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A Study on burden experienced by the families of osteo-arthritis patients

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Abstract:

The study was conducted with the aim of investigating the burden experienced by the families of osteo-arthritis patients. 102 families of patients suffering from osteo-arthritis knee were included in the study. The study was conducted in the Clinical Department of Physiotherapy, run by a Charitable Trust. The patients residing within the radius of 40 kilometers from study site and the patients without fracture or any other major health problem limiting their movements at the time of study were selected. Socio-demographic factors and the burden experienced by the families of patients were studied. The data were analysed using correlation, t test and F test. It was found that socio-demographic factors did not have any influence over most of the aspects of burden experienced by the families of osteo-arthritis patients.

Key words:Burden, Osteo-arthritis, Family, Patient

Introduction

Disease is not purely a biological problem and It is associated with psycho-social causes and consequences mostly. It is true with osteoarthritis also. Osteoarthritis is the most common types of arthritis. It is also known as degenerative arthritis of degenerative joint disease (Kaur et al. 2018). OA is ranked as one of the leading causes of disability among the elders (Brooks PM 2002, Guccione AA et al. 1994, Anna M. et al. 1995). As OA knee retards the mobility of the patient his functioning capacity is decreased and causes burden to self, family and the society. OA is a major public health problem in our country and is one of the most common causes of disability (Maharajan. A. et al. 2005). OA knee disturbs physical and psycho-social health of the patients and causes burden to the family and the country As OA knee retards functioning ability of the patients, they become dysfunctional in social aspects including vocation. This causes burden on the family. The burden is related to

economic aspects, routine family activities, family leisure, family interaction and health of the family members. The study tries to understand family burden of osteoarthritis patients.

Illness merely is not a biological or medical problem. It affects social dimension of the patients. It usually causes dysfunction and family burden. Osteoarthritis patients suffer from dysfunction which reduces the functioning capacity of the patients. As a result their families are burdened. Family burden denotes the impact of the individual's disabilities on the family. The affected family experiences burden in various areas like finance, routine family activities, family leisure, family interaction and physical and mental health of the family members. These were measured by Family Burden Interview Schedule developed by Pai and Kapur (1981) in a clinical setting. Finance of the family is disturbed because of disturbed vocational adjustment and due to expenditure of treatment. However such losses and expenditure are minimal. This health problem poses mild disturbances in family interaction, routine activities of the family members and family leisure. There may also be some influence on health aspect of the family members. However these disturbances on the families are mild because most of the patients do not lose the independent functioning.

Methodology

The research design applied for the present study was exploratory in nature. Studies on dysfunction of osteoarthritis are extremely sparse. The study tries to explore the above aspect. The research was carried out to study the socio-demographic profile of osteoarthritis knee patients and the burden of their families. The study was conducted in the Clinical Department of Physiotherapy, run by a Charitable Trust. The patients residing within the radius of 40 kilometers from study site, the patients without fracture or any other health problem limiting their movements and those living with their families at the time of study were selected. Thus there were 102 cases. The data were collected using 1) Schedule for socio-demographic factors and 2) Family Burden Interview Schedule (Pai and Kapur 1981). The spouse or parent of the patients was interviewed personally in a congenial atmosphere in a separate room. The researcher explained the respondents about the purpose of research, established rapport and data were collected. The data were analysed using SPSS.

Review of literature

Research studies on social and psychological aspects of osteoarthritis are relatively less. Knee osteoarthritis is a chronic illness that affects the patient, with the family as a primary source of support (WHO 1976). Any illness causes burden on the family. Burden of a disease includes the human and economic costs that arise due to health problem. According to Mahajan et al (2005) OA knee is a major public health problem in our country and is one of the most

common causes of disability. It not only impacts the physical & psycho-social health of the individual, but also places a tremendous burden on the family as well as healthcare resources of the country.

There are many factors contributing to burden of OA . Among them age is related with growth of man and degeneration of organs resulting in decline of health. India's elderly population (>60 yrs) increases drastically from around 7.4% in 2001 to around 19% in 2050.⁸ Majority of elderly women (>80%) and men (>40%) are economically dependent making them vulnerable (Central Statistics Office 2011).

Economic Burden is a natural result of any illness due to expenditure for treatment and alternate arrangements. According to Chen.A., et al (2012) the economic burden of OA may be divided into direct, indirect, and intangible costs. Direct cost is related to medical treatment. Indirect cost includes that due to loss of productivity, care giver time, cost incurred towards disability benefits, premature mortality, absenteeism and cost of coping. Intangible cost includes pain, depression and reduced quality of life.

Public expenditure on health as a percentage of gross domestic product (GDP) in India was only 1.28% in 2017–18. Only about 34% of the total population of India is covered under any form of health insurance. OA is usually managed on outpatient basis, requiring inpatient care in case of severe pain and during replacement surgery. With nearly 70% of hospitalization expenditure borne by household income and savings, and about 20% sourced from borrowings, chronic conditions like OA are a burden on the finances of the country as well as of the individual household.¹³ (Central Bureau of Health Intelligence. National health profile 2018)

The structure and quality of the family relationship can influence what chronically ill patients do to manage their illness as well as how they perceive their physical, mental and emotional health (Inem AV, et al. 2004, Lee HY, et al. 2008, Ethgen O, et al 2004). Chronic illness in a family member can cause emotional distress throughout the family and may impair the family's ability to support the patient.^{15,16} (Martire.LM et al 2007, Smith et al 2014) The pain experienced by patients with knee osteoarthritis sometimes acts as a mechanism regulating the relationship among family members. Studies have shown that better understanding among family members enhances relationship leading to better health outcomes. (Keefe FJ et al 2002, Adetunji AA.2007).

Mba (2007) reported that West Africa showcased the family as a key institution for elderly persons and their living arrangements are a fundamental determinant of their well-being. Smith et al (2014) and Wride M,&Bannigan(2018) viewed from the perspectives of care takers. According to them those who are in the immediate social environment may exert an influence on the mode of coping with their conditions. Family members and significant others of knee osteoarthritis patients usually provide care to the patients. By studying the perceptions and experiences of both patients and care takers, health professionals can understand how care takers are affected. This will help in the management of patients and care takers.

According to Wallis JA, *et al* (2019) the overall findings highlight the importance of equipping patients and care takers with information and self-management strategies to reduce the impact of knee osteoarthritis on their lives instead of simply providing information about osteoarthritis. , By reducing pain, maintaining function, increasing social and physical activity participation, helping patients to remain in employment and achieving optimal mental health, their psycho-social well-being can be improved.

Results and Discussion

The data regarding family burden of osteoarthritis were analyzed using correlation, “t” test and F test. They were tabulated and presented here.

Table 1: Correlation between age and family burden of osteoarthritis patients

Areas of Family Burden	r. value	df	Statistical significance
Financial burden	0.10	100	P < 0.50
Disruption of routine family activities	0.09	100	P > 0.05
Disruption of family leisure	0.01	100	P > 0.05
Disruption of family interaction	0.07	100	P > 0.05
Effect on physical health of others	0.10	100	P > 0.05
Total burden	0.07	100	P > 0.05

Table shows that there was no correlation between age of the patients and burden experienced by the families of osteoarthritis patients in all aspects except financial burden. But the families were able to cope up well and adjust in various other aspects. When the age is increased patients may not be able to involve in earning activities more and hence it may result in financial burden.

Table – 2: Family burden according to gender of osteoarthritis patients

Areas of family burden		Families of	Families of	Statistical Significance (df = 100)
		Male patients (N=34)	Female patients (N=68)	
Financial Burden	Mean	3.56	3.46	t :.27
	SD	2.06	1.63	p > 0.05
Disruption of routine family activities	Mean	3.21	3.49	t :.70
	SD	1.95	1.86	p > 0.05
Disruption of family leisure	Mean	2.91	3.13	t :.77
	SD	1.38	1.36	p > 0.05
Disruption of family interaction	Mean	2.03	2.31	t :1.09
	SD	1.19	1.24	p > 0.05
Effect on physical health of others	Mean	.24	4.41E-02	t :2.09
	SD	.65	.27	p < 0.05
Total burden	Mean	11.94	12.43	t :0.43
	SD	5.75	5.11	p >0.05

Families of male and female patients suffered similarly in various areas of family burden. There was no statistically significant difference between the groups. As the dysfunction is similar in both male and female patients family burden is also similar. Further families have adjusted well to compensate the losses posed by male and female patients.

Table–3; Family burden according to domicile of osteoarthritis patients

Areas of family burden		Families of Rural Patients (N=81)	Families of Urban Patients (N=21)	Statistical Significance (df=100)
Financial Burden	Mean	3.72	2.62	t :2.589
	SD	1.82	1.32	p < 0.05
Disruption of routine family activities	Mean	3.57	2.71	t :1.868
	SD	1.95	1.49	p > 0.05
Disruption of family leisure	Mean	3.12	2.81	t :.940
	SD	1.39	1.25	p > 0.05
Disruption of family interaction	Mean	2.31	1.86	t :1.516
	SD	1.20	1.28	p > 0.05
Effect on physical health of others	Mean	9.88	.14	t :.405
	SD	.44	.48	p > 0.05
Total burden	Mean	12.81	10.14	t :2.09
	SD	5.46	4.10	p >0.05

Families of rural patients suffered more in the area of financial burden. Statistically there was a significant difference between the groups. In other areas of burden also the mean scores show an increased burden in rural families But there was no statistically significant difference between the groups. This might be due to the increased dysfunction of rural patients. In rural areas income is usually less. Further patients and families from rural areas need to involve in hard physical labour. As osteo- arthritis prevents patients from hard physical work their income is affected and thereby families are burdened.

Table-4: Family burden according to educational status of osteoarthritis patients

Areas of family burden		Families of illiterate patients (N=23)	Families of patients with primary education (N=52)	Families of patients with secondary and above education (N=27)	Statistical Significance (df=2,99)
Financial Burden	Mean	3.61	3.67	3.04	F :1.21
	SD	1.62	1.80	1.85	p >0.05
Disruption of routine family activities	Mean	3.70	3.44	3.04	F :.79
	SD	2.14	1.88	1.68	p >0.05
Disruption of family leisure	Mean	3.22	3.04	2.96	F :.23
	SD	1.38	1.43	1.26	p >0.05
Disruption of family interaction	Mean	2.43	2.29	1.89	F :1.44
	SD	.94	1.21	1.40	p >0.05
Effect on physical health of others	Mean	8.70	.13	7.41	F :.20
	SD	.42	.52	.27	p >0.05
Total burden	Mean	13.04	12.58	11.00	F :1.11
	SD	4.89	5.58	5.06	p >0.05

Table shows that there was no significant difference in burden experienced by the families of patients with different levels of education. They suffered similar level of burden. Education has not played any role in determining family burden.

Table-5: Family burden according to marital status of osteoarthritis patients

Areas of family burden		Families of Married patients (N=90)	Families of Single / widowed patients (N=12)	Statistical Significance (df=100)
Financial Burden	Mean	3.61	2.58	t : 1.91
	SD	1.77	1.62	p >0.05
Disruption of routine family activities	Mean	3.48	2.75	t : 1.26
	SD	1.95	1.22	p >0.05
Disruption of family leisure	Mean	3.16	2.33	t : 1.99
	SD	1.39	.88	p <0.05
Disruption of family interaction	Mean	2.17	2.58	t : 1.11
	SD	1.13	1.78	p >0.05
Effect on physical health of others	Mean	.10	.16	t : 0.49
	SD	.42	.57	p >0.05
Total Burden	Mean	12.51	10.42	t : 0.434
	SD	5.41	4.17	p >0.05

Families of married and unmarried patients suffered from similar level of burden in all the areas of burden except family leisure. The families of married patients suffered more in the area of family leisure and the difference between the groups was statistically significant. This might be because the families of married patients had to sacrifice their leisure time in order to compensate the functional inadequacy of the patients. Further families of married patients had more responsibilities with regard to their life.

Table-6: Family burden according to occupational status of osteoarthritis patients

Areas of family burden		Families of Unskilled workers (N=52)	Families of Skilled workers (N=17)	Families of House wives/Unemployed (N=33)	Statistical Significance (df=2,99)
Financial Burden	Mean	3.90	3.41	2.88	F :3.54
	SD	1.82	2.06	1.39	p<0.05
Disruption of Routine family activities	Mean	3.58	3.47	3.06	F :0.77
	SD	2.08	1.81	1.60	p>0.05
Disruption of family leisure	Mean	3.19	3.06	2.85	F :0.64
	SD	1.47	1.25	1.25	p>0.05
Disruption of family interaction	Mean	2.29	2.29	2.06	F :0.39
	SD	1.14	1.49	1.22	p>0.05
Effect on physical health of others	Mean	0.13	0.02	0.02	F :0.22
	SD	0.53	0.24	0.38	p>0.05
Total burden	Mean	13.10	12.29	10.94	F : 1.69
	SD	5.69	5.53	4.36	p>0.05

Table shows that financial burden was more among the families' unskilled workers and skilled workers and housewife occupied successive positions respectively. Families of different occupational categories suffered from similar level of burden in other areas and there was no statistically significant difference among them. Families of unskilled workers suffered more in the area of financial burden. Among the other two groups families of skilled workers suffered more than the housewife/unemployed category. The families of unskilled workers are financially poor compared to skilled and other categories. Skilled category has got relatively better economic status while housewife / unemployed

category suffered less because their contribution to family economy was not significant even before the onset of illness. Further many of this category were housewives and their families did not involve then in wage earning. So these families suffered less economically. Further they were suffering form less dysfunction as they were not demanded much by the family. However in other areas of burden families of different occupations suffered similarly.

Table-7: Correlation between income and family burden of osteoarthritis patients

	r. value	df	Statistical significance
Financial burden	0.31	100	$p < 0.01$
Disruption of routine family activities	0.36	100	$p < 0.001$
Disruption of family leisure	0.08	100	$p > 0.05$
Disruption of family interaction	0.30	100	$p < 0.01$
Effect on physical health of others	0.01	100	$p > 0.05$
Total burden	0.320	100	$P < 0.01$

There was a significant correlation between income and various areas of family burden like financial burden, disruption of routine family activities and disruption of family interaction. No significant correlation was found between income and disruption of family leisure and effect on physical health of others. Income was found to have association with financial burden. Income decides the financial status of a family. So the reduced income and expenditure incurred due to the illness cause a strain on the financial aspect of the family. The correlation of income with disruption of routine family activities and disruption of family leisure indicate that dysfunction of the patients acted as intermediate variable. Dysfunction is a determinant of occupational adjustment and income level. So it caused difficulties on these aspects of family burden. Thus some aspects of families were burdened.

Table-8: Family burden according to family typology of osteoarthritis patients

Areas of family burden		Nuclear family (N=54)	Extended nuclear family (N=35)	Joint family (N=13)	Statistical Significance(df : 2,99)
Financial Burden	Mean	3.41	3.57	3.62	F :.125
	SD	1.76	1.91	1.56	p > 0.05
Disruption of routine family activities	Mean	3.31	3.17	4.31	F :1.842
	SD	1.98	1.76	1.70	p > 0.05
Disruption of family leisure	Mean	2.83	3.14	3.77	F :2.655
	SD	1.31	1.33	1.48	p > 0.05
Disruption of family interaction	Mean	2.15	2.26	2.38	F :.223
	SD	1.34	1.22	.65	p > 0.05
Effect on physical health of others	Mean	.11	.11	7.69	F :.036
	SD	.42	.53	.28	p > 0.05
Total burden	Mean	11.81	12.26	14.15	F :1.02
	SD	5.21	5.65	4.67	p >0.05

Table shows that families of patients belonging to different family typology. suffered from similar level of burden. There was no significant difference among different groups of family typology. Similarly families were suffering from mild burden. In such a condition it might be difficult to understand the influence of family typology. Further, supporting nature of people in rural and semi urban areas were compensating for mild difficulties. This support might be inadequate when the problems are more at the level of patients and their families.

Table-9: Family burden according to caste background of osteoarthritis patients

Areas of family burden		Scheduled caste patients (N=15)	Most backward caste patients (N=32)	Backward caste patients (N=45)	Forward caste patients (N=10)	Statistical Significance (df=3,98)
Financial Burden	Mean	3.33	3.69	3.53	2.90	F :0.54
	SD	1.80	1.73	1.70	2.33	p >0.05
Disruption of routine family activities	Mean	3.00	3.50	3.69	2.30	F : 1.78
	SD	1.73	1.93	1.99	.95	p >0.05
Disruption of family leisure	Mean	2.800	3.16	3.20	2.50	F : 0.96
	SD	1.37	1.39	1.39	1.08	p :>0.05
Disruption of family interaction	Mean	2.13	2.38	2.24	1.70	F : 0.80
	SD	1.46	1.26	1.07	1.42	p >0.05
Effect on physical health of others	Mean	.20	9.37	2.22	.40	F : 2.33
	SD	.77	.30	.15	.84	p >0.05
Total burden	Mean	11.47	12.81	12.69	9.80	F :1.04
	SD	5.18	5.31	5.48	4.52	p >0.05

Families of patients belonging to different caste background suffered from similar level of burden. There was no statistically significant difference among different groups of families. Caste did not influence the burden of their families. Patient's level of movements did not differ much among different groups of caste. Their dysfunctions were very less because osteoarthritis did not cause extreme limitations on the functions of the patients. Mild dysfunction of patients caused mild burden on the family. So the influence of caste was not found.

Table-10: Correlation between duration of illness and family burden of osteo-arthrititis patients

	r. value	df	Statistical significance
Financial burden	0.105	100	$p > 0.05$
Disruption of routine family activities	0.038	100	$p > 0.05$
Disruption of family leisure	0.172	100	$p > 0.05$
Disruption of family interaction	0.061	100	$p > 0.05$
Effect on physical health of others	0.214	100	$p < 0.05$
Total burden	0.097	100	$p > 0.05$

Table shows that there was a correlation between duration of illness of the patients and its effect on physical health of the family members. Duration of illness did not have significant correlation with other areas of family burden. Duration of illness indicates the duration of strain on the patients as well as their families. In the present study duration of illness was found to have significant correlation with vocational dysfunction and personal dysfunction. These are the areas in which physical movements are much involved. As the illness limits the physical movements they were suffering much in those areas. As osteoarthritis is a degenerative disorder, the degree of degeneration is according to the duration of illness. Hence there was a correlation of duration of illness with personal and vocational dysfunction. But duration of illness was not correlated with social dysfunction and family dysfunction. The result indicates that patients could adjust to some extent with these aspects and on the other hand these aspects did not demand much effort from the patients. There was no correlation between duration of illness and family burden. This indicates families could bear the burden and adapted to the altered conditions of the patients.

Conclusion:

Family burden indicates the natural result of any illness. In the case of Osteoarthritis knee, patients suffer from problems relating to mobility. As a result they become dysfunctional which causes burden. Families in the present study were found to suffer from mild burden in most aspects. Age, rural domicile and income level play a role in determining financial burden. Effect of patient's illness on the physical health of the families was more as they had to involve more in taking care of the patients. Families need to find out appropriate ways to reduce their burden and improve their adaptability. Counselling and guidance services may help the families to reduce their burden. Further study on this aspect may throw more light.

References

- 1) . Adetunji AA, Ladipo MMA, Irabor AE, Adeleye JO. Percieved family support and blood glucose control in type II diabetes. MERA: Diabetes. International 2007;32:18–19
- 2). Central Bureau of Health Intelligence. National health profile 2018. 13th issue. Available from www.cbhidghs.nic.in › assets › common › downloads › files › NHP 2018 [Accessed on November 8, 2019]
- .3. Central Statistics Office. Situation Analysis of the Elderly in India, 2011. Available from www.mospi.nic.in sites › default › files › publication reports › elderly in India [Accessed on November 8, 2019] (provide relevant link).
4. Chen A, Gupte C, Akhtar K, Smith P, Cobb J. The Global Economic Cost of Osteoarthritis: How the UK Compares. Arthritis. 2012;2012:1-6
5. Cross M, Smith E, Hoy D, et al. The global burden of hip and knee osteoarthritis: estimates from the global burden of disease 2010 study. Ann Rheum Dis. 2014;73(7):1323-30.
- 6) Ethgen O, Vanparijs P, Delhalle S, Rosant S, Bruyère O, Reginster JY. Social support and health-related quality of life in hip and knee osteoarthritis. Qual Life Res 2004;13:321–30.11.

- 7) Gignac MA, Davis AM, Hawker G, et al. “What do you expect? You’re just getting older”: a comparison of perceived osteoarthritis-related and aging-related health experiences in middle- and
- 8). Inem AV, Ayankogbe OO, Obazee M, Ladipo MM, Udonwa NE, Odusote K. Conceptual and contextual paradigm of the family as a unit of care. *Nig Med Pract* 2004;45(1):9–12.
- 9). Keefe FJ, Smith SJ, Buffington ALH, Gibson J, Studts JL, Caldwell DS Recent advances and future directions in the biopsychosocial assessment and treatment of arthritis. *Journal of Consulting and Clinical Psychology*. 2002;70:640 –55.
- 10). Lee HY, Jang SN, Lee S, Cho SI, Park EO. The relationship between social participation and self-rated health by sex and age: A cross-sectional survey. *Int J Nurs Stud*. 2008 Jul;45(7): 1042–54.
- 11). Mahajan A, Verma S, Tandon V. Osteoarthritis. *J Assoc Physicians India*. 2005;53: 634-41.
- 12). Martire LM, Schulz R, Francis JK, Rudy TE, Starz TW. Couple-Oriented Education and Support Intervention: Effects on Individuals with Osteoarthritis and Their Spouses *Rehabilitation Psychology*. 2007;52 (2):121–32.
- 13). Smith TO, Purdy R, Lister S, *et al*. Living with osteoarthritis: a systematic review and meta-ethnography. *Scand J Rheumatol* 2014;43:441–52.
- 14). World Health Organization. Statistical Indices of Family Health No. 1976;587
- 15). Wride JM, Bannigan K. ‘If you can’t help me, so help me God I will cut it off myself.’ The experience of living with knee pain: a qualitative meta-synthesis. *Physiotherapy* 2018; 104: 299–310.