid judgment, families or

caregivers may sometimes be in denial about the illness. Due to fear of stigma, denial or lack of knowledge, most mentally ill patients are not brought to treatment until illness becomes severe. Frustration, lack of patience or understanding leading to anger or physical abuse towards the patient negatively impacts treatment and recovery. So it is important to psycho-educate or counsel the caretakers as well to deal with the challenges faced as a result to be able to cope to provide better care.

2 Method

2.1 Research design

Present study used survey research design to explore and meet the research objectives. In the beginning of the present research, the affiliate stigma scale was translated and adapted. Forward and backward translation was done with the help of committee approach and Urdu version of the scale was finalized to be used. Participants were explained about the nature of study and importance of their participation in it. They were assured about the use of gathered information only for research purpose as well as the confidentiality of provided information. Then the scale translated was administered to find out relationship between affiliate stigma and its components along with the demographics sheet.

2.2 Participants

Purposive sample of 203 male and female family caregivers of psychiatric patients were taken from Islamabad and Rawalpindi hospitals to obtain a representative sample by using a sound judgment, which results in saving time and money (Black 2010). Family caregivers of psychiatric patients who were selected to participate in the study were providing care from at least 6 months. The patient was also taking psychiatric treatment from at least 6 months. Mother, father, children, siblings and spouse not less than 18 years of age who were throughout with the patient either hospitalized or at home were taken as family caregivers of psychiatric patients (Table 1).

2.3 Data collection

After taking permission from the author to translate and adapt Affiliate Stigma Scale (Winnie and Cheung 2008) to administer for this study, purposive convenient sample of 203 male and female family caregivers of psychiatric patients were taken from Islamabad and Rawalpindi hospital, that is, Pakistan Institute of Medical Sciences (PIMS), and Benazir Bhutto Hospital for the present study. Family caregivers of psychiatric patients who were selected to participate were briefed about the purpose of the study. After informed consent, they completed demographics information sheet along with Urdu translated version of Affiliate Stigma Scale in one sitting.

Only those individuals were included in the study that can fully understand and write Urdu and have consented to participate.

Table 1 Demographic details of the sample (N = 203)

Demographic variables	*f*	%
Gender		
Male	97	47.8
Female	106	52.2
Education		
Matric or below	90	44.3
F.A/F.Sc	40	19.7
B.A/B.Sc	51	25.1
M.A/M.Sc	22	10.8
Marital status		
Married	116	57.1
Unmarried	87	42.9
Employment status		
Employed	79	38.9
Unemployed	122	60.1
Monthly income (in Pak. Rs.)		
Up to 20,000	85	41.9
21,000–40,000	74	36.5
41,000–60,000	17	18.4
61,000–80,000	12	5.9

2.4 Demographic information sheet

Demographic information sheet was constructed which included information about caregiver's age, occupation, education, family system, monthly income, father's education and occupation, mother's education and occupation, number of siblings, birth order, diagnosed disorder of care recipient, duration of illness, relationship to care recipient, duration of providing care.

2.5 Affiliate stigma

Self-stigma and corresponding psychological responses of the associates known as Affiliate stigma is measured by scores obtained by caregivers on Affiliate Stigma Scale developed by Winnie and Cheung (2008). Scale consists of 22 items having 4-point likert scoring method with high score above the mean indicating presence of more affiliate stigma (Winnie and Cheung 2008). The scale consists of three subscales.

1. Affection

The affective component of affiliate stigma refers to the negative emotions associated with the internalized stigma that associates may have. It consists of 7 items with high score indicating the presence of more affiliate stigma (Winnie and Cheung 2008).

2. Cognition

Cognitive component refers to the negative thoughts in relation to caregiver's internalization of stigma as a result of having a close associate with a stigmatized status. It consists of 7 items with high scores indicating more affiliate stigma (Winnie and Cheung 2008).

3. Behavior

Behavioral component refers to the associated behavior or actions related to having internalized stigma. It consists of 8 items with high score indicating more affiliate stigma (Winnie and Cheung 2008).

2.6 Data analysis

A series of analysis was carried out using Statistical Package for Social Sciences (SPSS 18) to analyze the data. The demographics and the item scores of the Affiliate Stigma Scale were analyzed using descriptive statistical analyses such as mean, standard deviation (SD), and frequency. Moreover, *t*-test was applied to explain group differences among demographics and affiliate stigma and its components.

3 Results

3.1 Group differences on affiliate stigma

Differences on all sub-scales were analysed to check the gender, marital status, employment status differences. Therefore *t*-test was applied on male and female family caregivers employed and unemployed employment status, married and unmarried marital status. Then *cohen's* d was calculated to check the effect size.

3.2 Gender differences on affiliate stigma

Group differences were also looked for with reference to the gender of study participants. For this *t*-test was done to see whether male family caregivers were different from female family caregivers affiliate stigma. *Cohen's* d was calculated to check for effect size.

Table shows the mean difference of Affiliate Stigma Scale among male and female family caregivers of psychiatric patients. Results suggest significant mean difference among the male and female family caregivers of psychiatric patients on Affiliate Stigma Scale.

3.3 Marital status differences on affiliate stigma

For marital status differences of family caregivers affiliate stigma two groups were formed that are: married and unmarried and *t*-test was applied. Moreover, *cohen's d* was also calculated to see the effect size of significant group differences.

Table shows the mean difference of Affiliate Stigma Scale among married and unmarried family caregivers of psychiatric patients. Results suggest significant mean difference among the married and unmarried family caregivers of psychiatric patients on affection and behavioural component of affiliate Stigma Scale while no significant mean difference on cognitive component.

3.4 Employment status differences on social identity, social isolation and affiliate stigma

Respondents were divided into two groups of employment status; employed and unemployed to compare for mean differences. The *t*-test was applied to see mean differences on affiliate stigma. Further *cohen's d* was also computed to see the effect size.

Table shows the mean difference of Affiliate Stigma Scale among employed and unemployed family caregivers of psychiatric patients. Results suggest significant mean difference among the employed and unemployed family caregivers of psychiatric patients on affective and cognitive component of affiliate Stigma Scale while no significant difference on behavioural component.

4 Discussion

Affiliate stigma experienced by caregivers of patients with mental illness is a process in which a person is stigmatized by virtue of his or her association with another stigmatized individual. Affiliate stigma occurs when the people affiliated to a stigmatized individual such as caregivers, family members, and friends are personally affected by the public stigma that prevails in the society. These associates may develop affiliate stigma and thus feel unhappy and helpless about their affiliation with the stigmatized individual and also feel a negative influence on them. Due to this caregivers tend to conceal their status from others. They withdraw from social relations and alienate themselves from the patients in order to avoid association. Affiliate stigma thus includes both self-stigma and subsequent psychological responses of the associates.

In order to study the little known affiliate stigma, an instrument, The Affiliate Stigma Scale, was used that is useful and feasible for healthcare providers when assessing affiliate stigma. The psychometric properties of the Affiliate Stigma Scale with caregivers of people with psychiatric disorders were also examined, and the study findings are promising.

Mean differences were carried out among different groups in order to see the trend of affiliate stigma among gender, marital status and employment status.

4.1 Gender and affiliate stigma

It was hypothesized that female family caregiver of psychiatric patient will score high on affiliate stigma as compared to male family caregivers. When gender differences were explored, results of present study displayed significant differences on affiliate stigma and its components where female family caregivers were high than men family caregivers (see Table 2). This is consistent with previous research findings. The relationship between

Table 2 Gender differences on affiliate stigma (N = 203)

Variables	Male (n = 97)		Female (n = 106)		t (201)	*p*	95% CI		Cohen's d
	M	SD	M	SD			LL	UL	
Affiliate stigma scale									
Affection	17.99	3.69	19.07	4.56	− 1.83	0.05	− 2.23	0.08	− 0.26
Cognitive	16.05	3.85	17.60	4.39	− 2.66	0.01	− 2.69	− 0.41	− 0.38
Behavior	20.18	4.17	21.57	4.25	− 2.34	0.02	− 2.55	− 0.22	− 0.33

gender and mental health is complex. Sociological, psychological and feminist theories of gender difference provide support for the greater likelihood of women being caregivers than men. Providing care may be central to women's identity. Women have a special sense of attachment to their families; societal support of women as caregivers is reinforced as social ideologies, women is expected to stay home and the devaluing of their paid work is prevalent among society. They spend more time with the psychiatric patient present in their family and as a result feel more stigmatized (Stephan 2007). Mental illness stigma was found to be prevalent among female caregivers of persons with bipolar disorder than male caregivers of persons with bipolar disorders (Tompkins 2006).

4.2 Marital status and affiliate stigma

It was hypothesized that married family caregiver of psychiatric patient will score high on affiliate stigma as compared to unmarried family caregivers. When marital status differences were explored it became evident that married family caregivers showed significant high scores on affective and behavior components of affiliate stigma than unmarried family caregivers, non-significant differences were observed on cognitive component. However, unmarried caregivers were showing non-significant differences on social identity and family social isolation and significant differences on friend social isolation (see Table 3).

Relatives especially spouse must share the burden of giving assistance to psychiatric patient in all of their activities, that is, coping with abnormal behavior, giving emotional support and concrete assistance. They also have to assist the patient mentally, physically and financially. They also must love and assist the patient and have a positive relationship with mentally ill person. It has been supported by the literature that spouse will be most important source of support as in western cultures people mostly do not live with their parents. The primacy of spousal relationship and emotional attachment ensure greater support to the patient. As spouses spend more time the patient; chances are more that he/she will internalize the stigma attached to mental illness which in turn does affect the caregiving process (Miller and Guo 2000).

4.3 Employment status and affiliate stigma

It was hypothesized that unemployed family caregivers will score high on affiliate stigma than employed family caregivers. When mean differences were seen for affiliate stigma, it became clear that differences were significant at affective and cognitive component of affiliate stigma but non-significant on behavior component (see Table 4). In one study British Asians were interviewed who were receiving psychiatric treatment, selected to be

Table 3 Mean differences of married and unmarried family caregivers on affiliate stigma (N = 203)

Variable	Married (n = 116)		Unmarried (n = 87)		t (201)	*p*	95% CI		Cohen's d
	M	SD	M	SD			LL	UL	
Affiliate stigma scale									
Affection subscale	19.07	4.22	17.86	4.08	2.05	0.04	0.05	2.38	0.29
Cognitive subscale	17.26	4.18	16.34	4.20	1.54	0.13	− 0.26	2.09	0.22
Behavior subscale	21.56	4.08	20.03	4.36	2.56	0.01	0.35	2.69	0.36

equivalent in age and a number of demographic variables. Consistent with the present study findings, results showed that the employed group was less affected by the affiliate stigma than unemployed group (Green and Kreuter 2005).

Several studies have investigated public and family stigma experienced by caregivers of individuals being diagnosed with psychiatric illness (Ali et al. 2012). However, research on the impact of affiliate stigma is scant (Werner and Shulman 2013), particularly so in the context of caregivers to individuals with mood disorders, schizophrenia (Werner and Shulman 2015; Werner et al. 2012), autism spectrum disorder (ASD), specific learning disability (SLD) and intellectual and developmental disabilities (IDD). Only six studies specifically from the Asian subcontinent have focused on affiliate stigma (Mak and Cheung 2008; Mak and Kwok 2010; Chiu et al. 2013, 2015; Werner and Shulman 2013, 2015) and its impact on caregiver's well-being (Chiu et al. 2013, 2015; Werner and Shulman 2015).

4.4 Limitation and suggestions

The present study was cross-sectional in nature so directions in terms of causality cannot be determined. For future studies longitudinal research should be conducted for capturing individual differences over longer time span that would yield better understanding of association between these constructs with respect to different age groups.

Due to resource and time constraints, sample represents a non-random, convenient sample of literate family caregivers of psychiatric patients of specified area, that is, Rawalpindi and Islamabad. The findings cannot be generalized to the entire country, which consists of illiterate population as well. For the purpose of generalizing the results, future research should be conducted with sample taken randomly from diversified geographical locations including illiterate population as well.

4.5 Implications

The Urdu translated versions of the scales measuring affiliate stigma among caregivers will be handy to use for further research when language constraints pose problems with indigenous research. The present research highlighted the stigma faced by caregivers of mentally ill individuals and the psychological pressures faced as a result. The Affiliate Stigma Scale proved to be a reliable and valid instrument for assessing affiliate stigma. Because the psychometric properties of the Affiliate Stigma Scale have been found satisfactory, healthcare providers might want to use it to understand caregivers' perspectives and to design appropriate interventions to reduce affiliate stigma.

Table 4 Means differences of employed and unemployed family caregivers on affiliate stigma (N = 203)

Variables	Employed (n = 79		Unemployed (n = 122)		t (199)	*p*	95% CI		Cohen's d
	M	SD	M	SD			LL	UL	
Affiliate stigma scale									
Affective subscale	17.87	3.99	19.04	4.23	− 1.97	0.05	− 2.35	0.03	− 0.28
Cognitive subscale	15.76	4.15	17.63	4.06	− 3.17	0.00	− 3.04	− 0.71	− 0.45
Behavior subscale	20.27	4.27	21.37	4.18	− 1.79	0.07	− 2.29	0.11	− 0.25

Many people do not seek psychological treatment even if they need help due to stigma prevalent in the society; the present research will highlights the issue that clinicians need to address caregivers and patient's concerns about the negative perceptions seeking treatment, thus emphasizing the need to develop intervention programs to help caregivers cope with the negative psychological effects thus reducing the burden caregiving carries thus reducing the chances of becoming socially isolated.

The study has collected evidence on the role of affiliate stigma to explain its impact on caregiver's life. Given the high rate of affiliate stigma experienced by caregivers, it echoes the need for developing anti-stigma campaigns or strategies that address the psychological well-being of family members providing care. Strategies could include either parent or special educators, or school social worker-led support groups, teaching family members the strategies to appraise stress positively. It also serves to direct interventions to reduce affiliate stigma among the caregivers so as to enhance their caregiving experience. For further studies, it can help researchers who are interested to study stigma to work on the strategies designed to help the family caregivers combat with the negativities of affiliate stigma and its consequences.

The media have often been accused of sensationalism by portraying mental illness inaccurately in their quest to gain higher ratings and ultimately promoting stigma related to mental illness. However, the media can also play an important role in reaching out to many different audiences to promote mental health literacy thus reducing the stigma attached to it. In designing, implementing and evaluating services, interventions, anti-discrimination activities and stigma reduction campaigns people should be enables affected by mental health problems (both individuals and their families) to be empowered to act as partners in care, treatment and recovery, and as advocates in anti-discrimination work.

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