

Study of Barrier to Help Seeking and its Relationships with Disability in Patients with Headache

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ABSTRACT

Introduction: Headache is among the first three most prevalent disorders with a wide treatment gap due to barriers in help seeking. Headache has been associated with disability. However, the relationship of barriers to help-seeking and disability are unexplored.

Aim: To find out the barriers to help seeking and its relationship with headache related disability in patients with headache.

Materials and Methods: In this hospital based cross-sectional study, 200 consecutive subjects with headache attending a tertiary care centre were recruited as per selection criteria and assessed with Sociodemographic & Clinical Proforma, Mini International Neuropsychiatric Interview (MINI), Barriers to Help Seeking Scale (BHSS), The Henry Ford Hospital Headache Disability Inventory (HDI).

Results: High mean score was observed on BHSS subscale need for control and self reliance (19.45; SD \pm 9.66) and minimizing

problem and resignation (10.02; SD \pm 6.98). Mean score on the HDI was 25.65 (SD \pm 14.09). Socioeconomic status of the patient was statistically significant and positively associated with need for control and self reliance ($p=0.035$), concrete barriers and distrust of care givers ($p=0.039$), emotional control ($p=0.005$), and privacy ($p=0.002$). Occupational status had significant association with need for control and self-reliance ($p=0.01$), minimizing problem and resignation ($p=0.033$), and emotional control ($p=0.006$). Score on hospital headache disability inventory significantly predicted the value of score on concrete barriers and distrust of caregivers domain of HDI ($p=0.001$).

Conclusion: Autonomy and under estimation of seriousness of headache are common barriers to help seeking. Pattern of help seeking barriers may vary with socio-economic status and occupational status, while disability varies with gender and severity of headache. Headache associated disability is positively associated with concrete barriers.

Keywords: Functional impairment, Illness behaviour, Treatment barriers

INTRODUCTION

Globally, the percentage of the adult population with an active headache disorder is 46%, out of which, 11% have migraine, tension-type headache constitute 42% [1,2]. On the World Health Organization's ranking and the Global Burden of Disease Study 2010 (GBD2010) the Tension-Type Headache (TTH) and migraine were reported to be the most prevalent disorders worldwide [1,3]. Despite the high prevalence of headache, half of the patients may not seek treatment or they try self remedies [4]. Headache care professionals have expressed the concern of high treatment gap and a global campaign was initiated by World Health Organization [5].

Empirically, myths, misconceptions and poor knowledge about headache along with low socioeconomic status are the major barriers to help seeking [4]. Help-seeking is defined as a problem focused, planned behaviour, involving interpersonal interaction with a qualified health-care professional [6]. Experimental or correlational research reveals that people are less likely to seek help for problems that are highly ego-central and non-normative [7], and when autonomy is threatened [8]. Inadequate emotional control, insufficient social & financial resources, cost of help, lack of awareness of remedial options, concerns about confrontation, and not wanting to share personal problems (self-disclosure) may obstruct the help seeking [9-11].

The findings regarding relationships of help-seeking behaviour and disability among non-headache population is contradictory. Some studies could not find any relationship [12-15]; while one study found positive association [16]; and others found negative association [17,18]. The differences in the findings in the reported studies can likely be explained in part by the differences in sampling frame and study design.

Headache is a disabling illness. Headache impairs functioning and productivity with effects on their well-being and ability to fulfill their usual roles as a student, worker, and/or family member [19]. Headache related disability may mediate the help seeking behaviour [20]. Attempts have been made to examine factors that mediate treatment seeking (a component of help seeking) and reported that disability attracts treatment seeking while stigma repels such behaviour [21,22].

Relationships of barriers to help seeking and disability were under-explored. Understanding this relationship may help to overcome the barriers, or reduce the treatment barriers in patient with headache related disability. This study was undertaken to know the relationship of disability and barriers to help seeking behaviour in patients with headache. We hypothesized that barriers to help seeking was positively associated with headache related disability.

MATERIALS AND METHODS

This cross-sectional study was conducted at a tertiary care centre in Southern India over a period of six month (May -October 2015) after approval from ethics committee. The study centre caters service to both rural and urban population. Study participants were, subjects attending the Department of Neurology for treatment of headache. They were consecutively enrolled in this study based on the study selection criteria after obtaining an informed consent. Participants were eligible for the study if they were males or females between the age of 18 -65; a diagnosis of primary headache (as per International Classification of Headache Disorders (ICHD-III) by The International Headache Society for minimum of 3 months duration (IHS vs. 3rd) [23]; and no consultation to any physician for headache for last six months. Participants were excluded if they had

any ongoing psychiatric illness (as per International Classification of Diseases 10th Revision) or physical disability as it is a known barrier in help seeking. Similarly, those with secondary headache (ruled out by clinical examination and investigation including imaging) were also excluded from the study as the nature of aetiology may influence the help seeking. All participants underwent physical, neurological and psychiatric evaluation by qualified physician, neurologist and psychiatrist to ascertain eligibility criteria. A total of 200 subjects who met the study criteria were further assessed with the following tools:

1- Sociodemographic and Clinical Proforma: This proforma included demographic and clinical details such as age, education, employment, socioeconomic status, religion, marital status, residence, family type etc.

2- Mini International Neuropsychiatric Interview (MINI Plus): It is a structured interview tool with options of 'yes' and 'no' as responses, two to four screening questions per disorder, organized in diagnostic sections and uses branching tree logic. It contains 16 sections and all together 27 past and current disorders are covered in the tool [24].

3- Barriers to Help Seeking Scale (BHSS): This scale consists of 31 item and assess the multiple domains of barrier to help-seeking behaviour {Need for Control and Self-reliance (NCS), Minimizing Problem and Resignation (MRP), Concrete barriers and Distrust of caregivers (CBD), Privacy (PRI), Emotional Control (EMC)}. The scale asks participants to use a Likert-type scale ranging from 0 to 4 (0 - not at all, 4- very much) to rate how much of a reason each item would be to not seek help for the problem described above [25]. Initially the scale was developed to measure the Barriers to help seeking among males but later it was found to be useful in both genders [26,27].

4- The Henry Ford Hospital Headache Disability Inventory (HDI): The questionnaire was developed by Gary Jacobson et al., in 1993 to evaluate the self -perceived disability effects (emotional and functional) of headaches. It consists of a 25 item, and can be grouped in to emotional domain (13 items) and functional domain (12 items). The scale asks participants to use a 5-point Likert-type scale ranging from 0 to 4 (0 = not at all, 4 = very much) to rate how much of a reason each item would be to not seek help for the problem described above. The minimum score is 0, maximum emotional subscale is 52, and maximal functional subscale is 48. Maximum score obtainable on the index is 100. The developers have reported that the 25-item Headache Disability Inventory has good internal consistency reliability, robust long-term (2 month) test-retest stability, and good construct validity [28].

STATISTICAL ANALYSIS

Data was analysed using SPSS vs. 16.0 (SPSS, Inc, Chicago, Illinois). Descriptive statistics was used for sociodemographic and clinical characteristics. For further analysis data was examined for distribution. Since normal distribution of demographic data could not be ascertained, non-parametric test was carried out. A Kruskal-Wallis H test was done to compare three or more variable and Mann-Whitney Test was done to compare two variables. After normalising the data, a multiple linear regression analysis was carried out. Score on BHSS subscales (HDI, NCS, MRP, CBD, PRI, EMC) was entered as predictor variables while total score on HDI was entered as dependent variable. For all the tests, statistical significance was set to 0.05 in this study.

RESULTS

Majority of the participants were females Hindu, educated, employed, belonged to middle to low socioeconomic status and were suffering from moderate to severe headache. Mean score for age was 35.6 years; duration of headache was 32 months while frequency was 10 per month. Mean score on BHSS was

40.9, while HDI was 25.6. Relatively more score was observed in Need for Control and Self reliance (NCS) (Mean 19.45, SD± 9.66) and Minimizing Problem and Resignation (MPR) (Mean 10.02, SD± 6.98) subscale of BHSS. Score on emotional and functional domain of HDI were identical [Table/Fig-1,2a&b].

Relationships of Socio-demographic and Barrier to Help Seeking

[Table/Fig-2a&b] presents data on relationships of socio-demographic and barrier to help seeking. On Kruskal-Wallis H

N=200	Min	Max	Mean	Std. deviation
Age (Year)	18	74	35.62	11.03
Duration (Month)	13	360	32.83	45.50
Frequency (Per Month)	1	30	10.66	10.71
BHSS Score	0	89	40.90	19.19
Need for control and self reliance (NCS)	0	40	19.45	9.66
Minimizing problem and resignation (MPR)	0	24	10.02	6.98
Concrete barriers and Distrust of caregivers (CBD)	0	21	5.37	5.14
Privacy (PRI)	0	20	5.05	4.73
Emotional control(EMC)	0	16	6.06	5.64
HDI Score	0	68.00	25.65	14.09
HDI Emotional Score	0	36.00	12.16	7.66
HDI Functional Score	0	35.00	13.49	6.83

[Table/Fig-1]: Demographics characteristics.

N=200		N	Mean rank	Chi-square	df	Asy. sig
Severity* Privacy	Mild	16	65.20	6.150	2	0.046*
	Moderate	99	101.69			
	severe	85	104.17			
Socioeconomic status* NCS	Low	90	89.19	6.722	2	0.035*
	Middle	97	111.13			
	high	13	99.50			
Socioeconomic status* CBD	Low	90	111.27	6.489	2	0.039*
	Middle	97	93.38			
	high	13	79.04			
Socioeconomic status* PRI	Low	90	86.99	12.740	2	0.002**
	Middle	97	107.76			
	high	13	139.88			
Socioeconomic status* EMC	Low	90	89.96	10.567	2	0.005**
	Middle	97	104.65			
	high	13	142.46			
Religion*PRI	Hindu	171	96.25	9.209	2	0.010**
	Muslim	20	113.90			
	Christian	9	151.56			
Education* CBD	Uneducated	26	107.90	15.87	2	0.007**
	Primary	25	138.98			
	Secondary	55	93.46			
	Pre university	35	100.96			
	Graduate	46	88.99			
	Post graduate	13	80.96			
Education* EMC	Uneducated	26	86.42	18.95	2	0.002**
	Primary	25	76.24			
	Secondary	55	101.04			
	Pre university	35	101.90			
	Graduate	46	103.97			
	Post graduate	13	157.00			

[Table/Fig-2a]: Relationships of socio-demographic and help seeking barrier. Kruskal-Wallis, *p<0.05, ** p<0.01 significant. NCS= Need for control and self-reliance, CBD=Concrete barriers and distrust of caregivers, PRI =Privacy, EMC=Emotional control.

N=200		N	Mean rank	Sum of ranks	Mann Whitney-U	Z	Asy. sig
Occupation* NCS	Un-employed	90	83.80	7542.0	3.447	-3.69	0.001**
	employed	110	114.16	12558			
Occupation* MPR	Unemployed	90	90.91	8181.5	4.086	-2.12	0.033*
	Employed	110	108.35	11918			
Occupation* EMC	Unemployed	90	88.17	7935.5	3.840	-2.75	0.006**
	Employed	110	110.59	12164.5			
Gender* NCS	Male	70	125.66	8796	2.789	-4.51	0.001**
	Female	130	86.95	11304			
Gender* MPR	Male	70	114.92	8044.50	3.540	-2.59	0.010**
	Female	130	92.73	12055.5			
Gender* EMC	Male	70	119.41	8358.50	3.226	-3.43	0.001**
	Female	130	90.32	11741.50			

[Table/Fig-2b]: Relationships of socio-demographic and help seeking barrier. Mann-Whitney U test, *p<0.05 significant, ** p<0.01 significant. NCS= Need for control and self-reliance, MRP =Minimizing problem and resignation, EMC=Emotional control.

test the socioeconomic status of participants had a statistically significant group difference on the score of BHSS subscales- Need for control and self reliance (p=0.035), CBD (p=0.039), emotional control (p=0.005), and privacy (p=0.002). Participants with higher socioeconomic status were more likely to score more on subscale Privacy, emotional control and vice versa on CBD subscale, while participants with middle socioeconomic status scored more on need for control and self-reliance.

Education grades had a statistically significant group difference on score of subscale CBD (p=0.007) and Emotional control (p=0.002). Participant with primary education scored more on subscale Concrete barriers and distrust of caregivers while post graduate scored more on emotional control subscale.

Privacy subscale of BHSS also had a statistically significant association with severity of headache (p=0.046) and religion (p=0.010) of the participants. Score on privacy subscale were more if participant had more severe headache and belonged to religious minority.

On Mann-Whitney Test [Table/Fig-2b] employed participants had a statistically significant score more on BHSS subscales- Need for control and self-reliance (MU=3.447, p=0.01), minimizing problem and resignation (MU=4.086, p=0.033), and emotional control (MU=3.840, p=0.006). Similarly, female participants also had a statistically significant more score on BHSS subscales - Need for control and self-reliance (MU=2.789, p=0.01), minimizing problem and resignation (MU=3.540, p=0.010), and emotional control (MU=3.226, p=0.001).

Relationships of Headache Disability with Demographic Variables

Headache disability did not have a statistically significant association with most of the demographic and clinical variables [Table/Fig-3a,3b]. Among the demographic variables only gender had a statistically significant association with total HDI score (MU=3.781, p= .049) and Functional domain of HDI (MU=3813.0, p=.059). Among clinical variables, the severity of headache was statistically significantly associated with HDI score ($\chi^2 =33.99$, df=2, p=.001) and score of both emotional ($\chi^2 =30.120$, df=2, p=.001) and functional domain ($\chi^2 =36.278$, df=2, p=.001).

Relationships of Headache Disability with Barriers to Help Seeking

In order to test our hypothesis, we conducted a linear regression analysis (BHSS subscales were entered as predictor variable and HDI score was entered as outcome variable) ($R^2=.097$, SD=13.56, DF=5, F=4.161, p=.001). HDI score statistically significantly and positively predicted the value of score on CBD domain of BHSS (p=.001) [Table/Fig-4].

N=200		N	Mean rank	Sum of ranks	Mann Whitney-U	Z	Asy. sig
Gender* HDI score	Male	70	89.51	6266.00	3.781	-1.970	0.049*
	Female	130	106.42	13834.00			
Gender* HDI Emotional domain Score	Male	70	90.69	6348.50	3863.5	-1.760	0.070
	Female	130	105.78	13751.50			
Gender* HDI Functional domain Score	Male	70	89.97	6298.00	3813.0	-1.890	0.059*
	Female	130	106.17	13802.00			

[Table/Fig-3a]: Relationships of headache disability and demographic variables. Mann-Whitney U test, *p<0.05 significant. HDI =Headache Disability Inventory.

N=200		N	Mean rank	Chi-square	df	Asy. sig
Severity* HDI score	Mild	16	43.62	33.991	2	0.001**
	Moderate	99	89.06			
	Severity	85	124.53			
Severity*HDI Emotional domain Score	Mild	16	42.84	30.120	2	0.001**
	Moderate	99	91.37			
	Severity	85	121.99			
Severity*HDI Functional domain Score	Mild	16	49.00	36.278	2	0.001**
	Moderate	99	86.26			
	Severity	85	126.78			

[Table/Fig-3b]: Relationships of headache disability and clinical variables. Kruskal-Wallis, *p<0.05, ** p<0.01 significant. HDI =Headache Disability Inventory.

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig
		B	Std. Error	Beta		
1	(Constant)	20.760	2.367		8.770	0.001**
	NCS	.033	.129	.023	.256	0.799
	MPR	-.107	.173	-.053	-.616	0.538
	CBD	.712	.197	.260	3.610	0.001**
	PRI	.356	.226	.119	1.575	0.117
	EMC	-.050	.194	-.020	-.256	0.798

[Table/Fig-4]: Relationship of headache disability and barriers to help-seeking. $R^2=.097$, SD=13.56, df=5, F=4.161, p=.001; Dependent Variable: HDI Score; *p <0.05, ** p<0.01 significant. HDI =Headache Disability Inventory, NCS= Need for control and self-reliance, MRP =Minimizing problem and resignation, CBD=Concrete barriers and distrust of caregivers, PRI =Privacy, EMC=Emotional control.

DISCUSSION

This study was conducted to know the relationship of disability and barriers to help seeking in patients with headache. Although the data was collected at a tertiary care centre, the demographic characteristics were similar to the community based study conducted in southern India [28].

We observed elevated mean score in the domains of NCS and MPR on BHSS subscales. This indicates concerns for autonomy and under estimation of seriousness of headache were major barriers in help seeking. It underscores need to enquire and address any autonomy related factors in patients with headache. Less help-seeking has been observed in experimental or correlational research, when problems are highly ego-central, non-normative and when autonomy is perceived to be threatened [7,8,29]. In this study, a significantly elevated level of disability is consistent with the previous report and may be possibly due to elevated score on subscales of BHSS (e.g., NCS and MPR) that may contribute in delaying treatment seeking, till severity had significant impact on their life [30].

Relationships of Socio-demographic and Barrier to Help Seeking

Result reveals that participants with different socioeconomic status experienced different pattern of help-seeking barriers. Those with low socioeconomic status had more distrust on care givers and faced more concrete barriers, while autonomy

and privacy was correspondingly a major barrier among middle and high socioeconomic status. Lower socioeconomic status is commonly accompanied with financial difficulty, poor information of healthcare provider, illness and treatment [30]; while need for autonomy is common with middle socio-economic status, that may influence the decision for health seeking [31,32]. Those with higher socioeconomic status may experience difficulty in emotional control (particularly negative emotion) due to variation in stress exposure attributable to socioeconomic environments [33]. The pattern of relationship between socioeconomic status and experience of barrier to help seeking can also be partially explained based on the Reserve Capacity Model, that is enhanced vulnerability reflects inadequate resource reserves that could otherwise attenuate negative appraisals or facilitate adaptive coping [34]. Trust building may enhance help seeking among lower socio-economic status while measures to address emotional control may enhance help seeking in higher socio-economic status.

We observed that lower level of education was associated with a concrete barrier. Low Socioeconomic Status (SES) are likely to face concrete barriers and distrust in caregiver due to poor information of health care provider, illness and treatment; while low emotional control may act as barrier not only to help seeking but academic achievement as well [30,35,36]. This finding is consistent with the WHO recommendation that adequate provision of basic facilities such as education, particularly health education in general population is helpful in primary and secondary prevention of psychological and physical health [5].

Studies have found that females are more likely than males to seek help for headache as observed in this study [13,37]. We observed an association of male gender and need for autonomy, under estimation of need for help, and emotional control; is in the line with other report that highlighted psychological barriers in men as: (1) Embarrassment/anxiety/distress/fear related to using health-care services; (2) Need for emotional control/guarded vulnerability; (3) Viewing symptoms as minor and insignificant; and (4) Poor communication/rapport with health professionals [37]. Male gender is known to have need for expression of autonomy, and seek treatment when their socio-occupational function is significantly hampered [35]. This observation highlights the needs for gender specific psychological intervention to enhance help seeking in males [38].

We found that employed participant experienced more psychological barrier in terms of need for control and self-reliance, minimizing problem and resignation, emotional control. Relationship of unemployment and poor health is well documented [39]. Unemployed are more likely to face concrete barriers such as financial difficulties. Need for autonomy is important for employed, as any restriction may result in impaired occupational performance. However, more needs of autonomy or self-reliance may reduce the willingness to seek psychological help [25]. Possible reason for such observation could be that male population are more likely to be employed, and male gender is more likely to experience such psychological barriers as observed in this study.

Privacy emerged as barrier in participants with severe headache and those who belonged to religious minority. Culture of minorities may shape help-seeking behaviour due to differences in understandings of illness and treatment; different expressions of aetiology, symptoms and pain; different perceptions of the role of patients and clinicians, cultural norms, religious practices and customs [40]. Privacy concerns may inhibit help-seeking. Some ethnic minority patients fear discrimination based on current and previous experiences, which may lead to mistrust of the health care system. Thus need for privacy delays the approach for help among religious minority who contemplate for help seeking [41]. This finding highlights the ever emphasised role of culture competency, maintaining required privacy in care of headache.

Relationships of Headache Disability with Demographic and Clinical Variables

In this study, female gender was positively associated with overall severity of headache in both emotional and functional domains of disability. Higher level of headache related disability in women has been consistently reported across the continent [42]. Several factors that may contribute to experience more disability among women are: they are more sensitive to pain due to social conditioning, psychosocial factors, psychological, and experiential factors, sex hormones influence on pain sensitivity, different pattern of activation of mu-receptors & kappa-opioids, and low levels of the neuraxis [43]. This observation has a prognostic implication, and highlights the needs to identify and address both emotional and functional disability in care of women with headache.

Relationships of Headache Disability with Barriers to Help Seeking

We observed a significant positive association between HDI score and a BHSS subscale CBD. Our hypothesis was partially true. CBD appears to be major factor in delaying or not seeking help in patients even with higher headache disability, and experience more personal or emotional problems [13,25,35]. Trust enhances doctor-patient interaction and utilization of health care services [41,44]. Delay or underutilisation of health care due to mistrust may contribute to the development of various degrees of disability, which may later drive the help-seeking intentions [45]. Individuals are most likely to seek help in areas that are most valued or salient to them [46]. Functional impairment in those areas may serve as an important indicator that help-seeking is warranted [45]. Inability to bear the cost of care, lack of knowledge of services available, transportation limitations, poor accessibility to healthcare facility significantly hamper help seeking [47,48]. Availability of services, free of cost is common reason for preferring to the public health facility but lack of health care professionals is a major drawback in public health care in India [49]. Avoidance strategy reported with headache are substance abuse, denial of unhappiness, suppression of anger, psychosomatic symptoms, withdrawal from people, denial of memories, avoidance through sleep/lack of energy, distraction through activity, passive distraction (Fantasy, daydreaming, television and passive blocking of upsetting emotions) [50]. This finding signifies that due to concrete barriers patient may not seek treatment till disability increases significantly. This supports the recommendation by world health organisation that developing countries like India needs to improve on basic needs of general population in order to reduce burden of headache across the world [5].

CONCLUSION

Autonomy and under estimation of seriousness of headache are common barriers to help seeking. Pattern of help seeking barriers may vary with socio-economic status and occupational status while disability varies with gender and severity of headache. Headache associated disability is positively associated with concrete barriers. However, finding of this study is applicable among patients availing service from tertiary care and further study is needed with more sample size in community setting.

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