Wellbeing of Palliative Care Workers during Covid-19 Pandemic
Implications for Social Work Practice

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Abstract

The present study is aimed at examining the wellbeing of palliative care workers in India (n =114) with special reference to work related variables. The World Health Organization's five item wellbeing index was used to measure the wellbeing of the respondents. In general, the wellbeing of the respondents was found to be good. Furthermore, the age of the respondent ($p<0.001$), gender ($p<0.05$), work setting (hospital vs. non-hospital) ($p<0.05$), work environment ($p<0.01$), recent unemployment (job loss) ($p<0.01$), years of experience in palliative care ($p<0.05$), number of hours of work per week ($p<0.05$), and the number of clients who died in the previous month ($p<0.01$), were all found to be associated with the wellbeing of the respondents. Specifically, young and female respondents, those engaged in hospital based palliative care, having a poor work environment, facing recent unemployment, having less experience, working for more number of hours, and having more number of patients dying in the previous month, all had a lower level of wellbeing. The implications for social work practice have also been discussed in detail.

Keywords: Wellbeing; Palliative Care; Social Work; Work Environment

Introduction

Palliative care is a specialized field that requires educational preparation as well as training (Csikai & Raymer, 2005). However, the current pandemic scenario has made it more challenging than ever before. The covid-19 pandemic has left a trail of death and destruction, the likes of which the world has never witnessed since the outbreak of the Spanish flu in 1918 (Ashton, 2020). Ever since the beginning of the pandemic, millions around the globe have met their end and hundreds still continue to die on a daily basis. Due to the combination of under-testing and underestimation of the deaths in the initial months, the gravity of the situation wasn't realized until it became impossible to ignore (Lin et al., 2021).

India, a developing country, was grossly unprepared with only two Intensive Care Unit beds per 100,000 people (Chowdhury & Jomo, 2020) and as predicted, the healthcare system was eventually overwhelmed (Chatterjee et al., 2020a). Among the workers in the Indian healthcare system, amongst the most affected were the palliative care workers including social workers who worked together with other hospital staff to render care services (Pai et al., 2020) in the midst of the pandemic.

Palliative care workers play multitude of roles that encompass addressing both physical and psychological care needs of clients (De Lima et al., 2012). With viruses such as covid-19 disproportionately impacting older adults (Morrow-Howell et al., 2020) and with the steady rise in the global aging population, palliative care workers have greater responsibilities than ever before (O'Brien, 2013). In India, there exists a great need for the services of palliative care workers and although some progress has been made to strengthen and recognize it (Palat & Venkateswaran, 2012), there still exists a gap between the level of requirement and delivery of services along with the necessity to improve the level of awareness regarding the scope of palliative care services among doctors (Butola, 2014). Community participation in

palliative care is yet to fully blossom in the country (Kumar, 2020), and until then, there is an urgent requirement to improve palliative care services and to support palliative care workers who are understaffed and overburdened by the volume of cases that have spiked due to the pandemic. Since palliative care is a form of holistic care, especially for those who are severely ill, (Radbruch et al., 2020a), it has become even more challenging for palliative care workers during these times to deliver their array of services due to the excessive stress laid on the health care system, especially in low and middle income countries (Radbruch et al., 2020b).

The frequent lockdowns have escalated the risk of public health challenges such as diabetes and cardiovascular disease (Gopalan & Misra, 2020) which in turn will further increase the burden on palliative care workers. If unaddressed, this excessive burden is bound to lead to provider burnout being experienced by healthcare workers (Sahu & Cerny, 2020) who must turn to self-care to reduce the long term negative impact on their own mental health (Wallace et al., 2020). Over the past few decades, discussions on mental health related issues have gravitated towards the concept of wellbeing. Though there isn't a universally accepted definition of wellbeing across societies (Mansfield et al., 2020), wellbeing generally refers to good mental state (Chatterjee et al., 2020b) and can be measured both objectively and subjectively. Improved subjective wellbeing is important as it offers co-benefits such as improved health, productivity, and social relationships, among other key improvements (Maccagnan et al., 2019). From the pandemic point of view, there is a desperate need to examine the concept of wellbeing, particularly among those employed in the healthcare sector. This is because they are more likely to face occupational stress as a result of increased demand for healthcare services, leading to an overall decline in their wellbeing, as occupation stress has been associated with decreased wellbeing (Gu et al., 2019). Moreover, working

with individuals with end -of- life chronic illnesses on a regular basis places a risk on the wellbeing of palliative care workers (Zanatta et al., 2020). Currently, there is a lack of information on the extent of preparedness of the Indian palliative care professionals in the context of covid-19 (Lin et al, 2021). More importantly, there is a paucity of knowledge on the mental health, and in particular, the wellbeing of Indian palliative care workers under the present circumstances.

One qualitative study has examined the experiences of volunteers and patients receiving home based palliative care in one southern union territory of India (Subramanian et al., 2021). However, there is a need to conduct a quantitative study that measures the level of wellbeing of palliative care workers across the country. Finally, the role of social work practitioners in this context deserves attention as social workers are an integral part of the palliative care team (Thiel et al., 2021). Social work practitioners are also keenly aware of the barriers that can prevent clients from accessing essential services due to the pandemic and have resorted to the use of information communication technologies in an attempt to circumvent these barriers (Mishna et al., 2021). Nevertheless, even after two years since the pandemic first broke out, it continues to loom large and could pose a mental health challenge to palliative care workers (Nestor et al., 2021). Thus, in order to empirically assess the wellbeing of Indian palliative care workers in the current scenario and to highlight the implications for social work practice, the present study was undertaken.

Materials and Methods

Research design

The present study is descriptive in nature. On the one hand, the study will include a description of the level of wellbeing of the respondents, while on the other, it will investigate

the association between the independent variables and the respondents' wellbeing scores. Both these exercises fall under the ambit of descriptive research (Dulock, 1993).

Study Participants

The Indian Association of Palliative Care (IAPC), which was established in the year 1994 (Chaturvedi & Chandra, 1998), graciously accepted to aid the researchers in carrying out the present study by contacting and sending the online questionnaire to those members who were willing to be a part of the study. In the present study, palliative care workers refers to physicians, nurses, counselors, and social workers. Currently, there are 2002 registered IAPC members. A total of 116 responses were received of which two were incomplete and as a result had to be discarded. Thus, a total of 114 respondents were part of the present study (n = 114).

Inclusion and Exclusion Criteria

In order to be a part of this study, participants needed to be a member of the Indian Association of Palliative Care. They also had to be 18 years old or older and had to be working in the palliative care setting for at least one year. This particular criterion was introduced to ensure that the participants were working in the palliative care setting when the second, and the so far worst wave of the pandemic hit India (Samarasekera, 2021). Those who were still undergoing initial palliative care training and did not have any hands on palliative care experience, were excluded from the study.

Ethical Considerations

Written consent was obtained from all the respondents. Furthermore, the researchers have adhered to the principles laid out in the Belmont Report (Zucker, 2007). The researchers have also secured ethical approval from the institution to conduct the present study.

Tools of Data Collection

An online questionnaire was used to collect data from the respondents. The questionnaire had two parts. The first part of the questionnaire included questions involving the basic details of the respondents that have been treated as the independent variables in the present study. These include age of the respondents, gender, marital status, educational qualification, and income per month, apart from work related questions such as the number of years of experience in palliative care, setting in which they are practising palliative care (hospital vs non-hospital setting), number of hours of work per week, number of clients that have died in the past month, and rating of the work environment with special reference to the social support received from co-workers and supervisors. While the basic details are essential to understand the typical respondent and their characteristics, the work-related questions were included since a previous study suggests that increased workload, including long work weeks, and lack of support, impact the psychological wellbeing of hospice social workers (Quinn-Lee et al., 2014). There is also evidence that points to an inverse relationship between the social support received at the workplace by healthcare workers and emotional exhaustion (Escribà-Agüir et al., 2006), which prompted the researchers to include work environment related questions in the questionnaire. The most crucial set of variables in the first half of the questionnaire were the questions relating to the impact of covid-19, particularly the possible influence of covid-19 restrictions such as lockdowns on the ability of the palliative care workers to deliver their services. In one recent study by Gergerich et al. (2021), social work professionals working in hospice settings revealed the professional isolation experienced by them due to the covid-19 restrictions. One other question in the first half of the questionnaire was whether the respondent experienced job loss in the past two years as a result of the pandemic. There are two reasons as to why this question was included. Firstly, there has been

considerable research done to highlight the role of the pandemic, which first began in 2020, in causing unemployment (Bauer & Weber, 2021; Rosén & Stenbeck, 2021; Su et al., 2021). This is increasingly worrying for a developing country such as India, which has been projected to battle with a high unemployment rate due to the effects of the pandemic (Lai et al., 2021). Secondly, unemployment is known to impair mental health (Paul & Moser, 2009). Since wellbeing is treated as the dependent variable study, the second part of the questionnaire contained the five item wellbeing index developed by the World Health Organization (World Health Organization. Regional Office for Europe, 1998), that has also been recently used in the covid-19 context (Guzman et al., 2021). The index has been acknowledged to be a valid tool for measuring the subjective wellbeing of respondents (Topp et al., 2015). The reliability of the scale was tested and the cronbach alpha value of 0.88, indicates that the scale is reliable (Taber, 2018). A pre-test was conducted among six palliative care workers who did not find any problems in understanding or responding to the questionnaire. Hence, no changes were made to the questionnaire before finalizing it.

Data Storage and Analysis

The collected data was downloaded and stored in a password protected computer and analyzed using a free data analysis software -PSPP (Sto. -Tomas et al., 2019). Apart from a basic percentage analysis, to throw light on to the basic details of the respondents, a series of Kruskal-Wallis tests were conducted to examine whether there were any statistically significant differences in the mean rank of wellbeing with regard to the independent variables in the study. Only the statistically significant results have been reported in order to prevent overloading of the table. The Kruskal-Wallis test was preferred over the one-way analysis of variance as the data did not meet the normality assumption and because the Kruskal-Wallis

test is more appropriate and powerful than the one-way analysis of variance while dealing with non- symmetrical distributions (Hecke, 2012).

Results of the Basic Percentage Analysis (Table 1)

The results of the basic percentage analysis, revealed that majority of the respondents have either a good level of wellbeing (44.7 per cent) or an excellent level of wellbeing (24.6 per cent). As far as the income of the respondents is concerned, the minimum is 0 because a few respondents are volunteers and do not draw a salary for their services.

Results of the Kruskal Wallis Test With Wellbeing as the Dependent Variable (Table 2)

Age and Wellbeing

In general, those who are older seem to have a better level of wellbeing than those who are younger ($p<0.001$). This is in contrast to the finding that wellbeing generally declines with age (Steptoe et al., 2015). There are two possible explanations for this- the nature of work (palliative care) and the lack of sufficient data on wellbeing and aging from developing countries such as India. There could be an inverse relationship between aging and wellbeing among certain groups of people engaged in very meaningful work such as palliative care, right into their old age. This warrants further investigation.

Gender and Wellbeing

To understand the possible reason for female respondents having a lower level of wellbeing when compared to male respondents, one has to take cognizance of the fact that working women in India are still struggling to overcome gender roles that involve balancing both domestic responsibilities and needing to contribute economically to the family (Reddy et al., 2010). Palliative care, though rewarding, can also consume a lot of time and energy and the struggle to balance both domestic and work- related responsibilities might be causing the

female respondents to have a lower level of wellbeing when compared to the male respondents in the present study.

Work Setting and Wellbeing

Respondents employed in the hospital setting not only have to care for those in the palliative ward but also have other responsibilities in the hospital. Whereas, those working in the non-hospital setting in India are often employed in non-governmental organizations or other non-clinical settings where often, their only responsibility is to care for their palliative clients. It might be helpful if healthcare workers are not overburdened with administrative responsibilities too, especially during emergencies like the pandemic.

Work Related Variables and Wellbeing

As expected and highlighted by existing literature on the importance of having a good work environment (Escribà-Agüir et al., 2006; Marmo & Berkman, 2018), in the present study, the work environment was found to be closely associated with the wellbeing of the respondents. Those who experienced job loss in the past two years had a lower mean rank of wellbeing when compared to others. This is in line with the finding that unemployment has a negative impact on the mental health of individuals (Paul & Moser, 2009). Caring for someone who is about to die requires the ability to stay calm as well as maturity. This undoubtedly comes with experience and therefore, it is not surprising to note that those who are more experienced in palliative care have better wellbeing than others. The recent pandemic has led to an increase in the roles and responsibilities of all medical staff including those involved in palliative care. This increase in work pressure comes at the cost of mental health and explains why those respondents who work more hours per week have a lower mean rank of wellbeing. Palliative care routinely involves witnessing the death of patients. Although palliative care workers are trained to handle such situations, there could be a

significant impact on their mental health. Accordingly, the results suggest that the greater the number of clients who have recently died , the lower the wellbeing of the respondents.

Discussion

Apart from the visible physical damage, the long term mental health impact of the virus on health care professionals, and particularly palliative care workers in India, is yet to be examined. One study conducted among health care professionals in India found that there was a high prevalence of anxiety and depression among the respondents amidst the first wave of the pandemic in the country (Suryavanshi et al., 2020). It is interesting to note that a systematic review of studies has shown that more than psychological help, health care professionals were concerned about protecting their job, rest (lack of it), and social support in these troubled times (Muller et al., 2020). This is not to suggest that there was no mental health impact of covid 19 on health care professionals. In fact, the study by Muller et al. (2020) also found that factors such as workload and exposure to COVID-19 infected patients were correlated with the mental health of the respondents, thus warranting further investigation into the impact of the pandemic on the mental health of healthcare worker in general, and palliative care professionals in particular as it is they who are regularly exposed to death and serious illness in an already stressful pandemic environment combined with the difficult work-environment. Hospitals could make specific efforts to improve work environment by helping in stress management and social support for healthcare workers for e.g. regular online debriefing and staff support meetings for palliative care workers in particular. The government also needs to ensure that hospitals and non-governmental organizations (NGOs) are not pressurizing young mothers to rejoin work immediately after their official maternity leave. Bonding exercises and other measures that can help improve team cohesion could be conducted for palliative care workers. Long hours of work need to be

avoided to ensure rest and work-life balance. The majority (69.3 per cent) of the respondents work more than 31 hours a week with some working for almost 72 hours a week. This is bound to lead to mental exhaustion and poor wellbeing. Therefore, the hospital or agency administration (for those employed in non-hospital setting), could ensure equal distribution of workload and set a maximum number of work hours per day. It is also not surprising to note that those engaged in non-hospital based palliative care have a better wellbeing than those working in the hospital setting as the hospital setting requires workers to play multiple roles, with little scope for relaxation of rules such as the number of holidays. On the other hand, palliative care workers in agency settings (non-hospital settings) usually have a more flexible work environment with a more friendly administrative system. On the whole, the results have pointed out to the need to protect the wellbeing of those palliative workers who are female, young and inexperienced, those who experience the death of a greater number of clients on a regular basis, those who work in a hospital setting, and work for more number of hours than what is normal .

Implications for Social Work Practice

Owing to the comparatively flexible work-environment in NGOs, palliative care workers will have reduced amounts of work pressure and thereby experience better wellbeing. Social work professionals could also conduct group work sessions with palliative care workers to identify and resolve underlying problems that might be affecting the work-environment or team cohesion. Psychiatric social workers in consultation with the hospital administration could set up a counseling center specifically for palliative care workers so as to provide them with the necessary emotional support if required, especially after the death of a client. Students pursuing a social work degree could be encouraged to opt for palliative care, and begin training early in their career so as to enable them to identify and overcome

any barriers. In several educational institutions that offer a social work degree, palliative care is only mentioned as a passing reference or as a small sub-topic in the syllabi. It is estimated that India will soon have a large aging population due to the decreasing birth rates (Zaidi, 2022). This means that there will be a greater demand for palliative care services. Hence, there must be greater emphasis on palliative care in the social work curriculum in the country. They could consider establishing more palliative care centers in rural areas so as to better balance the rural- urban ratio of palliative services. Finally, the results of the study point to the need for more active involvement of social work professionals in palliative care. Although there are palliative care workers in India with a social work background, they are not sufficient in number to meet the huge and growing demand. Hence, if more social workers voluntarily choose this field of work, it would supplement the multi-disciplinary teams and would also reduce the burden on the existing palliative care workers.

Limitations of this Study

A bigger sample size could have been adopted. Moreover, the study could have included a few tools to secure qualitative data from the respondents, further enriching the study. However, due to the busy schedule of the palliative care workers, this was not possible Also, a few of our respondents were volunteers and provided free services so the data related to income and wellbeing could be affected by this. In other words, some of our respondents were providing voluntary palliative care service without deriving any income from the service being provided. As far as suggestions for future studies on this front is concerned, a comparative study on the wellbeing of palliative care workers in India and one of the western countries could be conducted to identify the best practices in both countries and to discover possible areas of improvement in terms of wellbeing of palliative care workers in both countries.

Conclusion

The results have indicated that the age of the respondent, their gender, work setting (hospital vs. non-hospital), work environment, recent unemployment (job loss), years of experience in palliative care, number of hours of work per week, and the number of clients who have died in the previous month, are all associated with the wellbeing of the respondents. The existing literature on the matter supports the findings of this study. In general, the wellbeing of palliative care workers, despite the great work pressure, is good. Finally, social work professionals could help promote the concept of agency-based/NGO based palliative care in India. This will help increase the access to palliative care services for a lot of people who cannot afford hospital based palliative care.

Declaration of Interest

The authors report that there are no competing interests to declare.

Table 1. Basic Percentage Analysis (n =114)

Variables	N	%	$\bar{x}$ (min) (max)
Age group (yrs)			
30 and below	09	7.9	
31 or 40	26	22.8	
41-50	31	27.2	49.28 (25) (75)
51-60	22	19.3	
61 and above	26	22.8	
Gender			
Female	76	66.7	
Male	38	33.3	
Marital status			
Unmarried	21	18.4	
Married	84	73.7	
Separated	01	0.9	
Divorced	02	1.8	
Widowed	0.6	5.2	
Highest qualification			
High School	04	3.5	
Bachelors	38	33.3	
Masters	58	50.9	
PhD	02	1.8	
Post doctorate	12	10.5	
Monthly income (in Indian Rupees)			
50000 and below	95	83.3	
50001 and above	19	16.7	71668 (0) (300000)
Years of experience in palliative care			

0-5 6-10 11-15 16-20	44 35 25 10	38.6 30.7 21.9 8.8	8.79 (0.1) (40)
Work Setting			
Hospital Non-Hospital	61 53	53.5 46.5	
Number of hours of work per week			
1-30 31 and above	35 79	30.7 69.3	35.49 (1) (72)
Number of clients who died in the previous month			
0-15 16 or more	96 18	84.2 15.8	8.82 (0) (70)
Work environment			
Very Poor Poor Average Good Excellent	1 3 17 52 41	0.9 2.6 14.9 45.6 36	
Has covid 19 along with govt. restrictions affected your ability to work effectively?			
Strongly Disagree Disagree Neither Agree nor Disagree Agree Strongly Agree	03 18 14 60 19	2.6 15.8 12.3 52.6 16.7	
Most powerful factor that affected ability to work			

Fear of Covid-19 Lockdowns Govt. Restrictions None of the above	31 24 31 28	27.2 21.1 27.2 24.5	
Job loss in the past two years			
No Yes	102 12	89.5 10.5	
Level of wellbeing			
Very Poor Poor Average Good Very Good	1 8 26 51 28	0.9 7.0 22.8 44.7 24.6	17.46 (4) (25)

Table 1-Percentage distribution of respondents based on their socio-demographic, economic, and work related details apart from their level of wellbeing.

Table 2. Kruskal Wallis test with wellbeing as the dependent variable (n = 114)

Age group (yrs)	N	$\bar{x}$ rank	χ^2	df	p value
30 and below	9	39.61	29.37	4	**0.000*** **
31-40	26	33.98			
41-50	31	58.37			
51-60	22	64.52			
61 and above	26	80.23			
Gender					
Female	76	52.14	6.05	1	**0.014***
Male	38	68.22			
Work setting					
Hospital	61	51.60	4.22	1	**0.040***
Non-hospital	53	64.29			
Work environment					
Very Poor	1	14	14.54	4	**0.006****
Poor	3	24			
Average	17	50			
Good	52	51			
Excellent	41	71			
Job loss					
No	102	60.84	10	1	**0.002****
Yes	12	29.08			
Years of experience in palliative care					

0-5	44	46.56	9.31	3	**0.025***
6-10	35	61.23			
11-15	25	64.50			
16-20	10	75.10			
Number of hours of work per week					
1-30	35	66.71	3.96	1	**0.047***
31 or more	79	53.42			
Number of clients who died in the previous month					
0-15	96	61.58	9.34	1	**0.002****
16 or more	18	35.75			

Table 2-Association between the independent variables in the present study and wellbeing of the respondents.

Note. *** p<0.001 ** p<0.01 * p<0.05

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