

Analysing the Burden of Healthcare Professionals in Home Care

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ABSTRACT

Advancements in technologies and changes in the health care system have resulted in shortened hospital stays, moving the focus of care from hospitals to homes. These services include nursing care, professional caregiving to chronically ill and patients of which substantial numbers are bedridden, immobile or suffer from chronic illnesses like dementia, cancer, heart, lungs, liver, kidney, etc. The burden experienced by family caregivers and paid caregivers is the most important caregiver-related variable in care at home in the care of a chronically-ill person. The extent of subjective burden (which is borne by the caregivers) has a significant impact on the emotional and physical well-being of the family caregivers and the paid caregivers (nurses and general duty assistants), and even influences the mortality of spouse caregivers. In the present study, the researchers interviewed 40 nursing staff, 40 general duty assistants, and 40 family caregivers to analyze the burden they bear instead of their duties in caring for sick patients. The results analyzed were found to be highly significant showing a strong association of home health care workers who provides and hold the bulk of responsibilities and burden as home care staff at their workplace. The output of the study shows the evidence for many national and international agencies to recognize the need to provide support to homecare workers and long —term care in improving their job conditions. The importance of respect, appreciation and the value of understanding the basic job functions cannot be overlooked if retention of workers is required.

Keywords: Nursing care, Caregivers, Patients, Burden, family caregivers.

1. INTRODUCTION

Home-based health care goes far back in time. It has been present since the existence of the nursing and medical professions. In the early 19th century, taking care of the sick (who are chronically ill, or are dying) and giving birth were all considered part of domestic life, while hospitals were meant for those patients (for their last resort)who did not have any families. Families with good finances tend to hire doctors, nurses, or midwives to serve the patient's in their homes.

Homecare was started by "The Charleston Ladies Benevolent Society" in 1813. Benevolent ladies (serving a charitable rather than profit-making purpose) across the United States started organizations for helping the sick and poor people and provided medical care, and other types of charitable help, to the "worthy" poor. These organizations trained nurses and provided care to the sick and poor people thus preventing the spread of any contagious diseases.

By 1920, there was a change in the healthcare system, hospitals became an indispensable institution and an accepted part of medical care. Policy holders now increasingly sought hospital care when they were seriously ill and lived longer (Wilkerson).[27,28]



Plate No. 1: Nurses outside their office ready to serve the chronically ill patients ready for the day's work. Visiting Nurse Society of Philadelphia, c.1909

(Source:https://www.nursing.upenn.edu/live/image/gid/97/width/650/src_region/0,0,634,450/3931_visiting_nurses_outsi de_their_offices.jpg)

A New Home Care Movement-Federal Policy for Home Care

By the 1930s and 1940s, the locus of care for the chronically ill was compromised in the hospitals, and home care was preferred, this was considered a less expensive alternative to hospital care. Initially, in the case of seriously sick patients where the coverage was limited, home care would a better option to be included in the insurance programs. In the 1960s, finally, home care was included in medicare, medicaid, and the older American act. It was through homecare, the hospital beds could be emptied that added to its inclusion in the medicare program.

To begin with, home health care nurses worked alone with little support received from their agencies and spend more time on documentation than the hospital nurses, they also have to spend more time dealing with reimbursement issues. (National Association for Home Health Care & Hospice; Anthony and Milone). [17,4]. Caregivers fall into 2 broad categories: caregivers working on a payroll and are called formal home healthcare care workers) and unpaid or "informal" caregivers usually the family members (Townsend *et al.*; Browne *et al.*; Addington-Hall *et al.*) [26,6,2]who have deeper attachment and commitment towards their patient. Sergi-Swinehart [24] has called this tradition of family caregiving fundamental to our society. The professional home care staff (nurses and caregivers) provides a spectrum of services including professional caregiving, activities of daily living such as bathing, grooming, and dressing to technical services provided by nursing staff to serve, support, and empower patients and their families with their care. However yet the burden of family caregiving yet remains a multifaceted issue (Wilkerson).[27]

The array of services provided at home are generally monitored and taken care of by the family caregivers, also referred to as "informal services" (Johnson *et al.*).[14] This phrase grossly underestimates the critical role family caregivers play in the care of patients at home. It is examined that among patients with multiple limitations on ADLs (activities of daily living), caregiving is crucial. Without caregivers at home, health care at home is rather very difficult for those with functional limitations. AARP(American Association of Retired Persons) investigated that 34.2 million adults alone served as caregivers in the year 2014(AARP).[3]

According to the Urban Institute's "The Retirement Project," in 2000, approximately about 2.2 million individuals received "formal personal care services," also known as 'personal care services' that are paid. This percentage has risen to 2.5 million in 2010 (Johnson *et al.*)[14]. The market size of home health care in India is valued at USD 7.4 billion in 2021 and is expected to grow at a compound annual growth rate (CAGR) of 19.27% from 2022 to 2030. According to the Economic and Social Commission for Asia and the Pacific, the aging population of India is expected to reach 298 million by 2051, accounting for 17% of the national population. With the introduction of advanced home healthcare services in the country, high-quality healthcare can now be delivered in the comfort of one's own home.¹

2. METHODS AND METHODOLOGY

After formulating the aim and objectives of the study, a pilot study was conducted. The main focus of pilot study was to demarcate the area of study and establish a rapport. The researcher visited Max hospital, Mohali and Hauz Home Health Care Services, Panchkula and 10 % (19) of the respondents were taken for this purpose of pretesting and finalizing the Interview schedule. The interview schedules were pre-tested during course of the pilot study by interviewing 15 nursing staff

¹(India Home Healthcare Market Size, Share & Trends Analysis Report by Equipment (Therapeutic, Diagnostic, Mobility Assist Equipment) by Services (Skilled Home Care, Unskilled Home Care), and Segment Forecasts, 2022-2030 (researchandmarkets.com)

and 15 general duty assistants who are employed and working in home care. Snowball sampling method was used to gather further information about more respondents who could be a part of the study. A total sample of 40 nurses, 40 general duty assistants, and 40 family caregivers comprised the total sample of the study who were interviewed to to understand the problems and perspectives of general duty assistants, and nurses in home health care. Henceforth, 28 question were framed for analyzing caregiver's burden at their workplace. Burden Scale for Family Caregivers (Grasel)[12] was used to analyse the burden felt by caregivers working for the patients in home care. The extent to which the family caregivers feel burdened has a significant influence on the caring style, as well as upon the continuation of home care. Burden scale was further analyzed for age, gender, marital status, current residence, and social- economic status of the respondents.

3. RESULTS AND DISCUSSION

The burden experienced by family caregivers and paid caregivers is the most important caregiver-related variable in care at home in the care of a chronically-ill person. The extent of subjective burden (which is borne by the caregivers) has a significant impact on the emotional and physical well-being of the family caregivers and the paid caregivers (nurses and general duty assistants), and even influences the mortality of spouse caregivers. A comparison with a non-caregiving group shows that over 4.5 years, the risk of death of spouses burdened with caregiving was 63 % greater than the spouses who did not perceive home care as a burden (Schulz and Beach)[25]. In the present study, the researcher interviewed 40 nursing staff, 40 general duty assistants, and 40 family caregivers to analyze the burden they bear in lieu of their duties in caring for sick patients. It affects the way the family caregivers especially the primary caregivers, nurses, and general duty assistants deal with the care receiver and determines the time of institutionalization. In the present study, the paid caregivers tend to stay with one patient for a period of 6 months to 1 year continuously, some tend to continuously stay for 3 years also. The Burden Scale for Family Caregivers (BSFC) (Grasel)[12] is a 28-item questionnaire that was developed to determine the burden felt by caregivers working for the patients.

BSFC Subjective Risk of Family Nurses G.D.As Score burden Caregivers psychosomatic categories symptoms 0 - 41None to mild Not at risk a 59.5 % 40% 76.9% Increased risk b 42-55 moderate 12.5 % 52.5% 20.5% 56-84 Severe to very At very high risk c 28% 7.5% 2.6% severe

Table 1: Interpretation of the BSFC score for Caregivers of Individuals

Note: Chi-square test value = 11.07***, among above categories with p value = .004

Source: Original data

corresponds to the expected value in the "normal population", that is, 50% of those caregivers have a percentile rank (PR) of physical

symptoms < 50 and the other 50% a PR > 50.

Overall, it was found that 76.9 % of general duty assistants, 59.5 % of family caregivers and 40 % of nurses, BSFC scores ranged between 0 to 41, which means 50% of the caregivers have an average extent of physical symptoms. However, 52.5 % of the nursing staff, 20.5 % of the general duty assistants, and 12.5 % of the family caregivers' BSFC score range from 42 to 55, and 74% of those caregivers have an above-average extent of physical symptoms. Henceforth, for 7.5% of the nurses, 28 % of the family caregivers, and 2.6 % of the home aides, BSFC score ranges from 56 to 84, 90% of those caregivers have an above-average extent of physical symptoms. The results analyzed were found to be highly significant (p<0.05) as is evident from the chi-square value which is equal to (11.07***) showing a strong association of home health care workers who deliver the majority of home care services and shoulder the bulk of burden and responsibilities at the workplace. Burden scale was further analyzed for age, gender, marital status, current residence, and social- economic status of the respondents. Arafa *et al.* [5] also discussed in their study about moderate to severe psychosomatic symptoms in 21.7 % of nurses which is an indication of mental health problems.

^a If the BSFC score ranges from 0 to 41, the extent of overall physical symptoms

^b If the BSFC score ranges from 42 to 55, 74% of those caregivers have an above average extent of physical symptoms (PR > 50).

^c If the BSFC score ranges from 56 to 84, 90% of those caregivers have an above average extent of physical symptoms (PR > 50).

Burden Scale with Regard to the Age Group of the Respondents

When the researcher tried to analyse data with respect to all the age groups of the respondents (nurses and general duty assistants). The results were indicated in Table 2

Maximum respondents in the age group of 26-28, i.e. 66.7% and 100% of the nursing staff were moderately and severely burdened as compared to the other age groups. With regards to the general duty assistants, 50% of the respondents in the age groups (23-25) were moderately and (17-19, 20-22) were severely burdened. The total score can range from 0-84, with a score of above 42 or more indicative of significant psychosomatic symptoms (fatigue, insomnia, aches and pains, indigestion, hypertension, headaches, and migraine). It was gathered from an in-depth interview that they tend to stay with the patient 'round the clock' which leaves behind little time for self-care and social activities for oneself and one may feel emotionally, physically, and mentally drained.

This is this age group where respondents are on the verge of getting married or are newly married and the same thoughts are shared by both the male and female respondents where they believe that this is the profession where one has to be with the patient for 12 hours or 24 hours and this occupation cannot be taken further after marriage. However, the results were found to be significant as is evident from the chi-square value which is equal to (18.9*). With regards to general duty assistants, 17-19 years of age or 20-22 years of age means, they have just started their career and in many cases, it is due to the financial needs of the family, one has to work as a caregiver.

Sansoni *et al.* [23] have confirmed the presence of both physical and psychological illnesses among caregivers due to the stress that comes with the job. The 'round the clock' nature of caregiving for such patients leaves behind little time for oneself and one may feel emotionally, physically, and mentally drained, similar findings presented by Ferrara, *et al.* [9] confirm this assertion.

Table 2: Burden scale with regard to the Age Group of the Respondents

Age Group of the Respondents				Burden so	Burden scale groups			
				0-41	42-55	56-84	1	
Nurses	Age	20-22	Count	0	1	0	1	
			% within Burden scale groups	0.0%	4.8%	0.0%	2.5%	
		23-25	Count	7	3	0	10	
			% within Burden scale groups	43.8%	14.3%	0.0%	25.0%	
		26-28	Count	2	14	3	19	
			% within Burden scale groups	12.5%	66.7%	100.0%	47.5%	
		29-31	Count	3	3	0	6	
			% within Burden scale groups	18.8%	14.3%	0.0%	15.0%	
		32-34	Count	1	0	0	1	
			% within Burden scale groups	6.3%	0.0%	0.0%	2.5%	
		35-37	Count	3	0	0	3	
			% within Burden scale groups	18.8%	0.0%	0.0%	7.5%	
	Total		Count	16	21	3	40	
			% within Burden scale groups	100.0%	100.0%	100.0%	100.0%	
Note: Chi-s	square i	test valu	e = 18.9*, among above categories	with p value	= .041			
General	Age	e 17-19	Count	2	0	1	3	
duty assistants			% within Burden scale groups	6.7%	125%	50.0%	7.5%	
		20-22	Count	9	1	1	11	
			% within Burden scale groups	30.0%	0.0%	50.0%	275%	

	23-25	Count	6	4	0	10
		% within Burden scale groups	20.0%	50.0%	0.0%	25.0%
	26-28	Count	9	1	0	10
		% within Burden scale groups	30.0%	12.5%	0.0%	25.0%
	29-31	Count	1	0	0	1
		% within Burden scale groups	3.3%	0.0%	0.0%	2.5%
	32-34	Count	0	1	0	1
		% within Burden scale groups	0.0%	12.5%	0.0%	2.5%
	35-37	Count	1	0	0	1
		% within Burden scale groups	3.3%	0.0%	0.0%	2.5%
	38-40	Count	1	0	0	1
		% within Burden scale groups	3.3%	0.0%	0.0%	2.5%
	44-46	Count	1	1	0	2
		% within Burden scale groups	3.3%	12.5%	0.0%	5.1%
To	tal	Count	30	8	2	40
		% within Burden scale groups	100.0%	100.0%	100.0%	100.0%

Note: Chi-square test value = 11.3, among above categories with p value = .181

Findings of stress and pressure among caregivers are consistent across cultures (Ferrara *et al.*, Grant *et al.*, 2002 and Lutgendorf and Laundenslager) [9,11,16]because of the severity of the disease, a caregiver is required to do much more than just look after the patient. To name a few, getting the patient in and out of bed, feeding them, dressing them, getting them to and from the toilet, bathing them etc., are some of the many duties that a caregiver performs, along with providing necessary medical attention. This leads to consequences for the caregiver in the form of physical and psychological distress. It also affects their sleep patterns overall reflecting poorly on their quality of life, well-being, and health.

Our life is bound in home care, biggest loss that we suffer is that we have stay at somebody's place for 24 hours. Some families keep us so busy that they never provide you time for yourself and we are not able to live your own life. In 24 hours shift, as one has to stay at patient's home, one has no life of their own, eat the way they want, sleep the way as per the family's schedule. Eventually, we have to do all chores according to the wishes of the family. It has been 8 months, since I have been home because no leaves are allowed". (Nursing Staff, age 26 years, Experience- 5 years). Piko [19] also discussed the presence of psychosomatic symptoms such as sleeping disorders, headaches and exhaustion that were found among homecare workers

Burden Scale with regard to Gender of the Respondents

The researcher wishes to correlate the burden bared by nursing staff and general duty assistants at their workplace for gender. The extent of subjective burden can be visualised from the table 3.

Gender of the Respondents Burden scale groups Total 0-41 42-55 56-84 Nurses 4 Gender Male 8 Count % within Burden scale groups 25.0% 19.0% 0.0% 20.0% Female 12 Count 17 32 % within Burden scale groups 75.0% 81.0% 100.0% 80.0%

Table 3: Burden Scale with regard to Gender of the Respondents

	Total		Count	16	21	3	40
			% within Burden scale groups	100.0%	100.0%	100.0%	100.0%
Note: Chi-	square test	value = 1.	10, among above categories with	p value = .	603		
GDA	Gender	Male	Count	17	5	0	22
			% within Burden scale groups	56.7%	62.5%	0.0%	55.0%
		Female	Count	13	3	2	18
			% within Burden scale groups	43.3%	37.5%	100.0%	45.0%
	Total		Count	30	8	2	40
			% within Burden scale groups	100.0%	100.0%	100.0%	100.0%

Note: Chi-square test value = 2.66, among above categories with p value = .264

It was found that 81 % and 100 % of the female nursing staff's BSFC scores ranged from 42 to 55 and 56 to 84. Thereby, meaning that the female staffs were at an increased risk and a very high risk of psychosomatic symptoms as compared to the male staff.

Concerning the GDAs, it was investigated that 37.5% of the female staff were moderately burdened and 100 % of the female staff were severely burdened as compared to 62.5 % of the male staff who felt moderately burdened at their workplace.

One of the female staff, who worked with a volatile patient for several months shared her views that "There is no future in homecare, as we work on one patient, less of learning as compared to learning in hospitals. Sometimes, continuously working for 24 hours makes our own life difficult. Sometimes you feel depressed and frustrated" (General duty Assistant, Unmarried, age 24 years, Experience-6 years). The greater the subjective burden of the caregiver, the more the caregiver's somatic symptoms (Grasel)[12]

Burden Scale with regard to Marital Status of the Respondents

The researcher further wished to analyze the burden concerning the marital status of the respondents. The results are explained in Table 4

Interestingly, concerning the nursing staff, it was found that 76.2 % and 100% of the unmarried respondents were moderately and severely burdened as compared to 62.5% and 100% of general duty assistant's unmarried respondents. It was summed from the data that the burden visualized by the unmarried respondents in the study was much more than the married respondents. As it was analyzed from in-depth interviews that generally the married respondents were working during the night shifts where after completing their all-day work, they tend to sleep in the patient's room and they are very much occupied with the responsibilities of their own families too and they have no time for any further thoughts. As has been found among the few home care workers, the emotional demands workers faced on the job also affected their personal lives as many of them have sick parents at home. However, where the respondents are unmarried, they tend to stay with the patient for a longer period such as 6 months or more than a year.

Table 4: Burden Scale with regard to Marital Status of the Respondents

42-55	56-84	Total
16	3	29
76.2%	100.0%	72.5%
5	0	11
23.8%	0.0%	27.5%
21	3	40
100.0%	100.0%	100.0%
		100.0% 100.0%

GDA			Count	20	5	2	27
stat	status		% within Burden scale groups	66.7%	62.5%	100.0%	67.5%
		Married	Count	10	3	0	13
	Total		% within Burden scale groups	33.3%	37.5%	0.0%	32.5%
			Count	30	8	2	40
			% within Burden scale groups	100.0%	100.0%	100.0%	100.0%

Note: Chi-square test value = 1.06, among above categories with p value = .588

Similar findings were discussed by (Arafa *et al.*)[5] where the unmarried nurses experienced more psychological distress as compared to married nurses.

Burden Scale with regard to Current Residence of the Respondents

The respondents were interviewed to know the burden related to their current residence of the respondents. The results are shown in Table 5.

Table 5: Burden Scale with Regard to Current Residence of the Respondents

Current residence of the respondents			s	Burden s	Burden scale groups		
				0-41	42-55	56-84	
Nurses	Current	Patient-	Count	7	10	2	19
	residence	owned	% within Burden scale groups	43.8%	47.6%	66.7%	47.5%
		Rented	Count	5	8	0	13
			% within Burden scale groups	31.3%	38.1%	0.0%	32.5%
		Hostel-	Count	4	3	1	8
			% within Burden scale groups	25.0%	14.3%	33.3%	20.0%
	Total	1	Count	16	21	3	40
			% within Burden scale groups	100.0%	100.0%	100.0%	100.0%
No	te: Chi-square	e test value = 2	2.27, among above categories with p va	lue = .686		l	
GDA	Current residence	Patient- owned	Count	18	5	2	25
			% within Burden scale groups	60.0%	62.5%	100.0%	62.5%
		Rented Hostel-	Count	11	1	0	12
			% within Current residence	91.7%	8.3%	0.0%	100.0%
			Count	1	2	0	3
			% within Burden scale groups	3.3%	25.0%	0.0%	7.5%
	Total	•	Count	30	8	2	40
			% within Burden scale groups	100.0%	100.0%	100.0%	100.0%

• Note: Chi-square test value = 6.45, among above categories with p value = .168

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As the present study showed, home healthcare workers are steering with a host of psychological distress
on and off the jobs. It was examined from the data that whether it was nurses or general duty assistants,
the respondents who stayed at the patient-owned residences were moderate to severely burdened. 66.7 %
of nurses followed by 47.6% who were at increased risk for psychosomatic symptoms while 62.5%

followed by100% of GDAs who were staying in patient-owned residences were moderately and severely burdened. As they sense that their professional value was undermined by family members as they perceived them as housemaids.

• Similar findings were studied by Franzosa *et al.* [10] where the authors clearly described the role of a few families who asked the aides to take on an extra task that is not permitted by the agencies and perceived them as 'housekeepers'.

Burden Scale Regarding Socio-Economic Status of the Respondent

Respondents were interviewed to relate their socioeconomic status with the burden perceived by the respondents. The results are shown in Table 6.

Table 6: Burden Scale Regarding Socio-Economic status of the Respondent

Socio-E	Socio-Economic Status of the Respondent			Burden s	Burden scale groups			
				0-41	42-55	56-84	Total	
Nurses	SES	26-29 Upper (I)	Count	3	0	0	3	
			% within Burden scale groups	18.8%	0.0%	0.0%	7.5%	
		Middle (II)	Count	6	4	1	11	
			% within Burden scale groups	37.5%	19.0%	33.3%	27.5%	
		11-15 Lower	Count	5	9	0	14	
		Middle (III)	% within Burden scale groups	31.3%	42.9%	0.0%	35.0%	
		5-10 Upper Lower(IV)	Count	2	8	1	11	
			% within Burden scale groups	12.5%	38.1%	33.3%	27.5%	
		<5 Lower (V)	Count	0	0	1	1	
			% within Burden scale groups	0.0%	0.0%	33.3%	2.5%	
	Total		Count	16	21	3	40	
			% within Burden scale groups	100.0%	100.0%	100.0%	100.09	
Note: C	hi-squa	re test value = 21	.6**, among above categories with	th p value =	.004			
GDAs	SES	Middle(II) 11-15 Lower	Count	1	1	0	2	
			% within Burden scale groups	3.3%	12.5%	0.0%	5.0%	
			Count	11	2	1	14	
		Middle(III)	% within Burden scale groups	36.7%	25.0%	50.0%	35.0%	
			Count	18	4	1	23	
		Lower(IV) <5 Lower(V)	% within Burden scale groups	60.0%	50.0%	50.0%	57.5%	
			Count	0	1	0	1	
			% within Burden scale groups	0.0%	12.5%	0.0%	2.5%	
	Total		Count	30	8	2	40	
			% within Burden scale groups	100.0%	100.0%	100.0%	100.09	

Note: Chi-square test value = 5.67, among above categories with p value = .460

The analysis of the socio-economic status of respondents shows the burden felt by them at the workplace, 33.3% of each of the nursing staff were severely burdened in the upper middle, upper lower, and lower segments. When asked about their job challenges, home health workers said that due to financial problems in the family they have to unwillingly work in home

care. Moreover, the hospitals no longer provide jobs to ANMs and GNMs, and also the salaries provided in-home care to nursing staff are pretty good. The results analyzed were found to be moderately significant (p>0.05) as is evident from the chi-square value which is equal to (21.6**).

Personal duty assistants also faced job challenges and shoulder the bulk of emotional labor while caring for the geriatric population. It was found that 50 % of the respondents from both categories were at increased risk of psychosomatic symptoms and were from the lower middle and upper lower socio-economic groups. Donaldson and Burns [8] explored the availability of support systems, the relationship between patients, and the attitude of caregivers play a major role in determining how burdensome and stressful they find their role. Juozapavicius and Weber [15] found that caregivers caring for Alzheimer's patients recounted many stories regarding their stress, coping strategies, barriers faced, and regrets.

4. CONCLUSION

All healthcare workers have to undergo some kind of emotional distress ensuring the trust of the patients and their family members. The majority of home care services are delivered by home care aides and personal care assistants who shoulder the bulk of the responsibility required for patients (Butler *et al.*, Rodat). [7,20]

Due to the nature of their work, homecare nurses and GDAs sometimes face stressful environments. Participants in the study loved their job, some believe in giving free service to the client's in need. There were many who faced various issues at their work place such as workplace violence is also widespread in health care settings. Violence can be in the form of verbal abuse, aggressive behaviour, lack of respect, and humiliation. Further, they elaborated that patients are largest source of violence but they are not the only one. The patients sometimes treat them as maid, expect domestic chores. Consequently, the aggressive behavior of the patients makes the home care workers depressed and exhausted. Many a times, the respondents felt hurt as they are made to feel that there is lack of respect and recognition in this profession along with job insecurity.

A study undertaken by (Arts *et al.*; Hakanen *et al.*; National Institute for Occupational Safety and Health) [1,13,17] reported similar findings, caregivers reported intense stress caring for the sick, dying, belligerent patients and prioritized patient's needs and happiness above their own needs. In addition, in order to visit their patients, the nurses and aides who work for HHC have to travel significant distances; hence, the time and money spent travelling have a negative impact on the quality of care they provides. Needless to mention, big part of the HHC service is not organized which raises questions of safety and ethnicity too. Unexpectedly, this population of health care workers due to their job chores falls to injuries and infections and all together this occupation is placed among the 30 riskiest occupations(Seavey)[23]

The study also concluded that the stress of caring for a family member has adverse effects on the health of primary caregivers. They tend to develop depression and anxiety symptoms in the process of their caring However, most of the family caregivers interviewed in the present study found caring for their sick member also increases the burden on the family finances, disruption of normal family routine, sleep sickness, separation anxiety and the production of stress symptoms in both the caregivers and patients. The physical dependency of the patient reduces their interaction with other family members, relatives and also curtail their participation in social activities. Research also focuses on how the tradition of caregiving has taken a dramatic emotional, physical and financial tool on the primary caregivers (Sarkar and Anand) [22]Having a home care staff is a blessing, as families don't have time for their loved ones and most importantly, home care is often the preferred option for many patients and their families.

However, in many cases, with the support of caregivers, the families which were earlier not able to carry their activities of daily routine were freed due to the help provided by the homecare staff. Thus such support has resulted in providing the family a breathing space and a break from caregiving distress. It is further concluded that to ensure successful and long term care for the elderly, the agencies should understand the demand and value for trained manpower .

A supportive work environments that recognizes and acknowledge their full scope of work is very much needed for reducing their physical and emotional burden. By valuing the full scope of home care workers labour force, we can improve their wellbeing and retain and build a committed and skilled work force which our aging population will need. It is very important to explore the family caregivers, community and health care professional's model where these all should be trained and a detailed training curriculum should be designed to built their capacities to take care of elderly at home.

Policies for the Home Care Staff

Certain suggestions should be included to help the caregivers to reduce their burden:

- Time allowed for the caregiver working hours should not exceed more than eight hours a day. while maximum weekly hours of work allowed shall be 48 hours per week.
- Pay overtime shall be entitled to the workers whose working hours exceeds eight hours per week. Weekly offs should be allowed to the workers. Agencies should constitute safety committee for the caregivers.
- The workers should be entitled to earn an hour of paid time off for every 48 hours worked.

- The women's who are working between 8pm 6am shall be provided transport pick and drop facility.
- There should be a provision for health insurance for the caregivers and their dependents.
- The minimum wage rates should be fixed by the government.

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REFERENCES

- [1] Arts SE, Kerkstra A, Van Der Zee J, Huyer Abu-Saad H. Workload, capacity for coping and psychological and physical outcomes amongst home helps in the Netherlands. Heal. & Soc Care . 1999; 7: 79–90. doi:10.1046/j.1365-2524.1999.00167.x
- [2] Addington-Hall JM, MacDonald LD, Chamberlain J, Freeling P, Bland JM, Raferty J. 1992. Randomised controlled trial of effects of coordinating care for terminally ill cancer patients. Brit Med. J Clin. T.1992; 305 (6865):1317–22.
- [3] American Association of Retired Persons (AARP). Caregiving in the U.S. research report. AARP Public Policy Institute. 2015. http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf.Published June. (accessed February 15, 2023).
- [4] Anthony A, Milone PN. Factors attracting and keeping nurses in home health care. Hom Heal. Nurse.2005; 23 (6):372-377.
- [5] Arafa MA, Nazel MWA, Ibrahim NK, Attia A. Predictors of psychological well-being of nurses in Alexandria, Egypt. Intern. J of Nurs. Prac. 2003; 9(5): 313-320.
- [6] Browne G, Roberts J, Watt S, Gafni A, Stockwell M, Alcock S. Community rehabilitation: strategies, outcomes, expenditures. Can J of Rehab. 1994 8:9–22.
- [7] Butler S S, Wardamasky S, Brennan-Ing M. Older women caring for older women: The rewards and challenges of the home care aide job. J of Wom and Ag.2012; 24: 194–215. doi:10.1080/08952841.2012.639667
- [8] Donaldson C, Burns A. Burden of Alzheimer's disease: helping the patient and caregiver. J of Ger Psych and Neur.1999; 12: 21-28.
- [9] Ferrara M , Langiano E, Brango TDi, De Vito E, Cioccio L Di, Bauco C. Prevalence of stress, anxiety, and depression in with Alzheimer caregiver. 2008. Heal and Qual of Lif Outc 6:93. Data from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2586019/. [PubMed: 18990207]
- [10] Franzosa E, Tsui EK, Baron S.Who's caring for us? Understanding and addressing the effects of emotional labor on home health aides' well-being. Th Geron. 2018; 59(6): 1055-1064. (doi: 10.1093/geront/gny099).
- [11] Grant I, Adler K, Patterson TL, Dimsdale JE, Ziegler MG, Irwin MR. Health consequences of Alzheimer's caregiving transitions: effects of placement and bereavement. Psycho Med. 2002;64:477–486. http://www.psychosomaticmedicine.org/content/64/3/477.full. [PubMed: 12021421].
- [12] Grasel E. Somatic symptoms and caregiving strain among family caregivers of older patient with progressive nursing needs. Arch of Geron and Geri.1995; 21: 253-266
- [13] Hakanen J J, Schaufeli WB, Ahola K. The job demands-resources model: A three-year cross-lagged study of burnout, depression, commitment, and work engagement. Wo & Str. 2008; 22: 224–241. doi:10.1080/02678370802379432
- [14] Johnson RW, Toohey D, Weiner JM. Meeting the long-term care needs of the baby boomers: how changing families will affect paid helpers and institutions. The Urban Institute, May 2007. http://www.urban.org/sites/default/ files/alfresco/publication-pdfs/311451-Meeting-the-Long-Term-Care-Needs-of-the-Baby-Boomers. PDF. (accessed August 2, 2024).
- [15] Juozapavicius KP, Weber JA . A reflective study of Alzheimer's caregivers. Amer J of Alzh Dis and Other Dem 2001;16 (1): 11-20.
- [16] Lutgendorf SK, Laundenslager ML. Care of the caregiver: stress and dysregulation of inflammatory control in cancer caregivers. J of Clin. Onco. 2009;27(18):2894–28.http://jco.ascopubs.org/content/27/18/2894. [PubMed: 19433678].
- [17] National Association for Home Health Care and Hospice. Basic Statistics about Home Health Care.2006. http://www.nahc.org/04HC_Stats.pdf. (accessed on April, 2023).
- [18] National Institute for Occupational Safety and Health. NIOSH hazard review: Occupational hazards in home healthcare. 2010. Washington, DC: Centres for Disease Control and Prevention.

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- [19] Piko B. Work related stress among nurses: a challenge for health care institutions. *J of Roy Soc of Heal* 1999; 156–162.
- [20] Rodat, C. Training New York City's home care aides: A landscape survey. 2014. New York, NY: PHI.
- [21] Sansoni J, Vellone E, Giovanni P. Anxiety and depression in community-dwelling Italian Alzheimer's disease caregivers. Inter J of Nurs Prac. 2004;10:93–100. [PubMed: 15056348]
- [22] Sarkar S, Anand KS. Assessing the burden on family caregivers. As Pac J of Res. 2013; I (X): 64-74.
- [23] Seavey D. Caregivers on the front line: building a better direct care workforce. Gener.2010;34(4): 27–35.
- [24] Sergi-Swinehart P. Hospice Home Care: how to get patients home and help them stay there. Sem. in Onc. 1985;12:461–5.
- [25] Schulz R, Beach. SR. Caregiving as a risk factor for mortality. The caregiver health effect study. J of the Amer Med Asso. 1999;282: 2215-2219.
- [26] Townsend J, Frank AO, Fermont D, Dryer S, Karran O, Walgrove et al. Terminal cancer care and patients' preference for place of death: a prospective study. Brit Med J. 1990;301(6749):415–7.
- [27] Wilkerson KB. *No Place Like Home: A History of Nursing and Home Care in the United States*. 2001.Baltimore: Johns Hopkins University Press.
- [28] Wilkerson, K.B.. Care of the chronically ill at home: an unresolved dilemma in health policy for the Unites States. Mil Quar. 2007;85(4): 611-39.

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